

MASTER THESIS

“Parents’ Perspectives on Care Pathways in Preventive Child Healthcare: A Mixed-Methods Study”

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ENGLISH ABSTRACT

Title: Parents' Perspectives on Care Pathways in Preventive Child Healthcare: A Mixed-Methods Study

Background: In the Netherlands, health and social care for children is often fragmented, due to insufficient care within care organisations. Other care environments have successfully implemented care pathways, reducing fragmentation of care. Therefore, two care pathways were developed for 18-months-old children in Preventive Child Healthcare (PCH). The modular care pathway aims to optimise coordination and offers care to risk groups. The e-consult care pathway creates flexibility of contact moments, while adjusting tasks of PCH on a scientific basis.

Aim: In order to adjust care pathways to the needs of parents, this study evaluated parents' perspectives on two care pathways for 18-months-old children in PCH.

Method: A mixed-methods explanatory sequential design was used. First, an online survey was used to identify parents' perspectives on care pathways. Second, two online focus groups were undertaken to explore those perspectives in more depth. Quantitative data were analysed with descriptive statistics and qualitative data were thematically analysed.

Results: Parents considered regular contact moments at PCH-center to be sufficient, but not always useful. Parents were properly referred to caregivers, and experienced an adequate collaboration. The information about care pathways was understandable and adequate. Parents noticed the added value of e-consults in care pathways, for instance as an information source. Parents considered that e-consults saved time, were practical and easy to use, and helped them to have more control of their child's care. Parents expressed their concern about loss of personal contact with PCH-nurses when using e-consults.

Conclusion: This study researched the perspectives of 78 parents regarding care pathways in PCH. Parents expressed generally positive perspectives. Attention should be paid to the worries of parents regarding the loss of face-to-face contact with PCH-nurses.

Recommendations: This study has provided insight in 78 parents' perspectives. Further research regarding parents' and professional's perspectives on care pathways complete the insight.

Keywords: Care pathways, Preventive Child Healthcare, Youth Family Centers, Process Evaluation, Parents' Perspectives.

DUTCH ABSTRACT

Titel: Perspectieven van ouders over zorgpaden in de jeugdgezondheidszorg: een mixed-methoden onderzoek

Achtergrond: In Nederland zijn jeugdzorg instellingen vaak gefragmenteerd vanwege slechte coördinatie. In andere zorgsettings is de fragmentatie tegen gegaan door het implementeren van zorgpaden. Om deze redenen zijn er twee zorgpaden ontwikkeld voor kinderen van 18 maanden oud in de jeugdgezondheidszorg (JGZ). Het modulaire zorgpad optimaliseert coördinatie en creëert extra zorg die nodig is voor risico groepen. Het standaard zorgpad creëert flexibiliteit van contactmomenten en past het takenpakket van JGZ aan op wetenschappelijke basis.

Doel: Het doel van deze studie was het evalueren van twee zorgpaden voor kinderen van 18 maanden oud in de JGZ. Dit met als hoofddoel het aanpassen van de zorgpaden aan de behoeften van ouders.

Methode: In deze studie is gebruik gemaakt van een verklarende mixed-methoden studie. Als eerste werd er een kwantitatieve online vragenlijst gebruikt om perspectieven van ouders over zorgpaden te onderzoeken. Vervolgens zijn er twee online focusgroepen opgestart om deze perspectieven gedetailleerder te onderzoeken. Kwantitatieve data is geanalyseerd door middel van beschrijvende statistiek en kwalitatieve data door middel van thematische analyse.

Resultaten: De reguliere contactmomenten op het consultatiebureau waren voldoende maar niet altijd nuttig. Ouders werden goed doorverwezen naar andere professionals. Door e-consulten kregen ouders meer de touwtjes in handen over de zorg van hun kind. De e-consulten waren praktisch, makkelijk in gebruik, tijdbesparend en een informatiebron. Ouders hadden de angst dat door het invoeren van e-consulten er kans is op minder persoonlijk contact met jeugdverpleegkundigen.

Conclusie: Deze studie onderzocht de perspectieven van 78 ouders ten opzichte van zorgpaden. Ouders hadden in het algemeen positieve perspectieven. De zorg van ouders over het verliezen van persoonlijk contact met professionals is een belangrijk aandachtspunt.

Aanbevelingen: Deze studie geeft inzicht in perspectieven van 78 ouders over zorgpaden. Verder onderzoek naar de perspectieven van ouders en professionals is nodig om een zo gedetailleerd mogelijk beeld te krijgen.

Trefwoorden: Zorgpaden, Jeugdgezondheidszorg, Centrum jeugd en gezin, Proces Evaluatie, Perspectieven van ouders.

BACKGROUND

In the Netherlands, different services and institutions provide health and social care for children. Each organisation has different priorities and each professional has different responsibilities. Due to insufficient coordination of care and responsibilities, the care is often fragmented (1,2). Fragmented care and insufficient coordination therein increase the risk of poor care and have serious consequences for children, especially for those children with inadequate parenting or problematic development (3,4)

Other care environments have decreased fragmentation of care by implementing care pathways. Worldwide, care pathways have been implemented to standardise and simplify health care, and to create better care coordination and outcomes (5-7). Vanhaecht et al. (5) defined 'care pathways' as: *'a complex intervention for mutual decision-making and organisation of care processes for a well-defined group of patients.'* Care pathways add a clear objective and a description of all care elements, such as communication between professionals, patients, family and care process coordinators (8). Care pathways are based on evidence-based standards, best practices and patients' expectations (7).

In the Netherlands the concept of Youth Family Centres (YFC) was developed to play a central role in the provisioning of information and advice on different themes, such as parenting, raising and development. YFCs consisting of different social and healthcare institutions for children are part of a regional YFC. Preventive Child Healthcare (PCH) is one of the partners of YFCs and its core task is to promote and protect health, psychological and mental development of youth (9). YFCs have only recently been developed and are still being optimised, especially regarding the collaboration and coordination between the different partners.

The Dutch government emphasised that development of care pathways is in line with future direction and vision of PCH, when care is coordinated with parents, not only by professionals (1). Possible benefits of using pathways in PCH include increased collaboration and professionalism, more effective care and parents'/professionals' satisfaction (5,7,10). Currently, two PCH care pathways are developed in the province of Zeeland (the Netherlands) for research purposes. These pathways focus on the care for 18-months-old children, a critical age for early detection of developmental delays (3,4,11,12). The first care pathway is an e-consult care pathway, typically used with 'ordinary' children who show no signs of (or risk for) inadequate raising or developmental problems. The purpose of this care pathway is flexibility of contact moments, while adjusting tasks of PCH in the Netherlands on a scientific basis. E-consultations require fewer face-to-face contacts, thus leading to

additional time being available for children where extra care is needed (12). E-consults and contact moments at 18 months after birth will be performed by PCH-nurses. The second care pathway, the modular care pathway, is used when families with 18-months-old children have a high or heightened risk of parenting problems, and aims to optimise coordination and offers care for risk groups, to both professionals and parents. Core focus of this pathway is cooperation within the YFC (12). The perspectives of parents have not yet been investigated (12). Collins dictionary defines perspective as: “*a way of regarding situations, facts, and judging their relative importance*” (13). In this study perspectives are the viewpoint of parents on the two care pathways, and what influence care pathways have on care processes. Knowledge of perspectives will lead to insights, and provides possibilities to improve care pathways, eventually ensuring optimal care processes (10,14,15).

Problem statement

Effectiveness and parents’ and professionals’ perspectives of care pathways in PCH should be investigated, before these care pathways can be further developed. Using insight in parents’ and professionals’ perspectives, care pathways can be improved to meet their needs and eventually ensure optimal care processes.

Aim

In order to adjust the care pathways to the needs of parents, this study evaluated the viewpoint of parents on the two care pathways for 18-months-old children in PCH.

Research questions

This study had one research question:

“ What are the perspectives of parents on e-consult or modular care pathways for children that are 18-months-old in Preventive Child Healthcare?”

METHODS

This study was performed following a mixed-methods explanatory sequential design. A preliminary investigation of available literature did not indicate a clear preference for one specific method to assess perspectives on care pathways (6,14,15), due to lack of description of psychometric qualities, benefits and methodological orientation and theory. Therefore, we combined several methods, decreasing the chance of not capturing all perspectives. Performing both qualitative and quantitative research triangulated consistency of results (16).

An online quantitative survey examined parents' perspectives on care pathways and was used to make a topic list for an online focus group (OFG). Two OFGs were undertaken to explore qualitative in depth perspectives on care pathways. This study took place between January 2013 and July 2013, and is part of a larger study on researching the applicability of care pathways in PCH in the Netherlands (12). This study focused primarily on parents' perspectives regarding both care pathways. The larger study was approved by UMCU's Medical Ethical Committee.

Participants

In the main study, 127 E-parents (e-consult care pathway) and 40 M-parents (modular care pathway), with an 18-months-old child at any time during the research period, were selected for either pathway, using the Structural Problem Analysis of Raising Kids (SPARK). The SPARK is a validated and reliable instrument for early detection and risk assessment of parenting and development problems in young children (3,4,11,12).

For our study these parents were contacted for participation. Interested parents were invited by researcher SvB, sending an e-mail with a link to the "Zeeuwse Zorgpaden Evaluatie" (ZZE) survey (in English: Zeeland care pathway evaluation). Afterwards parents had the option to join the OFGs. Consent to participate was assumed when the respondent returned the completed survey. Participants in the OFGs also participated in the ZZE-survey, which enhanced the external validity (17-19). Parents who consented to participate in OFGs were approached via e-mail and received an information letter. Consent was given by logging on to the e-portal. Literature suggestions to start with approximately five to fifteen participants were maintained (20-22).

Quantitative procedure

As no suitable existing survey could be identified for assessing parents' perspectives on care pathways, one was developed for this study (ZZE-survey).

For the ZZE-survey, of the 66 items in total, 45 items were derived from the Consumer Quality Index (CQI) JGZ survey (23) and 21 items were self-developed. Not all questions from the CQI-JGZ were used, based on research objectives of this study. The developed items were based on experiences of the researchers and published survey methodology (17,24). The CQI-JGZ survey is an assessment tool to measure parents' experiences with PCH, and is based on 182 items with a 5 or 6 point likert-scale, ranging from 1 (excellent/always) to 5/6 (very poor/never) and open-ended questions. CQI-JGZ showed sufficient internal consistency, content and discriminant validity (23).

The ZZE-survey consisted of seven elements: introduction, contact moments ($\alpha = 0.435$), e-consults ($\alpha = 0.638$), PCH-doctors/nurses ($\alpha = 0.858$), collaboration with care professionals ($\alpha = 0.695$), information, and personal details. The ZZE-survey items used self-assessment items; three, five or six subscales ranging from 1 (excellent/always) to 5/6 (very poor/never), 1 (yes) to 3 (no) and open-ended questions. The ZZE-survey was pilot-tested with several content experts to ensure content validity (16,17).

Domain scores were calculated for the questions about PCH-nurses/doctors attitude and expertise. The lower the domain scores, the more satisfied parents were (0/ excellent to 5/ very poor). Because the survey used dynamic question routing, the number of responses to domains varied. Participants who did not fill in any domain were excluded. The ZZE-survey was conducted online, using "Limesurvey" (25). Several steps were taken to improve the response rate (24), like sending reminders (seven and fourteen days after sending the survey) and mentioning the study's importance. See table 1 for example questions of the ZZE-survey.

[Table 1]

Qualitative procedure

Two moderated asynchronous (non-real-time) OFGs were conducted during two weeks, to explore the survey data in detail. OFGs showed numerous advantages over face-to-face focus groups (e.g. anonymity, no travel time), while feasibility and effectiveness were comparable (20,21,26,27). The OFGs were conducted according to the guidelines for online data collection (20,26,27). For our study a custom OFG format was developed. The forum's safety was extensively tested, to ensure that information was stored confidentially and was protected (21,27). To secure internal validity, all focus group data remained available for

member-checking (21). The higher level of anonymity in OFGs enhanced participation comfort (20,21,27).

The participants received anonymous, individual logins and passwords, allowing independent access to the website during two weeks (20,21). SvB acted as moderator, regularly checking postings and introducing questions concerning care pathway perspectives. Semi-structured questions were derived from the topic list. The topic list consisted of the same domains for both qualitative and quantitative focus. On the third day non-responding participants received an e-mail reminder. Questions remained open for discussion. Memos of OFGs were made to document the moderator's process-driven impressions. Table 2 gives an impression of OFG questions.

[Table 2]

Study parameters

The dependent variable of the study was the perspective of parents on care pathways; measured with the ZZE-survey and OFGs.

Data analysis

Demographic information and participants' answers to items of the survey were analysed using frequency counts and cross tabulations with SPSS 21 software. OFG data and survey comments were thematically analysed using NVIVO. Transcripts were read several times by SvB to identify codes and key categories, using open and axial coding (18,19). Quotes from participants were translated into English.

The data analysis occurred in three phases: analysis of the quantitative data, analysis of the follow-up qualitative data, and analysis of whether and how qualitative data helped to explain quantitative results (16). Results of all three research phases were interpreted separately and discussed by SvB & HvS and data were connected in the result section.

RESULTS

Of 167 parents, 97 (59%) completed the surveys, of which 78 (47%) were suitable for analysis. Nineteen participants only partially completed the ZZE-survey. Attrition analysis showed that parents who were less satisfied with care pathways were less likely to complete the survey. Ten E-parents (parents in the e-consult care pathway) and seven M-parents (parents in the modular care pathway) agreed to participate in OFGs, of which four E-parents and three M-parents actually participated. Attrition reasons were unknown. Open comments in the ZZE-survey provided fully detailed qualitative data, in OFGs no new information was found. All parents completed the same survey, but E-parents additionally answered questions about e-consults.

In both care pathways most participants were between 25-34 years old, born in the Netherlands and had an intermediate or high education level. See table 3 for characteristics. Only one respondent in the modular care pathway group had a low education level. Detailed quantitative results are included in table 4.

Contact moments at PCH-centre

Ninety-eight percent of E-parents and 93% of M-parents experienced the number of contact moments at the PCH as sufficient, but 70% of E-parents and 69% of M-parents did not consider all contact moments useful. Replacing the current contact moment at 24-months with an e-consult was indicated as a good idea by 88% of E-parents. Replacing even more contact moments with e-consults was acceptable for 68% of E-parents.

Qualitative data showed that the PCH-centre was mainly visited for vaccinations and doctor consults. In particular, parents with more than one child felt more confident about the care for their children. They perceived contact moments mostly as 'not useful' and 'time-consuming'. E-parents' biggest concern in replacing contact moments with e-consults was losing sight of children with parenting problems. One E-parent expressed her concern:

"I think if this is the future there will be a lot trouble for people especially those with their first child. There will be a lack of information, support and appeasement by replacing more contact moments with an e-consult."

E-parents reported that other parents had to be made aware that extra face-to-face contact moments are available on request. E-parents considered this especially important for first-time parents, which was also supported by M-parents. For example, one M-parent indicated:

“Especially with a first baby, face-to-face contact is important. Everything is new and it is nice when someone is watching with an open mind and answers questions.”

Perspectives on PCH-nurses/doctors and collaboration between care professionals.

Parents were asked about their experiences with the attitude and expertise of PCH-doctors and nurses. Domain scores for expertise and attitude of doctors/nurses from answers of the ZZE-survey were calculated. A score of ‘0’ was very good and ‘5’ was poor. For attitude the domain scores were: 1.45 (nurse), 1.96 (doctor) and for expertise: 2.45 (nurse) and 2.67 (doctor). PCH nurses were graded as an ‘8’, and doctors as a ‘7’ (on a scale of 10/very good) by 60% of E-parents and 43% of M-parents. Qualitative data indicated that parents were properly referred to relevant caregivers and experienced an adequate collaboration. One M-parent illustrated her view on PCH-nurses:

“It is pleasant that I can talk about everything and get advice at the PCH-centre. The PCH-nurses are competent. ”

Information about the care pathway study

Parents understood the information from the main study they received, but the amount of information about the care pathways was too much for some parents. Both parent groups considered that repeating the information contributed to eventually remembering it. E-parents preferred the information to be available at the e-portal; M-parents wanted the information again at the next consult. Indicated by:

“I find that at the age-18-months contact moment I get a lot of information. I would prefer if the information would be repeated at the next consult.”

Experiences of e-consults

E-parents reported being curious and had high expectations before e-consults started (87%). They were comfortable using e-consults and considered e-consults practical, easy to use, and had an inviting design (68%). Furthermore e-consults covered the various topics excellently (88%).

Qualitative data indicated that some E-parents felt that in regular face-to-face contacts, PCH-doctors did not always listen to them or gave them advice they already received. By using e-consults, they felt more in control and less dependent of nurses and doctors. The e-consult portal allowed parents to monitor their children’s development, giving them a more confident feeling. One E-parent said:

“At the PCH-centre I have seen several PCH-doctors. One better than the other. Sometimes I returned from the PCH-centre and I felt they did not listen to me. Now I have been given the freedom to find out for myself. With the e-consult I can check myself and it appears that we are all doing well and that gives me more confidence.”

Some E-parents experienced technical problems when logging in to the e-portal. Professionals were open about issues with the e-portal, which prevented parents from developing negative feelings about the e-consult. Most problems with logging in were caused by DigiD (Dutch identity provider). Some E-parents did not know a DigiD account was required for e-consults. They felt that they should have been informed better and would prefer using a simple password instead of DigiD:

“Logging on is very cumbersome. Especially if you never use your DigiD. This should not have to be linked to DigiD.”

E-parents indicated that completing surveys on the portal was time-consuming, but they enjoyed completing them. E-parents suggested to include a better indication at which age a child is expected to have developed certain skills. Some E-parents expected that risk families were more likely to provide socially desirable answers, increasing the risk that problems within these families, such as child maltreatment, would be missed. E-parents reported that PCH-nurses did not always provide feedback after parents completed the surveys. Some parents saw this as a good sign, other wanted to receive feedback no matter what. One E-parent indicated:

“The PCH nurse did not provide the results of the e-consult back to me. I expect that everything is good hence my answers. But I know where to find her if necessary.”

Parents considered personal contact with the PCH-nurse very important, which was not provided in e-consults. Parents preferred to have the option to directly speak to a nurse, and to request a face-to-face consult with the nurse. Providing a phone number was considered a solution.

[Table 3]

[Table 4]

DISCUSSION

This study is the first to examine parents' perspectives on PCH care pathways. Both parents groups considered the frequency of contact moments at the PCH-centre to be sufficient, but not always useful. Most of the time parents were properly referred to relevant caregivers and experienced an adequate collaboration between care professionals. Parents understood the information that was provided about the care pathways. But E-parents preferred information to be available at the portal, while M-parents preferred to repeat the information at a next consult. E-parents were curious about e-consults, and had high expectations before e-consults started. They felt more in control of their child's care when using e-consults and considered e-consults practical, time-saving and easy to use. PCH-nurses did not always provide feedback after E-parents completed the surveys. Some E-parents saw this as a good sign, other wanted to receive feedback no matter what. E-parents were worried about less guidance for families with difficulties. Also E-parents expressed their concern about loss of personal contact with PCH-nurses when using e-consults.

Even though no prior studies have researched the parents' perspectives on care pathways in PCH, these studies have been performed in general health care (10,14,15). The patients and professionals who were included in those studies described generally positive perspectives on care pathways. These findings correspond with our findings in PCH.

In our study parents worried not so much about their own parenting skills but more about skills of others. It is possible that parents mentioned this so often because of the current media attention for problematic child care, such as newspaper articles (28).

This fear was unnecessary, because families with risk factors were excluded of e-consults, since the SPARK-criteria were used to select families (3,4,11,12). The fact that parents mentioned these worries also showed that they did not feel they were being assigned to a particular group, which was a concern of the professionals.

Literature described the numerous advantages and success of OFGs (20,21,26,27). However the interaction between parents in our study required constant stimulation by researchers in order to remain active. The final results and the low response rate were not what we expected. A possible explanation for this is that the OFGs from literature were intended for chronically ill patients, who used OFGs for social support, exchanging information and interaction with other patients, mainly about their experiences and how they resolved problems (25,26,28,29,30). The parents in our study did not experience any problems, probably causing the low response rate. Therefore we recommend the use of open-ended survey questions over the use of OFGs in this setting.

The findings of this study were strengthened by the use of mixed-methods data collection. The qualitative data provided a better understanding of quantitative responses.

However, this study's results should be viewed with caution. The CQI-JGZ scores of our study could not be compared to the national score. NIVEL did not have single questions scores, this making it impossible to interpret the answers outside this study. A self-developed, pilot-tested survey made it possible to measure the participants' perspective, but with limited validity. The data analysis was conducted by one researcher, making researcher subjectivity possible. Frequent consultation with academic supervisors reduced this chance, but it is still possible that researcher subjectivity has altered the results somewhat. The drop-out of less positive parents might have resulted in more positive results than in reality. Finally, the socio-demographic characteristics between this study and the main study slightly differed on educational level. Possible explanations may be: only the high-educated parents consented to participation or several parents were selected for the e-consult pathway in the main study, but not yet received an e-consult, thus answering the selection question of our study with 'no', causing them to end up in the modular care pathway group.

Keeping the limitations in mind, this study has provided insight in the perspectives of 78 parents on care pathways. Further research regarding parents' perspectives and professionals' perspectives on care pathways complete the insight.

CONCLUSION AND RECOMMENDATIONS

This study researched the perspectives of 78 parents regarding care pathways in PCH. Both parent groups expressed generally positive perspectives; Parents considered regular contact moments at PCH-centre sufficient but not always useful. Most of the time parents were properly referred to relevant caregivers and experienced an adequate collaboration between care professionals. The information that was provided in care pathways was understandable and adequate but sometimes too much. Parents saw the added value of e-consult care pathways, for instance as an information source. Parents who were working with the e-consult care pathway experienced that the care pathways saved time, were practical and easy to use, and helped them to have more control of their child's care. Attention should be paid to the concerns of parents regarding the loss of face-to-face contact with PCH-nurses when using e-consults, and PCH-nurses should be stimulated to always provide feedback to parents after surveys were completed. The parents' perspectives should be further researched, as should be professionals' perspectives.

REFERENCES

- (1) Van Yperen VW. Werk in Uitvoering (work in progress). Available at: <http://www.nji.nl/eCache/DEF/1/27/088.html>. Accessed 09/18, 2012.
- (2) De Waal S. Een betere zorg voor Jeugd. Decentralisatie van de Jeugdzorg als kans (Better care for Youth: Decentralisation of Youth as an opportunity). 2012; Available at: <http://www.nji.nl/eCache/DEF/1/24/120.html>. Accessed 09/18, 2012.
- (3) Staal IIE, Hermanns JMA, Schrijvers AJP, van Stel H. Risk assessment of parents' concerns at 18 months in preventive child health care predicted child abuse and neglect. *Child Abuse Neglect* 2013.
- (4) van Stel H, Staal IIE, Hermanns JMA, Schrijvers AJP. Validity and reliability of a structured interview for early detection and risk assessment of parenting and developmental problems in young children: a cross-sectional study. *BMC pediatrics* 2012;12:71-71.
- (5) Vanhaecht K, De Witte K, Depreitere R, Sermeus W. Clinical pathway audit tools: a systematic review. *J Nurs Manag* 2006 Oct;14(7):529-537.
- (6) De Bleser L, Depreitere R, De Waele K, Vanhaecht K, Vlayen J, Sermeus W. Defining pathways. *J Nurs Manag* 2006 (7):553-563.
- (7) Vanhaecht K, De Witte, De Witte KF, Depreitere R, Van Zelm R, De Bleser LF, Proost KF, et al. Development and validation of a care process self-evaluation tool. *Health services management research : an official journal of the Association of University Programs in Health Administration* 2010;1213.
- (8) Huiskens N, Schrijvers AJP. Het zorgpadenboek: voorbeelden van goede ziekenhuiszorg (The care pathway book: examples of good hospital practices). 1st ed. Amsterdam: Uitgeverij Thoeis 2011.
- (9) Jeugdgezondheidszorg (Preventive Child Healthcare). Available at: <http://www.ggdzeeland.nl/onderwerpen/jeugdgezondheidszorg/>. Accessed 01/20, 2013.
- (10) Renholm M, Leino Kilpi H, Suominen T. Critical pathways. A systematic review. *J Nurs Adm* 2002;32(4):196-202.
- (11) Staal IIE, van den Brink, H A G., Hermanns JMA, Schrijvers AJP, van Stel HF. Assessment of parenting and developmental problems in toddlers: development and feasibility of a structured interview. *Child care health and development* 2011;37(4):503-511.
- (12) ZonMw. toepassen van zorgpaden in de jeugdgezondheidszorg (applicability of care pathways in preventive child healthcare) 2013; Available at: <http://www.zonmw.nl/nl/projecten/project-detail/toepassen-van-zorgpaden-in-de-jeugdgezondheidszorg/samenvatting/>. Accessed 01/02, 2013.
- (13) Collins. Collins dictionaries thesaurus. 2013; Available at: <http://www.collinsdictionary.com/dictionary/english-thesaurus/perspective>. Accessed 06/08, 2013.
- (14) Hunter B, Segrott J. Using a clinical pathway to support normal birth: impact on practitioner roles and working practices. *Birth* 2010;37(3):227-236.

- (15) Hall J, Callaghan P. Focus group study of service user and carer experience of an Integrated Care Pathway. *Int J Care Pathways* 2011;06;15(2):44-48.
- (16) Creswell J, Plano Clark V. *Designing and conducting Mixed Methods Research*. Thousand Oaks: SAGE; 2011.
- (17) Pollit D, Beck C. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Philadelphia: Wolters Kuwer Health: Lippincott Williams & Wilkins; 2012.
- (18) Creswell J. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. 2nd ed. Thousand Oaks: Sage publications; 2007.
- (19) Boeije H. *Analyseren in kwalitatief onderzoek (qualitative analysis)*. Den Haag: Boom Lemma Uitgevers; 2005.
- (20) Tates K. Online focusgroepgesprekken als methode van data verzamelen (Online focus groups as data collection methods). *Kwalon* 2010;15(2).
- (21) Zwaanswijk M, Tates K, van Dulmen S, Hoogerbrugge P, Kamps W, Bensing J. Young patients', parents', and survivors' communication preferences in paediatric oncology: results of online focus groups. *BMC pediatrics* 2007;7:35-35.
- (22) van Uden-Kraan CF, Drossaert CHC, Taal E, Seydel ER, van de Laar, M A F J. Participation in online patient support groups endorses patients' empowerment. *Patient Educ Couns* 2009;74(1):61-69.
- (23) Reitsma van Rooijen M, Damman O, Sixma H, Spreeuwenberg P, Rademakers J. CQ-CQ-index Jeugdgezondheidszorg: meetinstrumentenontwikkeling, kwaliteit van de JGZ 0-19 jaar: vanuit het perspectief van ouders en kinderen (Index Preventive Child Healthcare: assessment tool development; quality of PCH 0-19 years from the perspectives of parents and children). Utrecht: NIVEL; 2009.
- (24) de Leeuw E, Hox J, Dillman D. *International Handbook of Survey Methodology*. 1st ed. New York: Psychology Press European Association of Methodology; 2008.
- (25) Chenu D. Limesurvey: the open source survey application refreshingly, easy and free. 2012; Available at: <http://www.limesurvey.org/nl>. Accessed 02/11, 2013.
- (26) Fox F, Morris M, Rumsey N. Doing synchronous online focus groups with young people: methodological reflections. *Qual Health Res* 2007;17(4):539-547.
- (27) Duffy M. Methodological issues in Web-based research. *Journal of nursing scholarship* 2002;34(1):83-88.
- (28) Trouw. Ouders van nu willen geen gehoorzaam kind (Parents do not want an obedient child). 2013; Available at: <http://www.trouw.nl/tr/nl/4556/Onderwijs/article/detail/3382836/2013/01/25/Ouders-van-nu-willen-geen-gehoorzaam-kind.dhtml>. Accessed 06/06, 2013.
- (29) Eysenbach CF. Self-Reported Differences in Empowerment Between Lurkers and Posters in Online Patient Support Groups. *Journal of medical internet research* 2008;10(2):101-109.

(30) Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ.British medical journal* 2004;328(7449):1166-1166.

(31) CBS. Statistics Netherlands. 2013; Available at: <http://www.cbs.nl/nl-NL/menu/themas/onderwijs/nieuws/default.htm>. Accessed 06/06, 2013.

TABLES

Table 1: Example of questions in the ZZE-survey

Topics	Example questions
<i>Introduction</i>	Our administration indicates that your child is under the age of four years old and is participating in one of the two care pathways in Preventive Child Healthcare in Zeeland. Is that correct? <input type="checkbox"/> Yes <input type="checkbox"/> No
Contact moments	Are the contact moments at the PCH centre sufficient? <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Never <input type="checkbox"/> Not applicable
PCH-doctors/nurses	Do you think that the PCH nurse is competent? <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Never <input type="checkbox"/> Not applicable
Collaboration with care professionals	Did the PCH centre reference you properly to other caregivers if necessary? <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Never <input type="checkbox"/> Not applicable
E-consults	In what ways covers the e-consult your needs and questions about parenting and developments themes in the care for your child? <input type="checkbox"/> Excellent <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Moderate <input type="checkbox"/> Bad
Information	Was the information about the care pathway study understandable? <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Never <input type="checkbox"/> Not applicable
<i>Personal details</i>	What is the native country of your child? <input type="checkbox"/> The Netherlands <input type="checkbox"/> Belgium <input type="checkbox"/> Germany <input type="checkbox"/> Turkey <input type="checkbox"/> Morocco <input type="checkbox"/> Other

Table 2: Example of questions in the OFG

Topics	Example questions
<i>Introduction</i>	Do you want to participate in the online focus group? <input type="checkbox"/> Yes <input type="checkbox"/> No
Contact moments	"I think the number of contact moments at the Preventive Child Healthcare Centre is sufficient, I also think the number of contact moments is useful" Do you agree?
PCH-doctors/nurses	"The PCH nurse is competent. I know where to find her if necessary" Do you agree?
Collaboration with care professionals	"I feel that I remain in control of the care of my child, because ..."
E-consults	"What were your expectations before the start of the e-consult care pathway and what did and what did not meet your expectations?"
Information	Was the information about the care pathway study understandable?
<i>Personal details</i>	x <i>To ensure anonymity no personal details were asked in OFGs.</i>

Table 3: Demographic characteristics of survey respondents*

Characteristics of parent who answered the survey		E** (%)	M*** (%)
		(n=46)	(n=32)
Gender of the parent	Female	84.8	93.8
	Male	15.2	6.2
Age of the parent	18-24 years	2.2	
	25-34 years	60.9	65.6
	34-44 years	26.1	28.1
	45-54 years		6.3
Highest level of education#	Low: no education or elementary education		3.2
	Intermediate: high-school or middle-level applied education	53.7	29.0
	High: higher professional or academic education	43.9	54.8
Number of children	One child	34.8	31.3
	Two children	43.5	43.8
	Three or more children	21.7	24.9
Native country of the child	The Netherlands	82.6	96.9
	Belgium	6.5	
Native country of the mother	The Netherlands	84.8	93.8
	Belgium	2.2	
	Germany	2.2	
	Poland		3.1
Native country of the father	The Netherlands		87.5
	Morocco	89.1	3.1
	Aruba		3.1

* Missing data is excluded

**E= E-consult care pathway

***M= Modular care pathway

Typology of level of education was derived from CBS Statistics (31)

Table 4: Parents perspectives on care pathways in PCH*

Topics			E** (%)	M*** (%)
Contact moments	Number of contact moments	Excellent/Good	97.8	93.8
		Moderate	2.2	
	Usefulness of contact moments	Always/Mostly	69.9	68.8
		Sometimes	28.3	31.3
		(n=46)	(n=32)	
Perspectives on PCH-nurses/doctors Collaboration between care professionals	Consistency of advice from professionals	Mostly	46.2	36.4
		Sometimes/Never		18.2
		Not applicable	53.8	45.5
	Adequate collaboration	Mostly	15.4	9.1
		Sometimes/Never	7.7	18.2
		Not applicable	76.9	72.7
	Referenced properly to relevant caregivers	Mostly	7.7	27.7
		Sometimes/Never	23.1	
		Not applicable	69.2	72.7
			(n=28)	(n=21)
Information about the care pathway study	Sufficiently informed	Always/Mostly	36.6	40.6
		Sometimes/ Never	54.3	53.1
	Understandable information	Always/Mostly	87.8	84.4
		Sometimes/ Never	53.1	12.5
		(n=28)	(n=21)	
E-consult	Expectations of the e-consult	Excellent/Good	87.0	
		Moderate/Bad	13.0	
	Succeed to login on the e-consult	Excellent/Good	63.0	
		Moderate/Bad	37.0	

Experiences of login on the e-consult	Excellent/Good	67.8	
	Moderate/Bad	32.2	
Replacement of current contact moment by an e-consult	Excellent/Good	88.0	
	Moderate/Bad	12.0	
Replacement of more contact moment by an e-consult	Excellent/Good	68.0	
	Moderate/Bad	32.0	
Experienced usefulness	Excellent/Good	92.9	
	Moderate/Bad	7.1	
E-consult covered the various topics	Excellent/Good	88.0	
	Moderate/Bad	12.0	
Feedback after completing the questionnaires (nurse)	Excellent/Good	72.0	
	Moderate/Bad	28.0	
		(n=46)	(n=0)

Table included percentages of parents' perspectives on care pathways in PCH. Perspectives were assessed by the ZZE-survey, which is specifically developed for this study and based on the CQI-JGZ survey (23) and self-developed items

*missing data excluded Forty-six parents answered questions about the e-consult care pathway and 32 parents about the modular care pathway. 12 parents answered questions about the PCH centre and 49 parents about collaboration with (other) care professionals

**E= E-consult care pathway

***M= Modular care pathway