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Measure of Processes of Care (MPOC) applied to measure parent's perception of the habilitation process in Sweden

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[1] This paper is dedicated to the memory of Ingrid Bjerre who sadly passed away before this article was published.

Abstract

Aim To evaluate the instrument Measure of Processes of Care (MPOC) in a Swedish context.

Methods The MPOC consists of 56 questions in the five scales: enabling and partnership; providing general information; providing specific information about the child; co-ordinated and comprehensive care; and respectful and supportive care. The questionnaire was translated into Swedish and distributed to 850 families, served by four habilitation centres. After two reminders, a response rate of 74.9% was obtained, and about 60% of the questionnaires qualified for further statistical analysis. Reliability, calculated as Cronbach's alpha, was high for four of the five scales and acceptable for the fifth (scale no. 3).

Results Significant differences were shown between centres as well as between age groups. These differences were reasonable as judged through background knowledge, indicating that the instrument was able to discriminate between actual differences in services. Commenting on the practical use of the questionaire, staff, as well as responding parents, found the questionnaire rather long and some parents reported difficulties in giving answers as specific as the questionnaire asked them to.

Conclusion The MPOC shows sufficient sensitivity to be used as an evaluation tool for services at a centre or program level, and can be recommended for research and practical use.

Keywords
family-centred service, child rehabilitation, Measure of Processes of Care (MPOC)

Introduction

Habilitation is the process by which comprehensive support is given to children and young people with disabilities in order to achieve the best possible development of the impaired function, and mental and physical well-being of the individual. Habilitation centres in Sweden often consist of multidisciplinary teams, which are composed of several experts, for example, physiotherapist, occupational therapist, speech therapist, social worker, psychologist and remedial teacher. Doctor, nurse, dietician and recreation officer may be members of the team or act as consultants. The teams provide assessment, treatment and counselling to children and young people (0–20 years of age). The law for dis-

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abled people (Disability Policies in Sweden 1997) states the right for the individual of self-determination and influence on the support and service. The National Board of Health directives concerning Quality in Health Care (SOSFS 1997) claim that the patients and their family shall be shown consideration and respect from the health staff, that they shall be informed and able to participate in decisions and that their suggestions and complaints shall be taken into consideration. In a newly published guideline for quality in habilitation (Bjerre *et al*. 1999), a standard for habilitation centres is suggested. One criterion of quality is that the habilitation is family-centred. According to Dunst *et al*. (1994) truly family-centred services means (1) an emphasis on families' strength rather than deficits; (2) the promotion of family choice and control over desired resources; and (3) the development of collaborative relationship between professionals and parents.

In order to evaluate if the habilitation process is family-centred and effective, reliable measures are needed. The Measure of Processes of Care (MPOC), constructed by King *et al*. (1995), seemed to be an instrument suitable for a Swedish field trial. After contact with the authors, we translated the MPOC into Swedish, and used it in four different habilitation centres (Karlstad, Lund, Malmö and Visby) in order to find out whether it is of use in measuring the parent's perception of the habilitation process in Sweden. The results are presented here.

Methods

The MPOC questionnaire was translated into Swedish, using a conceptual strategy, i.e. preserving the significance of the questions rather than following the text to the last letter (McKay *et al*. 1996). It was sent to a total of 850 families with disabled children receiving habilitation in one of four habilitation centres. The centres are situated in different parts of Sweden and cover both urban and rural areas:

- Karlstad is the central city in the county of Värmland in the middle of Sweden. The county had 280 000 inhabitants and 900 children in the habilitation register at the time of the study. There was one main centre in Karlstad and some smaller branches in the middle and northern parts of the county, which are forested and sparsely populated. The centre was part of the public medical service.
- Lund is a university town with a rural area, in southern Sweden. The inhabitants are academic teachers, students and middle-class people. Lund had about 100 000 inhabitants, and 400 children were registered in the habilitation register at the time of the study. There were two habilitation centres, one covering the northern and the other the southern part of Lund. They were administrated by a handicap and rehabilitation board, which was part of the social services.
- Malmö is an industrial city in southern Sweden with many immigrants and social problems. It had about 250 000 inhabitants, and 800 children were registered for habilitation at the time of the study. The habilitation centre, covering the whole city, was part of the public medical service.
- Visby is the central city in Gotland, which is an island in the Baltic Sea, east of the Swedish mainland. It had 50 000 inhabitants and 225 children registered for habilitation at the time of the study. It had one centre, which was part of the social services. Most of the inhabitants in Gotland live in Visby and the rest of the island is sparsely populated.

The centres were of different size and had a different number of children in their habilitation registers. They all had the responsibility of serving all children with disabilities in their county, which means that nearly all children with disabilities in the respective areas are accounted for. For practical and ethical reasons we refrained from making the total number of families to large. To obtain sufficient data for statistical analysis we decided on a sample size of about 200 families from each centre. We included in the study every fourth child in Karlstad and Malmö, every other in Lund and all children in Visby, which resulted in 200 families from two centres, 225 from the other two, and a total sample size of 850 families. The questionnaires were sent out by each centre, but returned directly

to two of the authors (I.B., M.L.) to guarantee strict confidence. The questionnaire was accompanied by a letter, with information about the study. Consent was given by returning the completed questionnaire. Two reminders were sent with an interval of 4–6 weeks between each. No comparison was made with official registers in order to preserve confidence.

The parents were asked to give certain information about their child, such as age and disabilities, and about themselves (who answered the questionnaire and what their native language was). Concerning disabilities, they were asked to mark one or more of eight specified and one open alternative, which were relevant to describe the disability of their child.

The questionnaire comprises 56 questions covering five factor-analytically constructed scales (King *et al.* 1995):

1 Enabling and partnership (16 questions);
2 Providing general information (9 questions);
3 Providing specific information about the child (5 questions);
4 Co-ordinated and comprehensive care (17 questions); and
5 Respectful and supportive care (9 questions).

All questions refer to behaviours occurring during the past year. Each question begins with the same stem: 'To what extent do the people who work with your child' . . . which is followed by an item, such as . . . 'tell you about the reasons for treatment or equipment?' They are answered on a seven-point scale, from 'to a great extent' (7) to 'never' (1), with an additional alternative of 'not applicable' (0). Parents who considered themselves unable to answer the questionnaire because of language difficulties were offered the help of a professional interpreter, but only a few used this help.

Results

Response rates

Some kind of response was obtained from 637 families (74.9%), after two reminders had been sent out (Table 1). To the last reminder a short questionnaire was added, asking for reasons for not responding, which was used by 33 parents (4%). The majority of those responding to this short questionnaire (23 families) had had 'little or no contact with the habilitation centre during the last year'.

Table 1. Response rates for the Swedish version of the Measure of Processes of Care

	n	No. reminded	No. responses	Response rate (%)
Malmö	200	121	143	71.50
Lund	200	110	155	77.50
Karlstad	225	186	183	81.33
Visby	225	133	156	69.33
Total	850	550	637	74.94

On 506 (59.5%) of the questionnaires descriptive data were completed. Five cases with ages more than 20 were excluded from further analyses. Between 438 and 444 (52%) questionnaires had enough items completed to qualify for further statistical analyses (the number depending on the specific analysis). The criterion used for inclusion in statistical analysis was completion of at least half of the items (29 or more), the alternative 'not applicable' not considered a valid response (following King *et al.* 1995; King *et al.* 1996).

Language

The respondents were asked to indicate their native language given eight specified categories and the alternative 'other language'. In 444 cases answers were obtained (Table 2). All of these cases were included in the statistical analyses. We offered the help of professional interpreter, but this was used only in about 10 cases. The help of others as interpreters (family members, friends, etc.) was not recorded. Families with other native languages than Swedish were more frequent in Malmö and Lund. We found no significant differences on the scales when we related them to language.

Age distribution

Means and standard deviation of ages of the disabled children at the four centres show an

Table 2. Language distribution at the four centres

	Karlstad	Lund	Malmö	Visby	Total
Swedish	106	88	77	123	394
Other languages	9	18	18	5	50
Total	115	106	95	128	444

Table 3. Means and standard deviation of ages of the disabled children at the four centres

	Centre				
	Karlstad	Lund	Malmö	Visby	Total
n	129	124	103	145	501
Mean	8.3	10.4	10.1	10.6	9.9
SD	4.7	5.1	4.9	4.9	5.0

One-way ANOVA shows significant difference between the centres ($F = 5.719$, d.f. = 3, $P = 0.001$), with Karlstad being different from Lund and Visby ($P < 0.05$, Scheffé *post hoc* analysis).

Table 4. Disabilities as reported by the parents

Disability	*n*
1. Motor disability	224
2. Mental retardation	195
3. Muscular disease	33
4. Visual impairment	109
5. Hearing impairment	37
6. Speech/language disabilities	184
7. Deficits in attention, motor function and perception (DAMP)	33
8. Autism	62
9. Other	102

Disabilities were stated in 499 cases. It was possible to mark more than one disability for each child. 8 specified alternatives were given and no attempt was made to grade the disabilities. In 234 cases one disability and in 265 cases two or more disabilities were marked.

uneven distribution. The children in Karlstad are significantly younger than those in Lund and Visby (Table 3).

Disabilities

The data on the disabilities of the children were obtained from the parents, who were asked to choose one or more of eight specified alternatives, or to describe the disability in their own words. This means that each child could be assigned more than one disability. Disabilities were stated in 499 cases. The maximum number of disabilities assigned to one child was seven (Table 4).

Table 5. Reliability for the 5 scales in the Measure of Processes of Care in the Swedish context

Scale	Number of questions	Alpha
Enabling and partnership	16	0.9573
Providing general information	9	0.9000
Providing specific information about the child	5	0.8009
Co-ordinated and comprehensive care	17	0.9328
Respectful and supportive care	9	0.9181

Scales and reliability

We were interested in examining the usefulness of the five subscales of the MPOC in the Swedish context. To do this, reliability scores were calculated (Cronbach's alpha). The results show a high reliability score for four of the five scales, and an acceptable score for the fifth (Scale 3: Providing specific information about the child) (Table 5).

Differences between the four habilitation centres

The instrument has to be able to differentiate between different modes of service provision to be an useful instrument for evaluation and development of habilitation services. Our study allows a comparison between the four habilitation centres. This comparison shows some significant differences, one centre having significantly lower scores on Scale 2 'Providing general information' (ANOVA, $F = 9.693$, $P = 0.00$) and a tendency to lower scores on Scale 3 'Providing specific information about the child' ($F = 2.835$, $P = 0.038$) (Table 6). *Post hoc* test (Scheffé) indicates that Malmö has significantly lower scores on Scale 2 ($P < 0.05$), compared with Lund, Karlstad and Visby, and significantly lower scores than Visby on Scale 3 ($P < 0.05$) (Table 6).

Table 6. Mean and standard deviation on the five scales at the four centres

Scale		Karlstad (*n* = 115)	Lund (*n* = 106)	Malmö (*n* = 95)	Visby (*n* = 128)	*F*	*p*
1	Mean	4.93	4.91	4.88	5.08	0511	0.675
	SD	1.47	1.27	1.42	1.40		
2	Mean	3.84	3.93	2.95	4.09	9693	0.000
	SD	1.62	1.50	1.56	1.84		
3	Mean	4.23	4.34	3.94	4.54	2835	0.038
	SD	1.66	1.41	1.52	1.56		
4	Mean	4.88	4.79	4.90	4.97	0278	0.841
	SD	1.56	1.40	1.64	1.50		
5	Mean	5.39	5.58	5.35	5.51	0656	0.580
	SD	1.50	1.12	1.29	1.27		

One-way ANOVA shows significant differences on Scales 2 and 3. *Post hoc* test shows lower scores for Mamö on Scale 2 ($P < 0.05$) compared with the other three centres, and on Scale 3 ($P < 0.05$) compared with Visby.

Table 7. Scores on the five scales for the three age groups. ANOVA shows a significant main effect on Scales 1, 4 and 5

Scale		Age category 0–6 years	7–13 years	14–20 years	*F*	*p*
1	Mean	5.40	4.82	4.69	10 474	0.000
	SD	1.25	1.36	1.46		
2	Mean	3.98	3.72	3.52	2 256	0.106
	SD	1.62	1.77	1.67		
3	Mean	4.46	4.31	4.03	2 254	0.106
	SD	1.52	1.56	1.56		
4	Mean	5.37	4.78	4.49	11 778	0.000
	SD	1.37	1.54	1.50		
5	Mean	5.87	5.39	5.16	10 405	0.000
	SD	1.48	1.27	1.40		

Table 8. Linear regression with the five scales as dependent variables, shows the relative influence of age and site as independent variables

	1		2		3		4		5	
Scale	**β**	***p***	**β**	***p***	**β**	***p***	**β**	***p***	**β**	***p***
Site	0.050	0.291	0.207	0.000	0.115	0.016	0.020	0.663	0.025	0.595
Age	–0.198	0.000	–0.117	0.013	–0.103	0.031	–0.226	0.000	–0.195	0.000

Differences between age groups

There were also differences between age groups regarding the parents' perception of services. On all scales, the mean scores were less with increasing age. ANOVA shows a significant main effect ($P < 0.001$). *Post hoc* test (Scheffé) indicates that age group 1 has significantly higher scores on Scales 1, 4 and 5 compared with groups 2 and 3 ($P < 0.05$). No significant differences were found *post hoc* between groups 2 and 3 (Table 7).

Because there were differences in age distribution between the centres, there is a possibility of interaction between age and centre. This question was investigated by a linear regression analysis, which also shows the relative influence of the two independent variables (Table 8). According to the regression analysis age has a significant influence on all five scales (the weaker influence of age in Table 7 can be explained by information lost when groups are constructed) while variation resulting from different sites are limited to two of the scales (2 and 3). This also shows that there is an independent influence from both variables, i.e. age and centre are not confounded.

Reactions from parents and staff

The parents were asked to comment on anything they wanted to. One hundred and seventy-two questionnaires contained such comments. In 28 cases the parents pointed our that it was difficult for them to define their answers only to 'the last year'. In 13 questionnaires the parents thought it was difficult to summarize their impressions to apply to 'all people who work with you or your child'. They would prefer to be more specific, for example, if they liked one therapist but were critical of others. Another common comment was about age 'my child is so old now, many questions don't apply for us' (21 cases).

The staff in the four centres were informed about the study in meetings, both before it started and afterwards with the results. Many were doubtful regarding the length of the questionnaire, and the type of questions. They thought that the questions were too personal and could upset the parents. They also found it unfair that the score applies to 'all people who work with you and your child', and many had preferred if there were separate questions for the different occupational groups.

Discussion

The therapy and support given by the habilitation processes are expected to give long-term effects, to minimize handicaps and increase quality of life for the disabled child. It is postulated that actions in which parents participate are more effective and create less stress in the parents (McConachie 1994). The parent's perception of the habilitation processes is very much influenced by the way in which services are provided by the habilitation staff (Snowdon *et al.* 1994; Leske & Jiricka 1998). It is thus important to follow up these aspects of care in order to achieve habilitation processes of good quality (Björck-Åkesson & Granlund 1995).

The MPOC is based on research into the needs of families with chronically ill and disabled children in Canada (Rosenbaum *et al.* 1992; King *et al.* 1996). It has been evaluated in several studies and found to be valid and consistent for Canadian children with different disabilities and chronic illnesses (King *et al.* 1997; Swaine *et al.* 1999).

Response rate

In this study we obtained an acceptable response rate of 75%. Non-response may to a certain extent be explained by language problems and insufficient updating of registers.

Nine per cent of those who answered stated another native language than Swedish. This is difficult to evaluate because we don't know how many with another native language there were in the non-response group, or how many were expected in the whole group. Although we offered interpreter only a few families used it. The most common explanation given by those who responded but did not fill in the questionnaire was 'no contact with the habilitation centre during the last year'. Another possible explanation for not responding may be the length of the questionnaire. Many centres have been hesitant to use the MPOC for that reason, and in Sweden several shorter versions have emerged (T. Granath, pers. comm.). We wanted to use MPOC in its original form, because it is thoroughly evaluated (King *et al.* 1995). The MPOC seems to function well concerning common statistical criteria and to have a discriminating capacity.

Habilitation centres

We believe the four habilitation centres to be fairly representative of Swedish habilitation services. They represent both urban and rural districts and are situated in different parts of the country, even if the most northerly counties are not represented. We also believe the distribution of ages and disabilities to be representative of the prevailing conditions. It has not been possible to compare in a more rigorous statistical manner the characteristics of the respondent group with the actual population.

One centre (Malmö) showed significantly lower results on Scale 2 (Providing general information) and a tendency to lower results on Scale 3 (Providing specific information). All centres, except Malmö, had various general information activities, such as open house or popular lectures, during the year preceding the study. This may explain the lower scores for Malmö on Scale 2. Concerning

Scale 3, the tendency to lower scores for Malmö may be explained by a greater difficulty in informing a socially less favourable group, where many parents come from another culture and have another native language. It may however, also be because of organizational differences. Malmö is solely an urban area. The distance to the habilitation centre is short, and communication easy. Therefore most children come to the centre for treatment and activities and few home visits are made. Older children often come alone or, if they are severely disabled, accompanied by an assistant. Both children and parents meet many different members of the staff, and it may be difficult to know what information is given and what is missing. The other three centres contain both urban and sparsely populated areas, where home visits are more common and often made by one or a few staff members. This may result in a better continuity, where one person is aware of what specific information is given and what must be completed.

Age

The fact that the younger age groups show higher scores (Table 7) may be explained by the fact that habilitation in Sweden during the last 10 years has been to a large extent directed towards early treatment, and proportionally more resources given to pre-school children than to school children in all centres. The young age groups are also those where the parents are naturally more involved in treatment and therefore know the therapists better, and maybe also receive more information (Janson 1995).

Conclusion

Our conclusion is that the translated version of the MPOC is reliable and potentially useful in the Swedish context and can be recommended for evaluation of the processes of habilitation in Sweden on the five scales: (1) Enabling and partnership; (2) Providing general information; (3) Providing specific information about the child; (4) Co-ordinated and comprehensive care; and (5) Respectful and supportive care. The measure has the capacity of discriminating differences in service, and can be used to compare different centres or follow up an organizational change (Larsson 2000). A clear disadvantage is the length of the questionnaire. Shorter versions are now on trial, both in Canada and in Sweden and hopefully they will be easier to handle and still as reliable.

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