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The value of a family-centered approach in preventive child healthcare

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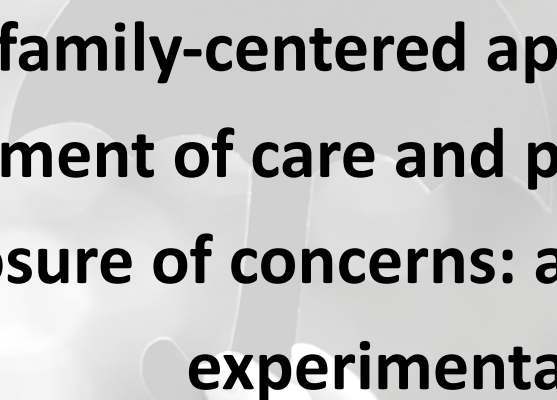
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5



Impact of a family-centered approach on attunement of care and parents' disclosure of concerns: a quasi- experimental study

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Abstract

Objective: To assess the importance parents place on family-centered care aspects in Preventive Child Healthcare (PCH) and to evaluate whether a family-centered approach influences the attunement of care to these preferences and the willingness of parents to disclose concerns.

Method: Parents of infants (mean age 11.4 weeks) attending Dutch PCH participated in the quasi-experimental study. Parents of infants receiving family-centered care (intervention condition) and parents of infants receiving care-as-usual (control condition) filled in a questionnaire regarding the importance of PCH professionals' *attitude*, parents' *empowerment*, and monitoring the *broad developmental context*. They also assessed their experiences regarding these aspects of care. Furthermore, parents rated their willingness to disclose concerns. We compared the two conditions, adjusting for background characteristics, and assessed interactions by socioeconomic status and child's social-emotional status.

Results: Data was provided by a sample of 2542 parents of infants receiving family-centered care and 2328 parents of infants receiving care-as-usual (return rate of questionnaires 86%). Parents rated the PCH professionals' *attitude* as most important and monitoring the *broad developmental context* as least important. Scores were high in both conditions. Compared to care-as-usual, parents receiving family-centered care reported better attunement of care to their preferences ($p < .001$, effect sizes .10–.27). Parents' willingness to disclose concerns was similar in both conditions ($p = .09$). Effects were stable across socioeconomic status and child's social-emotional status groups.

Conclusion: The family-centered approach improves attunement of care to parents' preferences, but it does not increase their already high willingness to disclose concerns.

Introduction

Family-centered care has been increasingly promoted in past decades and has been associated with improved health care outcomes.¹⁻³ The core principles of family-centered care according to the American Academy of Pediatrics are described in Table 1.³ Other authors also stress the consideration of psychosocial needs of all family members.⁴⁻⁶ In child health care, family-centered care can be described as “placing the needs of the child, in the context of their family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs.”(page 75)⁷ Attuning care to family-specific preferences and needs may be especially important for more vulnerable populations, such as families with low socioeconomic status (SES), since they might otherwise drop out of care services.⁸

Family-centered care has also been adopted as pivotal for the quality of care by preventive pediatrics, as reflected in guidelines like *Bright Futures* of the American Academy of Pediatrics,^{9,10} and may also be useful in monitoring infants’ social-emotional development. Based on this, a family-centered approach has been introduced in Dutch Preventive Child Healthcare (PCH).¹¹ Dutch PCH is similar to well-child care in the United States, but access is free of charge, regardless of insurance status. More than 90% of infants attend regularly. In addition to routine physical checks, a key activity during these visits is monitoring infants’ social-emotional development.¹² Despite the fact that PCH is well-organized and has such a high reach, there has also been some criticism on the system for being too keen on identifying child maltreatment (with having the possible adverse side effects that parents would not visit anymore, or would not mention possible concerns).¹³

The family-centered approach may enhance monitoring the social-emotional development because some aspects of the approach, such as questions about psychosocial issues and expressions of support, have been related to disclosure of sensitive information by parents.¹⁴ Disclosed information, in turn, seems to be a good starting point for early identification of problems.^{15,16}

Table 1.**Core principles of family-centered care according to the American Academy of Pediatrics**

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations and respecting different methods of coping
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. Collaborating with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health

It is unknown to what extent the family-centered approach enhances attunement of care to parents' preferences and whether all parents are similar in this regard. Nor do we know whether the family-centered approach does facilitate monitoring infants' social-emotional development. Therefore, we undertook a study with the following aims. First, we assessed the value parents place on three aspects of family-centered care (the attitude of the PCH professional, asking about the broad developmental context of the child and an empowering approach by the PCH professional, see Figure 1 for a detailed overview of the specific outcome measures). Second, we assessed the impact of the family-centered approach on the actual attunement of care to parents' preferences, as a measure of the quality of (family-centered) care.^{17,18} Third, we explored whether the family-centered approach is associated with greater willingness of parents to disclose concerns, compared to care-as-usual. Finally, we evaluated whether results differed according to parents' SES and child's social-emotional status. Because attunement is central in the family-centered approach, we expected its effects to apply to all parents, regardless of SES or child's social-emotional status.

Methods

Design

We conducted a non-blinded quasi-experimental study on regional units of a PCH organization in the northern Netherlands. We chose a quasi-experimental cluster design as full cluster-randomization was not possible because the organization had implemented the family-centered approach in some units but not yet in others. The reasons of inception were not dependent on the drive of units, but just on accidental reasons, in particular the vicinity to each other. This led to an intervention condition, in which all PCH professionals (57 in total) had been trained in working with the family-centered approach, and a control condition, in which all PCH professionals (49 in total) offered care-as-usual. All units worked within their own catchment area. Randomization per child/family was not possible as professionals served an entire region so that contamination would be inescapable in case of individual randomization. There were no differences between PCH professionals from both conditions regarding gender, age, and years of experience. The study was approved by the Medical Ethical Board of the University Medical Center Groningen. Further details are provided elsewhere.¹⁹

We minimized the likelihood of contamination by a number of measures. First, we prevented any professional to work in both the intervention and control condition. Second, we informed PCH professionals about the study separately per condition. Finally, no innovations regarding the social-emotional development of children aged 0-18 months were implemented in either the intervention or the control condition, during the study period.

Procedures and participants

Between October 2009 and June 2011, participating PCH professionals (i.e., nurses and doctors) asked parents of 8280 newborns to participate in the study (83% of all eligible parents). Eligible parents were those with sufficient mastery of the Dutch language. No important differences were found in either condition between parents who were and were not invited to participate (Cramer's $V = .06$ to $.13$).

During the first or second well-child visit (at 4 or 8 weeks of age), PCH professionals registered consent within the medical records of 5761 infants (total response of 70%; 69% in the family-centered care condition and 70% in the control condition). Participants and non-participants in both conditions were similar in background characteristics and child's social-emotional status (Cramer's $V = .05$ to $.13$). Participants gave consent to use information from their child's medical record or to use their address to mail them a questionnaire around the child age of 8 weeks and a follow-

up questionnaire around the child age of 18 months. Participants received a small gift (a children's book) for their participation after the follow-up questionnaire when the child was 18 months of age. The current study focuses on the results of the first questionnaire around the child age of 8 weeks. We sent the 5658 participating parents a questionnaire by mail; from the remaining 103 we did not receive informed consent. A reminder followed if it was not returned within two weeks and a telephone call after another two weeks. Of all participating parents, a total of 4870 parents returned the questionnaire (86%).

Intervention condition

A main aim of the family-centered approach is to foster trust and to empower parents in their strengths to enhance children's developmental context and subsequently their social-emotional development. Parents are regarded as experts on their child and partnership with parents is a central feature of the approach.

During each well-child visit, PCH professionals prompt parents to express possible concerns, providing a starting point for further communication. The family-centered approach format addresses five domains associated with children's social-emotional development: *competence of the parent* (e.g., "Do you feel uncertain or do you have any difficulties with certain aspects of care?"), *role of the partner* (e.g., "To what extent are you satisfied with the contribution of your partner?"), *social support* (e.g., "To what extent do you manage with the support you receive?"), *perceived barriers and life events within the caregiving context* (e.g., "Have there been any life events in the past year? If so: To what extent does this influence your contact with your child?"), and *wellbeing of the child* (e.g., "How does <<name>> respond to his/her environment?"). During the second well-child visit, when the infant is about 8 weeks of age, children are seen by a nurse, who has 15 minutes extra to discuss the five domains exhaustively (30 minutes in total).¹¹ Based on the appraisal of all domains, parents and the PCH professional jointly decided whether there were any concerns, resulting in the conclusion as *fine*, *not optimal* or a *problem*. In case of any concerns, an additional activity is planned aimed at the social-emotional development of the child (like an additional appointment to assess the situation more in depth or an intervention).

PCH professionals in the intervention condition received 32 hours of training in total, divided over four days). Training consisted of giving background information on the family-centered approach, work instructions, role-play sessions, and discussing case-vignettes. Within one month after training, PCH professionals had to videotape two well-child visits which were evaluated by trainers using standardized guidelines (with questions

like whether all parts of the family-centered approach were discussed and whether PCH-professionals used empowering communication skills). This procedure was repeated until the performance was rated as adequate. Most PCH professionals needed the evaluation of three recordings to be able to pass. Follow-up supervision meetings were held every three months. In the supervision session a recording of a well-child visit was discussed with again attention to the aforementioned questions. Sessions lasted two hours and were planned with four to six PCH professionals.

Control condition

Within the control condition, PCH professionals monitored children's general health and social-emotional development during routine 15-minute well-child visits following the guidelines of the National Centre for Child Health.¹²

Measures

The first primary outcome was the extent to which PCH professionals (i.e. the nurses and medical doctors with whom parents had with until they filled in the questionnaire) met parents' preferences. Therefore, parents filled in a questionnaire covering three aspects of family-centered care: (1) the PCH professional's *attitude* (7 items, Cronbach's $\alpha = .81$), (2) parental *empowerment* (8 items, Cronbach's $\alpha = .81$), and (3) monitoring the *broad developmental context* (4 items, Cronbach's $\alpha = .79$). The items that made up the *attitude* scale were based on a questionnaire measuring the quality of PCH.²⁰ Items were designed according to the concept of QUOTE questionnaires (Quality of Care Through the Patients' Eyes),¹⁸ measuring both the importance (*how important is it to you that...*) of items on a Likert scale (1=unimportant, 2=fairly important, 3=important, 4=very important) and then also the actual experience (*to what extent was this the case?*), again on a Likert scale (1=never, 2=sometimes, 3=usually, 4=always, or "not applicable"). The questionnaire was piloted with a sample of 18 parents outside the scope of this study, with no problems of comprehensibility found. Figure 1 lists all the items. The items were categorized into the three afore mentioned aspects in consultation with several experts on the family-centered approach.

To obtain a meaningful set of Quality Impact Indices (QIIs), we transformed importance scores (1=0, 2=3, 3=6, 4=10) and experience scores (1=1, 2=0.67, 3=0.33, 4=0), based on the procedure followed in other studies using QUOTE questionnaires.^{21,22} After transformation, we applied the formula $[10 - (\text{importance score} * \text{experience score})]$, derived from other QUOTE studies^{22,23}, resulting in QIIs ranging from 0 to 10. The higher QIIs represent better attunement of care to parents' preferences. An exception to the

formula was made for items rated as “unimportant” combined with experience scores of “sometimes”, “usually” or “always” as these combinations do not necessarily reflect perfect attunement. In these cases QIIs were similar to the QIIs that were computed for the “very important” dimension (so for example the QII of “not important” combined with “always”, was equal to the combination of “very important” combined with “never”). We computed QIIs per participant. Scores for each care aspect were summed and divided by the number of questions covering that aspect.

The second primary outcome was the *level of willingness to disclose concerns*, which was measured with the statement “I feel free to discuss all kinds of worries at the PCH center,” again using a Likert scale (1=not true at all, 2=mostly untrue, 3=sometimes true, 4=mostly true, 5=always true).

In addition, we assessed the following background characteristics of parents: *age, educational level, employment status and country of birth* and furthermore the *family composition* and having *one or more children*. Educational level was classified in three categories: “low” (primary school or less, lower vocational or lower general secondary education), “medium” (intermediate vocational education, intermediate or higher secondary education), and “high” (higher vocational education or university). The highest educational level attained by a parent provided the indicator of SES. Furthermore, PCH professionals recorded for all children whether they anticipated any risk of social-emotional problems, resulting in an assessment as *fine, not optimal or problematic*.

Analysis

Missing values (ranging from 0.7% to 2.1% per item) were imputed using SAS.9.2, assuming that missingness was random. Items designated as not applicable were not taken into account.

First, we compared the characteristics of children and their families in both conditions. The statistical significance of differences was assessed using chi-square tests, and Cramer’s V was used to assess the size of the differences. Second, we computed mean QIIs per item and compared QIIs on the three aspects of family-centered care (*attitude, empowerment, and broad developmental context*) for both conditions using independent *t* tests or Mann-Whitney tests in case of skewed data. We repeated our analyses without making an exception to the formula for the items rated as “unimportant”. Next we repeated comparisons, using regression analyses adjusting for background variables. Finally, we assessed whether differences between the conditions varied by parental SES and child’s social-emotional status. This was done by adding interactions of these variables with condition.

Using logistic regression, we performed the same analytical steps for willingness to disclose concerns. Based on the content and distribution of the disclosure question, the answer categories were dichotomized into “low” willingness to disclose (answer categories 1 to 3, *not true at all to sometimes true*) and “high” willingness to disclose (answer categories 4 and 5, *mostly true and always true*).

To rule out possible clustering of the data (parents nested within teams), we also performed multilevel analyses. Statistical analyses were performed in SPSS 20.0 with significance levels set at .05.

Results

Statistically significant differences between participants in the conditions were observed only for parental education, which was slightly higher in the control condition (Cramer’s $V = .12$) and the child’s social-emotional status for which within the intervention condition we found few more assessments of “not optimal” (Cramer’s $V = .05$).

Importance scores per item

Figure 1 shows the mean importance scores for all items. Items on *attitude* were rated as most important overall, whereas items on monitoring the *broad developmental context* were rated as least important.

Differences in QIIs on aspects of family-centered care

Figure 2 shows the QII scores per item. For all items, scores were significantly higher for the intervention condition than for the control condition. We found the largest differences for *broad developmental context*. Effect sizes ranged from very small to small ($r = .04$ to $.23$). Mean summed QIIs were significantly higher for parents receiving family-centered care (Table 2). This indicates that these parents perceived the care they received as better attuned to their preferences than parents receiving care-as-usual. For monitoring the *broad developmental context* a medium effect size was found. For *empowerment* and *attitude* of the PCH professional small effect sizes were found. Because of negatively skewed data, Mann-Whitney tests were also applied, generating the same p values. In the analyses without making the exception to the formula for the items rated as “unimportant” results remained similar (not shown).

Next, using regression analysis we adjusted for *parental educational level, employment status, country of birth, family composition, assessment of the child’s social-emotional development, number of children, and child’s age on completion of the questionnaire*. This yielded almost identical results (not shown).

Table 1 Characteristics of participants in the intervention and control condition

	Intervention condition N = 2542	Control condition N = 2328	P Value
Child's gender			
Male	1291 (50.8%)	1216 (52.2%)	.32
Female	1250 (49.2%)	1112 (47.8%)	
Education parent			
Lower	73 (2.9%)	62 (2.7%)	< .001
Secondary	1083 (42.9%)	733 (31.8%)	
Higher	1371 (54.3%)	1513 (65.5%)	
Parental age			
Mother	16 (0.6%)	15 (0.6%)	.77
< 20	2452 (96.8%)	2245 (97.1%)	
20 – 40	65 (2.6%)	52 (2.2%)	
40 and over			
Father	5 (0.2%)	7 (0.3%)	.14
< 20	2149 (89.1%)	1969 (90.6%)	
20 – < 40	258 (10.7%)	197 (9.1%)	
40 and over			
Employment status parent			
At least one parent works	2468 (97.7%)	2244 (97.1%)	.19
Neither parent works	59 (2.3%)	68 (2.9%)	
Country of birth parent			
At least one parent born in the Netherlands	2505 (99.2%)	2276 (99.0%)	.44
Both parents born outside the Netherlands	20 (0.8%)	23 (1.0%)	
Family composition			
Both biological parents or biological parent and partner	2460 (97.3%)	2267 (97.8%)	.20
One biological parent	69 (2.7%)	50 (2.2%)	
Number of children			
One child (only this one)	1092 (43.2%)	976 (42.3%)	.53
More children	1433 (56.8%)	1329 (57.7%)	
Social-emotional status child			
Fine	2010 (89.1%)	1805 (91.8%)	.01
Not optimal	213 (9.4%)	135 (6.9%)	
Problem	32 (1.4%)	27 (1.4%)	

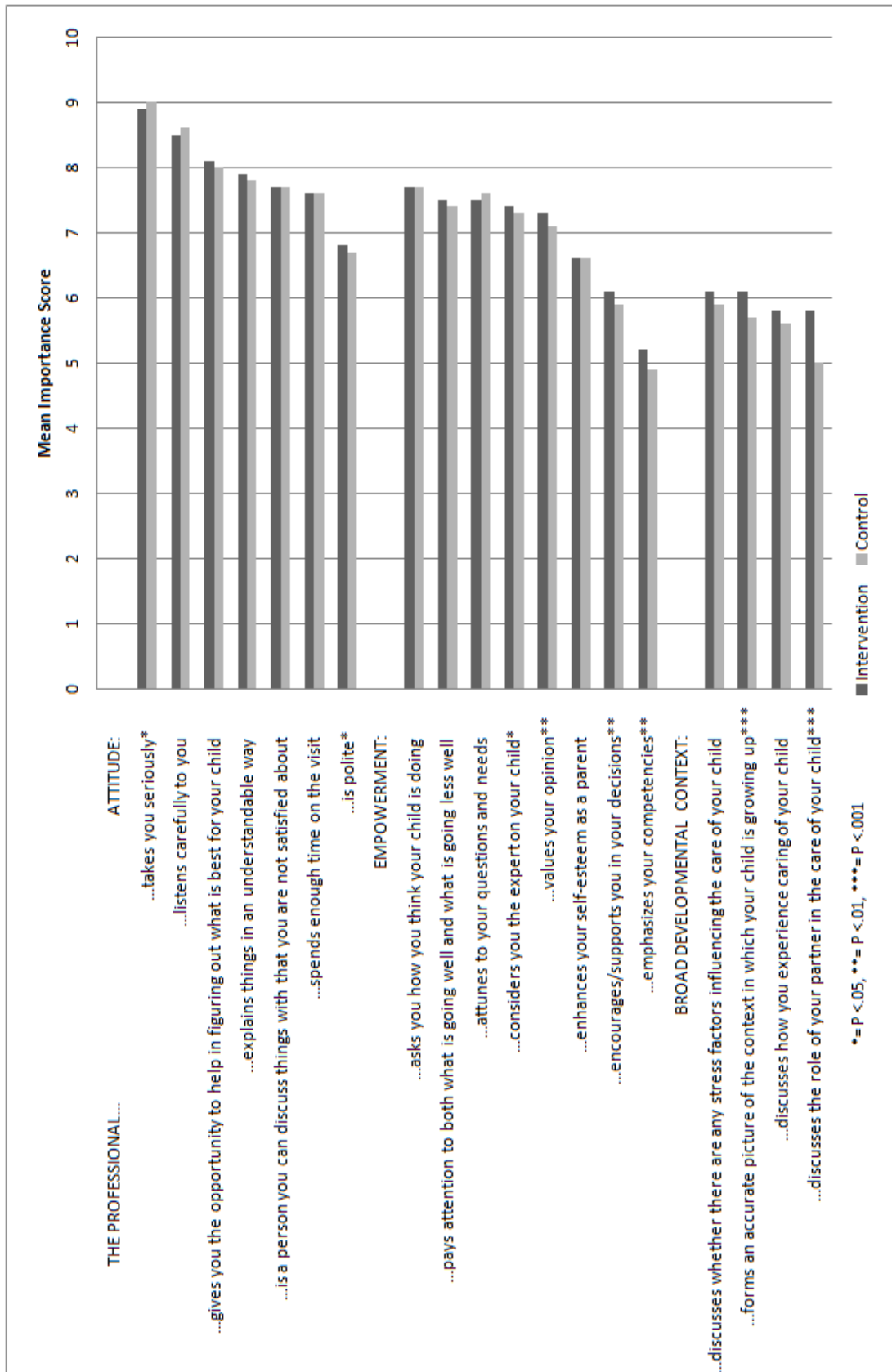


Figure 1. Parents' importance ratings on aspects of family-centered care. Meaning of importance scores: 0 = unimportant, 3 = fairly important, 6 = important, 10 = very important. *p < .05, **p < .01, ***p < .001.

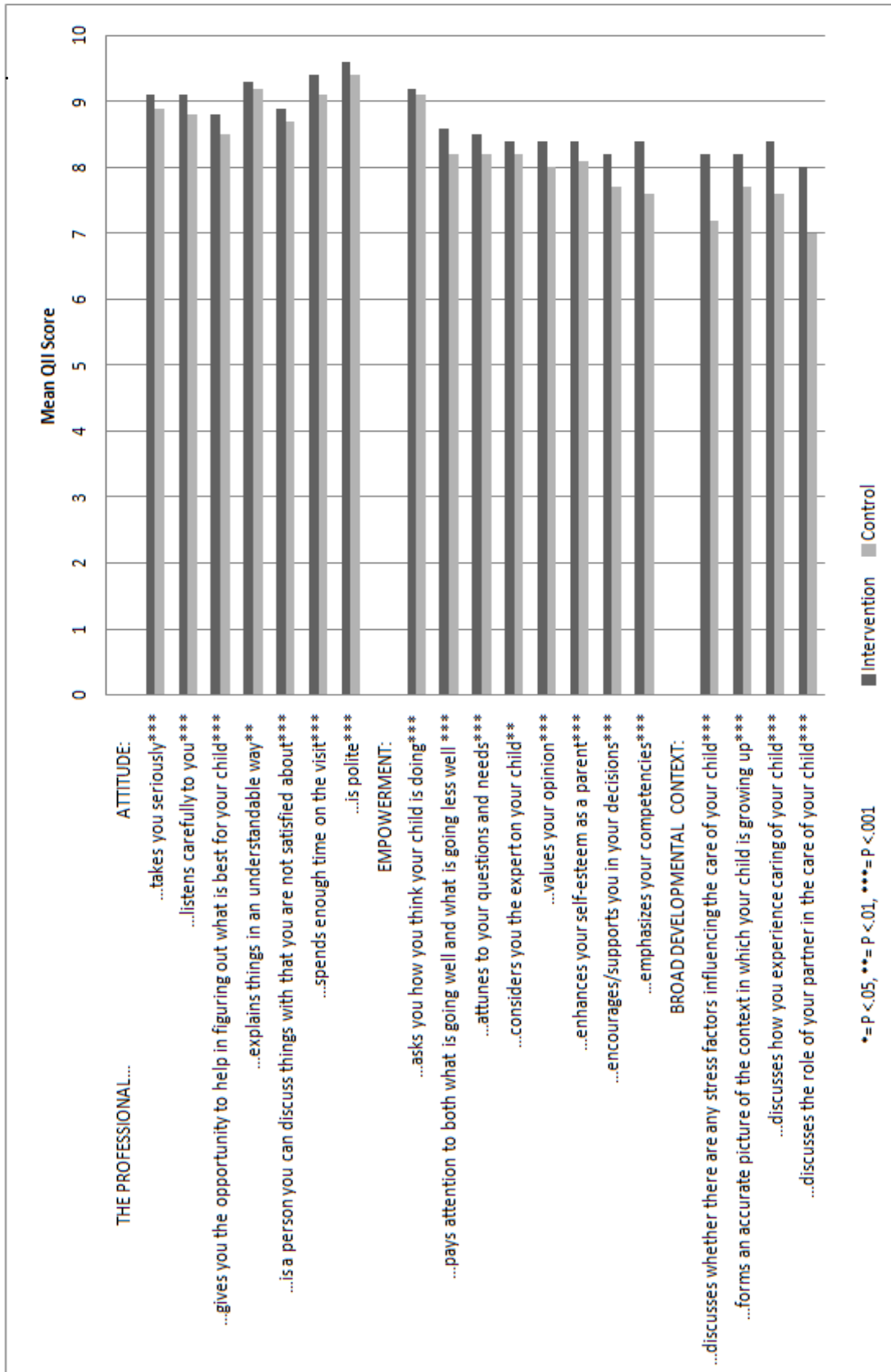


Figure 2. Mean quality impact index (QII) scores on each item. Higher QIIs represent better attunement of care to parents' preferences. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 2 Mean QIIs for the intervention and control condition and their differences

	Intervention		Control		Difference (95% CI)	P Value	Effect Size (<i>r</i>)
	Mean (N)	SD	Mean (N)	SD			
Attitude of the PCH professional	9.1 (1606)	1.1	8.9 (1467)	1.1	0.22 (0.14 to 0.30)	< .001	.10
Empowerment	8.4 (1621)	1.3	8.1 (1379)	1.3	0.33 (0.24 to 0.42)	< .001	.13
Broad developmental context	8.2 (1720)	1.4	7.3 (1362)	1.6	0.88 (0.75 to 0.97)	< .001	.27

QIIs ranged from 1 to 10, with higher scores representing better attunement.

CI, Confidence Interval

Modification by socioeconomic status and child's social-emotional status

Finally, we assessed the interaction effects of parental SES and child's social-emotional status with condition. Overall, parents with low SES rated items as more important than parents with medium or high SES, especially concerning the *broad developmental context*, though differences, if significant, were small (Cramer's $V = .04$ to $.10$). No interaction effect was found between SES and condition.

Considering the child's social-emotional status, parents rated nearly all items as less important when the child's status was assessed as *fine*, compared to *not optimal* or *problematic*. Effects were small in all cases, however (Cramer's $V = .04$ to $.05$). We found no notable differences between the conditions. There was no interaction effect of child's social-emotional status with condition.

Willingness to disclose concerns

Logistic regression analysis showed no significant effect of the family-centered approach on parents' willingness to disclose; in the intervention condition 86.7% of parents reported a high willingness to disclose concerns, versus 84.9% of parents in the control condition (OR: 1.15, $p = .09$). After adjusting for background variables, results remained

similar (not shown). No significant interactions were found regarding parental SES or child's social-emotional status with condition.

Most parents with a low willingness to disclose concerns reported that they sometimes (answer category 3) felt free to discuss all kinds of worries at the PCH center (78.7% in the intervention condition versus 81.1% in the control condition). Differences between conditions across the answer categories were not significant.

Multilevel analysis led to the same conclusions on our primary outcomes.

Discussion

The results of this study indicate, first, that parents consider the PCH professional's *attitude* as the most important of the three aspects of family-centered care and monitoring the *broad developmental context* as least important. Second, the family-centered approach was associated with better attunement of care to parents' preferences, compared to care-as-usual, though the effects were small. Third, the two conditions were alike regarding parents' willingness to disclose. Furthermore, findings on both attunement and disclosure were similar across our categories of parental SES and child social-emotional status.

Our finding that parents found monitoring the *broad developmental context* to be least important of the aspects mentioned (though still rather important), is comparable to a previous finding that 65% of parents considered discussing "family stress and family problems" during well-child visits as important, compared to higher percentages on child-related topics like physical development.²⁴ Perhaps parents view PCH as mainly child-focused and therefore find enquiries about developmental context to be less relevant. For parents who see little need for enquiries on the broad developmental context, PCH professionals may need to provide additional explanation regarding their importance. If parents are unwilling to discuss the developmental context with PCH professionals, then these professionals will need to find a balance between respecting this preference and providing care in the child's best interest.

The higher attunement scores within the family-centered care condition are consistent with a core principle of family-centered care: a tailored approach.³ That goal thus seems to be met. Measuring the quality of family-centered care by looking at parents' preferences as well as their actual experiences seems valid, since it provides insight into the extent to which care is tailored to needs. Within pediatric primary care, however, questionnaires used to assess family-centered care have focused only on experiences with care. Examples are the Consumer Assessment of Healthcare Providers and Systems²⁵ and the Promoting Healthy Development Survey.^{26,27} It is interesting to note

that parents' attunement scores on the three aspects of family-centered care were high in both conditions. Thus, in the control condition too, parents rated care as quite family-centered. The differences we found between conditions might have been larger if parents in both conditions would have rated all aspects as equally important, since for aspects rated as very important, attunement scores more heavily rely on the PCH professionals behavior compared to aspects rated as less important. Further research is needed to assess whether attunement scores also relate to adherence/ compliance, imparting parental knowledge, and to influencing parental attitudes and changing their behaviors.

Parents' willingness to disclose concerns was alike in the two conditions. The percentages that we found are in line with previous findings that, in general, parents are quite willing to discuss psychosocial concerns.^{28,29} Kahn et al. describe that more than 85% of mothers would not mind to discuss maternal health needs in pediatric settings²⁸. Furthermore, Horwitz et al. reported that 91.4% of parents of children aged 4-8 found it appropriate to discuss family problems with medical care providers in primary care.²⁹ However, reluctance stemming from mistrust and fear of judgment has also been described.³⁰ The latter apparently was not the case for the great majority of parents in our study. Whether parents are willing to disclose becomes most important when concerns actually exist, since parents may not always raise issues that concern them.^{16,29}

Effects of family-centered care were stable across parental SES levels and child's social-emotional status. Thus the improvements brought about by the family-centered approach on attunement of care would also seem to apply to more vulnerable groups, like those with low SES. In other countries, low SES and poorer child health have been related to less participation in well-child care.^{31,32} This is unfortunate, as especially these groups may benefit from well-child visits to provide preventive care in the child's best interest. Attunement of care may contribute to a positive attitude among parents toward care, prompting them to keep visiting.

Strengths and limitations

A strength of this study is the insight it offers into parents' preferences as well as their actual experiences with preventive care services for children and the extent that their preferences were met. This improves on previous questionnaires measuring family-centered care within pediatric primary care, which focused on the experiences only^{25,26} and not on parent-reported importance. Another strength is the computation of individual QIIs, as most studies using QUOTE questionnaires compute QIIs per patient group.^{17,18} The individual scores allowed us to incorporate background characteristics, like parental SES,

into the analyses. A last strength is our collection of data from a large sample with few exclusion criteria, therefore increasing the applicability of our findings.

Our study has limitations as well. First, we had a response of only 70%. However, response rates were nearly equal in both conditions, and the parents invited to participate were similar to those who were not, so we do not expect this to have influenced our results. Second, information bias might have played a role, since parents knew in which condition they were. It is unclear how this may have influenced results. Third, the effects found might be attributable to factors other than the family-centered approach, since we had no baseline information available before family-centered care was implemented. In particular, lengthening the well-child visit in the intervention condition when the infant was 8 weeks old may have influenced outcomes, as longer visits have been associated with higher family-centered care ratings.³³ Further research is needed to differentiate here. To disentangle the impact of time versus the family-centered approach, it would be interesting to compare the family-centered approach with care as usual to which also additional time had been given for the eight weeks' well-child visit. Fourth, contamination may have occurred, despite the effort we undertook to prevent this. If so, even though not highly likely, this would have led to our study underestimating the real effects of the family-centered approach.

Conclusion

The family-centered approach seems promising for raising the quality of preventive care services for children. Parents reported that the family-centered approach meets their expectations and preferences better than care-as-usual, in a PCH setting in which quality of care generally already was quite high. Moreover, it does so regardless of the parents' SES and the child's social-emotional status. Working with the family-centered approach therefore seems worthwhile. However, it would also be interesting to include other outcomes, like health care utilization and compliance with advices of PCH professionals. Furthermore, for organizations it would be good to consider both the benefits of the family-centered approach and its costs, to support a well-considered decision on possible implementation.

Our study may provide useful guidance for optimizing preventive care for children, since families' expectations and experiences are a critical determinant of the content of well-child visits.³⁴ Future research could point out whether findings are similar in groups with different cultural backgrounds and in different settings. Once organizations have insight in QIIs, like those presented in this study, it becomes clear which aspects are most in need of improvement^{17,18} so that quality of care might further be enhanced.

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