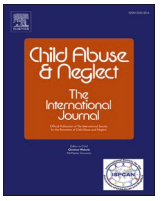
Child Abuse & Neglect 169 (2025) 107681

Contents lists available at ScienceDirect

Child Abuse & Neglect

journal homepage: www.elsevier.com/locate/chiabuneg



Characteristics of 86 families and 142 children diagnosed with Pediatric Condition Falsification in the Netherlands

P.I.M. Worm [a,*], A.H. Teeuw [b], M.J. Steketee [c]

[a] Pediatrician/confidential doctor at The Municipal or Community Health Service (in Dutch: GGD), Veilig Thuis, the Netherlands
[b] Pediatrician in social pediatrics at the Emma Children's Hospital-Amsterdam UMC, the Netherlands
[c] Department of Psychology, Education and Child studies, Erasmus University Rotterdam, Burgemeester Oudlaan 50, 3062 PA, Rotterdam, the Netherlands

ARTICLE INFO

Keywords:
Münchausen by proxy-fabricated and induced illness
Pediatric condition falsification
Medical child abuse
Factitious disorder imposed on self
Fabricated or induced illness
Caregiver fabricated illness

ABSTRACT

Background: The aim of this study is to analyse cases of Pediatric Condition Falsification reported to the Child Abuse Counseling and Reporting Center (CACRC) to gain more insight into possible trends or common factors that could result in an earlier diagnosis of Pediatric Condition Falsification (PCF) and identify which information is lacking. This study is the first to use the data of PCF cases reported to the CACRC in the Netherlands.
Methods: All CACRC-files with suspected and confirmed PCF were collected over a five-year period, from January 2008 to December 2013, two of 26 CACRCs did not deliver any files. The Medical Ethical Review Committee of the Erasmus Medical Centre, Rotterdam, decided on June 20, 2014, that informed consent could be waived (METC 2014 349). Files of 86 families, with 142 children were studied.
Results: This study has provided several new insights: about the reporter, involvement of (medical) professionals, the absence position of the fathers, restrictions in daily functioning and recovery of the PCF-victims, and the high number of formal complaints against the CACRC. This study showed a high rate of extensive medical history and a problematic childhood of the perpetrator, in accordance with literature. Information about the child's own point of view was lacking in the files.
Discussion: This study is the first PCF study in the Netherlands to use data from the CACRC. This study made clear that a more complete and uniform method of collecting information for the CACRC case file, incorporating the child's own point of view, has to be implemented.
Conclusion: Besides new information concerning the reporter, fathers' position, perpetrator's history and formal complaints, this study highlighted the need for uniform questionnaires. Implementing these will lead to better data collection, potentially resulting in more knowledge about PCF and the child's own perspective. A concept questionnaire has been added as an appendix (Dutch Guideline KMdF, 2025).

1. Introduction

Pediatric Condition Falsification (PCF) (previously called Munchausen by proxy) is a form of child abuse in which a parent or

* Corresponding author.
E-mail address: pworm@veiligthuisgz.nl (P.I.M. Worm).

https://doi.org/10.1016/j.chiabu.2025.107681
Received 27 May 2025; Received in revised form 5 September 2025; Accepted 8 September 2025
Available online 27 September 2025

caretaker falsifies illness in a child by fabricating or inducing symptoms and presenting the child for medical care while disclaiming knowledge of the cause of the problems.

Since the introduction of the term "Münchausen (Syndrome) by proxy" (M[*S*]BP) by Meadow in 1977, there has been a lot of debate about what M(*S*)BP exactly entails (Meadow, 2002). The definition overall includes characteristics of the behavior and/or intentions of a perpetrator, mostly a parent or caretaker, and characteristics of the abuse suffered by the proxy, mostly a child (Ayoub, Alexander, Beck, Bursch, et al., 2002). Meadow (1977) first described M(*S*)BP, referring to mothers deliberately falsifying illness in their children. Meadow used the term to describe the combination of the abuse (and neglect) and the motivation of the caregiver. However, confusion arose whether the term should be applied to the child as a victim of abuse or to the abuser who intentionally falsifies illness, and whether the motivational component should be part of its definition or not (American Professional Society on the Abuse Children, 2017; Mart, 2004). As a result, various definitions and new terminology have been introduced. Attempts have been made to capture the motivational component in the diagnosis/description of the psychopathology of the perpetrator engaging in M(*S*)BP abuse. The Diagnostic and Statistical Manual of Mental Disorders (DSM) proposed the term Factitious Disorder by Proxy (FD[*B*]P) in 1994 (DSM-IV, American Psychiatric Association, 1994). It was not until the fifth edition of the DSM (DSM-5, APA, 2013) that the diagnosis was officially included, now described by the term "Factitious Disorder Imposed on Another" (FDIA), and containing an altered set of criteria:

A. Falsification of physical or psychological signs or symptoms, or induction of injury or disease, in another, associated with identified deception.
B. The individual presents another individual (victim) to others as ill, impaired, or injured.
C. Deceptive behavior is evident even in the absence of obvious external rewards.
D. The behavior is not better explained by another mental disorder, such as delusional disorder or another psychotic disorder.

Still, with its focus on deception, this definition of FDIA does not encompass all possible psychopathology and/or motivations caregivers may have, underlying their behavior of falsifying physical or psychological signs or symptoms in their children.

Others criticize that by focusing on the perpetrator, half of the picture is neglected; the definition should also focus on the abuse and its victim (APSAC, 2017; Ayoub, Alexander, Beck, Christian, & Daniels, 2002; Frye & Feldman, 2012; Galvin et al., 2005), and many argue that the abuse should even be the primary focus (Mart, 2002; Mart, 2004; Davis et al., 2019; Glaser & Davis, 2019; RCPCH, 2021; Roesler, 2018). To address this issue, an APSAC taskforce introduced the term "Pediatric Condition Falsification" (PCF; Ayoub, Schreier, & Keller, 2002; in Frye & Feldman, 2012) to refer to a form of child maltreatment in which an adult falsifies physical or psychological signs or symptoms in a victim, causing the victim to be regarded as more ill or impaired than is objectively true (APSAC, 2017; Frye & Feldman, 2012). To clarify that this term refers to child abuse and neglect, they later added the words "abuse by" (APCF; APSAC, 2017). (A) PCF refers to child abuse regardless of motivation. Therefore, (A)PCF can exist without a parent being diagnosed with FDIA (Galvin et al., 2005).

However, APSAC has held on to the term M(*S*)BP as the umbrella term, with PCF defining the part of the abuse and FDIA the part of the psychopathology of the abuser. By applying this terminology, some have argued that the focus is still too much on the abuser and the implied psychopathology instead of the abused child, and the involvement of the third party, the health care professional, isn't addressed enough (RCPCH, 2021; Roesler, 2018). Furthermore, its categorical nature does not cover the full range of abuse and underlying motivations but implies only the most severe forms of abuse and parental behavior and motivation (Mart, 2004). Therefore, the abandonment of these potential prejudicial labels has been suggested in favor of what is suggested to be a more general term: "medical child abuse" (MCA; Mart, 2004; Roesler, 2018).

Roesler (2018) states that MCA clearly labels the behavior as a form of abuse, not as a diagnosis, while explicitly stating the medical connection. Just as physical and sexual child abuse, it refers not to any medical condition that the child may have, but to an event or series of events in a child's life which may have medical consequences. Just as the other forms of abuse can be described as occurring on a continuum of severity form mild to moderate to severe. Roesler stresses that for healthcare providers their priority should not lie with the parent and the motivation behind the abuse, but with the child and ensuring that potentially harmful therapies are stopped (Roesler, 2018). Roesler's line of thinking concurs with the most recent view of the American Academy of Pediatrics (AAP), which coined another term with a definition that is focused on the abused child and not, or less on the motivation of the caregiver: Caregiver-fabricated illness in a child (CFIC; Flaherty et al., 2013; in APSAC, 2017). It is defined as maltreatment that occurs when a child has received unnecessary and (potentially) harmful medical care because of the caregiver's fabricated claims, or signs and symptoms induced by the caregiver.

The Royal College of Paediatrics and Child Health (RCPCH) distanced themselves from M(*S*)BP and associated terminology and introduced their own terminology: the Perplexing Presentations (PP) and the Fabricated or Induced Illness (FII) spectrum (RCPCH, 2009; in Abdurrachid & Gama Marques, 2022; RCPCH, 2021). This terminology describes a wide range of possible cases of falsification of injury or disease in a child, with cases ranging in severity of signs and symptoms, their impact on a child's quality of life and functioning, and in the health professional's certainty about if and how a parent may be involved in the causation of the reported or observed signs and symptoms. The RCPCH (2021) guideline consistently uses the term "parent" in their definitions, specifying that the mother is nearly always involved in PP/FII. Other's (e.g. Davis et al., 2019) prefer the more general terms "carer" or "caregiver."

- Perplexing Presentations (PP) encompass clinical situations where there are alerting signs of possible FII. The essence of these alerting signs is the presence of discrepancies between reports, presentations of the child and independent observations of the child, implausible descriptions and unexplained findings. Furthermore, health professionals are alert to the possibility that there may be

an unusual and potentially harmful parent-child interaction that is causing or perpetuating the presentation, observing that parents are reluctant to support a rehabilitative approach to the child and focus or insist on continued investigations. However, while an adequate and realistic medical explanation is absent and the actual state of the child's health is not yet clear, the extent and risk of immediate harm to the child is not (yet) perceived, the association between the possible harm to the child and parents' actions not (yet) established (Glaser & Davis, 2019; RCPCH, 2021).

- Fabricated or Induced Illness (FII) refers to clinical situations in which a child is, or is very likely, harmed due to actions of a parent, carried out in order to convince health professionals that the child's state of physical and/or mental health or neurodevelopment is impaired, or more impaired than is actually the case. FII is a form of child abuse and neglect, physical and/or emotional, that results from behaviors or beliefs of a parent and from subsequent responses of the health professional (i.e. iatrogenic harm; RCPCH, 2021).

A key aspect of the RCPCH terminology is that understanding the parents' motivation is not essential to establish (apply the labels) PP/FII in a child. This is important for pediatricians, because they are not expected to understand parental motivation, but simply to understand the cause of the child's presenting illness. Contrary to FDIA, where deception is an essential criterium for its diagnosis, in FII, when motivation is evident, the parent does not necessarily intend to deceive.

The RCPCH (2021) (also in Davis et al., 2019) distinguishes two possible types of parental motivations for FII:

1. Parents may experience a gain from the recognition and treatment of their child as unwell. The parent is thus using the child to fulfil their needs, disregarding the effects on the child. Gains can be psychosocial (e.g. a need for sympathetic attention, support, continued closeness of their child, and/or a need to deflect blame for parenting difficulties or child behavioral problems) and/or material (e.g. financial support for care, improved housing). Personality disorders and deception are more likely in parents with this type of motivation.
2. Parents may have an extreme concern and anxiety about their child's health and may develop, with the aid of the internet, erroneous beliefs about what their child needs (e.g. support, treatment) based on a misinterpretation or misconstruction of aspects of their child's presentation and behavior. They then need these beliefs confirmed and acted upon to the detriment of their child. In rare cases, these beliefs about the child's health may become fixed or delusional. Anxiety disorders are more likely in parents with this type of motivation.

The following methods of falsification are known (APSAC, 2017; Galvin et al., 2005):

- Providing false information about the child's current situation and history of symptoms, limitations, or treatments;
- Withholding information that would help explain the child's current presentation;
- Exaggerating symptoms or limitations, so that the child is seen as more severely ill or impaired than is true;
- Simulating symptoms by manipulating test procedures or results;
- Neglecting the child by withholding nutrition, or treatments;
- Inducing symptoms or impairments;
- Coaching/manipulating the victim or another person involved to answer questions in a way that substantiates and corroborates the false claims of the abuser.

Just as the APSAC, the RCPCH (2021) (also in Davis et al., 2019) describes the different ways in which parents may falsify signs and symptoms and persuade health professionals to investigate and treat their child:

1. The most common way is by "using their mouth", presenting and erroneously reporting of their child's symptoms, history, results of investigations, medical opinions, interventions and diagnoses. Motivation for these actions may vary.
2. A less common way is by "using their hands" falsifying documents, interfering with investigations, specimens, lines and drainage bags, and (most extreme) inducing illness in their child (e.g. by withholding food or medication from the child, poisoning, suffocation). These actions nearly always include an element of deception.

Red flags for early detection of PCF are for instance:

- The reported signs and symptoms have only been seen by the parent or caregiver (not at school, not at day care);
- The child has an unexplained adverse reaction to the prescribed medication or treatment;
- The parent or caregiver repeatedly reports new symptoms.;
- The history of events is medically highly improbable.
- Despite a definitive medical conclusion, the parent or caregiver seeks medical advice from various experts and continues to challenge the conclusions drawn, with the child undergoing various tests or treatments for various complaints and symptoms;
- The child has few normal daily activities (e.g., frequent school absences), more than expected based on the existing symptoms or diagnosed illness;
- Family or other professionals express concerns about the situation, such as the frequent doctor visits;

None of these, so-called, red flags are conclusive, several other explanations are possible. In general, it concerns inconsistencies, for example, between reported signs and symptoms and the physical examination, the observation, the interview with the child alone or

additional tests.

In the Netherlands, working with the child abuse reporting code is mandatory in healthcare, education, childcare, social support, youth care and justice. The steps in the reporting code help professionals from the moment of signaling/suspecting child abuse to the decision of whether or not to make a report. For physicians the so called KNMG (Royal Dutch Medical Association) child abuse and domestic violence reporting code is mandatory (in short KNMG reporting code), reporting is not mandatory in the Netherlands.

A report can be made to the Child Abuse Counseling and Reporting Centre (CACRC), known in the Netherlands as Veilig Thuis (Safe Home). At the CACRC, process managers, work supervisors, behavioral scientists, confidential physicians, and administrative staff work closely together to ensure the safety of the elderly, children, and families. A confidential physician is a physician who specializes in assessing and addressing situations of child abuse, domestic violence, and elder abuse.

Victims, perpetrators, bystanders, and professionals can contact Veilig Thuis if they suspect child abuse or domestic violence. CACRC will work with the caller to determine the situation and what they can do themselves. If this isn't possible, or if the situation is too complex or serious, the caller can file a report. By Dutch law, the CACRC has the following responsibilities: Providing advice; Receiving reports; Investigating whether domestic violence or child abuse has actually occurred; If necessary, initiating follow-up steps such as transferring the case to voluntary services, informing the Child Protection Service, and/or reporting the incident to the police; Responding to the reporter.

The Child Protection Service (CPS) in the Netherlands (in Dutch Raad voor de Kinderbescherming) is a department of the Ministry of Justice and Security. The CPS performs a number of statutory duties relating to children, particularly those who are at risk of or already in trouble. These duties fall under both civil and criminal law. Key tasks of the CPS include advising on visitation, residence, and parental authority; advising on children facing criminal prosecution; Protecting children experiencing problems due to abuse and neglect; performing a few adoption-related tasks.

CACRC can decide to refer a case to the CPS. The CPS may, after conducting its own investigation, decide to submit the case to the court and request a protective measure, such as a supervision order and/or out-of-home placement, or the removal of parental authority.

In practice, every situation of suspicion of PCF does not always lead to a report to CACRC. Possible victims of PCF will not always be reported because, for instance, the reporting code is not initiated because the professional was unable to recognize the signs of PCF, for instance due to not being able to 'imagine the unimaginable', or had a threshold for reporting. Known thresholds are for instance lack of time, being afraid to falsely accuse, being afraid for complaints.

The task of CACRC is to assess the safety of the children. When the investigation of the CACRC has been completed and child abuse has been confirmed, agreements are made with care providers and the family. The purpose of these agreements is to ensure safety in the acute situation and in the long term. CACRC monitors and evaluates the case at three, six and twelve months. Another possibility is to refer the case to the CPS as described above.

The aim of this study is to analyse PCF cases reported to CACRC to gain more insight into common factors in these families, making it easier and earlier for professionals to recognize PCF. This study is the first one to use the data of PCF cases reported to the CACRC in the Netherlands.

1.1. Background of this study

PCF is a severe form of child abuse with high mortality, often recognized too late. Recognition is difficult due to misleading medical histories provided by perpetrators, causing doctors to unintentionally enable the abuse through unnecessary tests and treatments (Abdurrachid & Gama Marques, 2022; Ali-Panzarella et al., 2017). Early recognition is crucial (Abdurrachid & Gama Marques, 2022; Sheridan, 2003) as late detection can lead to morbidity, also due to unnecessary medical interventions, mortality, behavioral issues, eating disorders, negative impacts on cognitive and emotional development (Doughty et al., 2016; McGuire & Feldman, 1989; Sheridan, 2003). Frequent medical appointments and treatments harm the child, leading to school absenteeism and impaired daily activities (Abdurrachid & Gama Marques, 2022; RCPCH, 2021). Recurrence rates are high, with a 75 % rate of repeated falsification (Abdurrachid & Gama Marques, 2022). Frequent hospital visits without clear diagnoses are a key red flag (Bass & Jones, 2011; Ali-Panzarella et al., 2017).

Our research question was: What characteristics contribute to the suspicion of PCF, and which features support its confirmation? This insight might lead to a better understanding and better and earlier recognition of this form of child abuse in the future.

2. Methods

All CACRC-files concerning a report of a suspicion of PCF or with confirmed PCF after investigation by the CACRC were collected over a five-year period (January 2008–December 2013). The managers of the case file system of CACRC were approached to provide the file numbers and to send an anonymous printed version to the main researcher or to provide an opportunity to study the anonymized files on site. After data collection, the anonymized printed files were destroyed. The Medical Ethical Review Committee of the Erasmus Medical Centre, Rotterdam, assessed this study on June 20, 2014, as a non- medical scientific research act study in which informed consent may be waived.

The data analysis was conducted based on the anonymized file or directly at the CACRC location in the presence of a CACRC staff member. The analysis of the first 30 files was conducted independently by two researchers. Once it was established that both researchers documented the information consistently, the remain of the analysis was carried out by the main researcher. The main researcher used an Excel file to score the topics of the study.

To answer the research question, a topic list has been designed that covers various aspects of the process. The topic list is based on the subjects in the CACRC file, such as role of professionals, red flags, the involvement of medical and psychological professionals, the child's functioning, the parents' background, diagnostic processes, and the protection and support provided.

Our topics of interest were:

- The reporting professional
- Reasons for reporting
- (Medical) professionals involved at the time of reporting
- The child's demographic data
- The presumed somatic and psychiatric diagnoses
- The child's restrictions in daily functioning
- The child's functioning at school
- The child's own point of view
- The demographic data of the PCF perpetrators
- The parent's medical/psychological history
- The role of fathers
- Child's protection measures
- Provided help
- The final diagnoses
- Mechanism of falsification
- Other types of child abuse confirmed
- Formal complaints filed by the family

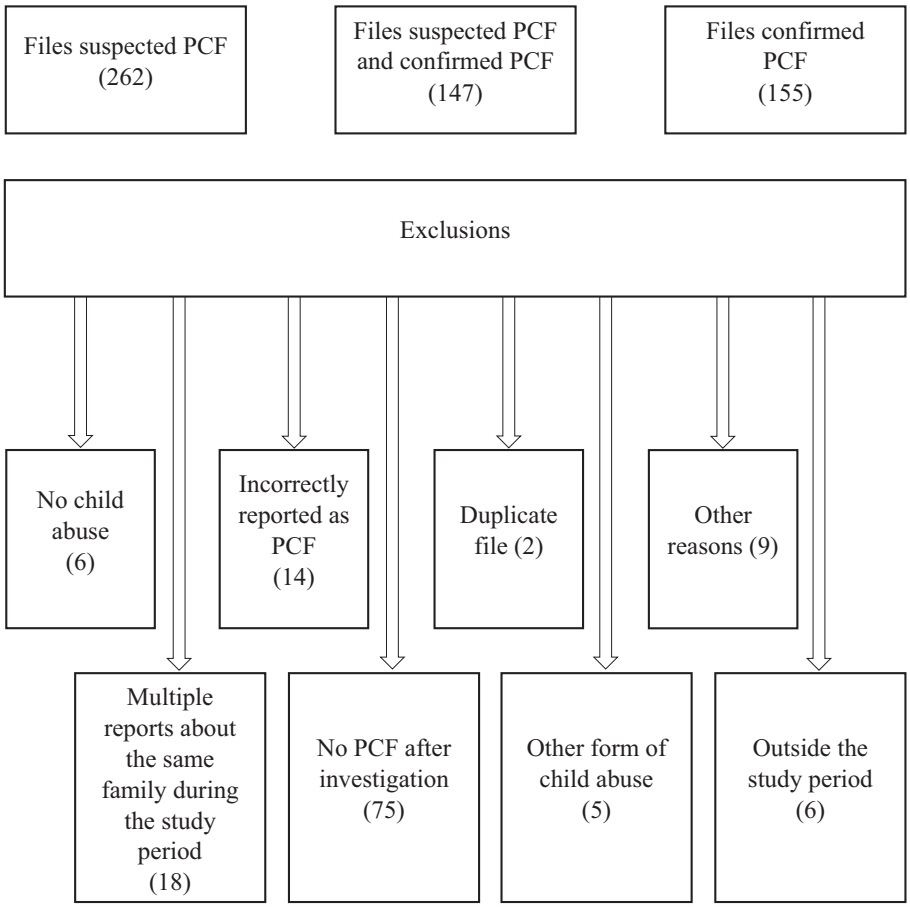


Fig. 1. Exclusions data collection.

2.1. Data collection

3 types of files were ultimately supplied by 24 of the 26 Dutch CACRC, namely:

1. Files of cases with both a suspicion of PCF by the reporter and confirmation of PCF by the CACRC.
2. Files with a suspicion of PCF by the reporter, but no confirmation of the suspicion by CACRC.
3. Files in which the suspicion of the reporter was unclear, but PCF was confirmed by the CACRC.

Data collection was difficult because CACRC used different case file systems. Therefore, not all requested types of files could be supplied. Two of the 26 CACRC didn't deliver any files.

Every report at CACRC received its own specific number. If there were multiple reports about the same family at the same time, there were multiple numbers that related to the same family. Fig. 1 shows the files which were excluded.

Because the CACRC's provided files in different ways, it was decided to use only the files where PCF was suspected at the beginning, and PCF was confirmed at the end of the investigation.

In the end, the remaining files represented 86 families and 200 children, of which in142 children PCF was confirmed.

2.2. Background information about children and parents

In slightly more girls (56,3 %) than boys PCF (43,7 %) was confirmed. In 44,2 % of families PCF was diagnosed with several children in the same family. The age of the victims showed a wide range; mean and median age was between 5 and 10 years old. Most victims were younger than ten years (57 %).

3. Results

3.1. Reporter

Table 1 shows that in most cases one professional reported the case to CACRC, in 11,6 % cases there were two professionals who reported the family. Most reports were made by a pediatrician (30,2 %). In 57 % of the families a pediatrician was involved, so this means that the pediatrician was not always the reporter.

3.2. The red flags within the reports

Doubts about the child's medical history and the amount of unexplained medical complaints were often reasons for reporting: medical overconsumptions of the child, meaning a strikingly high number of doctor and hospital visits not consistent with the symptoms (63,4 %), discrepancy between the history and observation about functioning by others (54,9 %), somatization (45,8 %), lying about (the seriousness of the) illness by the parent (43,7 %), medical unexplained complaints (39,4 %), social isolation of the child (37,3 %), conflicts between parents and professionals (36,6 %) and magnifying complaints (33,8 %). Less frequently mentioned reasons for reporting were withholding necessary help (24,7 %), second opinion which showed that the child was healthy (19,0 %), not allowing the exchange of medical information/having medical information destroyed (16,2 %), easily allowing medical interventions

Table 1
Reporter to the CACRC.

Reporter	*Number of families (total 86)*	*Percentage*
Pediatrician	26	30,2 %
Anonymous	9	10,5 %
School	8	9,3 %
Youth health care	7	8,1 %
Attendance officer	5	5,8 %
CACRC	5	5,8 %
Family guardian	5	5,8 %
Child and adolescent psychiatrist	4	4,7 %
Youth services	4	4,7 %
General practitioner	4	4,7 %
Child Protection Service	3	3,5 %
Revalidation	3	3,5 %
Friend of the family	2	2,3 %
Psychiatry	2	2,3 %
Pediatric neurologist	2	2,3 %
Police	2	2,3 %
Family	2	2,3 %
Institution for chronically ill children	1	1,2 %
School psychologist	1	1,2 %
Intensive care unit	1	1,2 %

(14,1 %) and concerns about unnecessary medication/intoxication (14,1 %).

Another indication of the suspicion of PCF was the involvement of multiple caregivers with the child. 52,1 % of the children had four or more (medical) professionals involved at start of the CACRC investigation and had visited several hospitals at the same time. Various somatic medical specialists were involved in 60 % of cases: pediatricians (57 %), general practitioners (38 %), pediatric neurologists (16,9 %), rehabilitation doctors (11,3 %), metabolic disease pediatricians (9,2 %) and pediatric gastroenterologists (8,5 %). Physiotherapy was the most common paramedical involvement (12 %). Alternative medicine practitioners were involved in 10,6 %. School professionals were actively involved in the reports to CARC in 16,5 %. Other involved professions were child psychiatry (25,4 %), youth health care (18,3 %), psychological child counseling (14,8 %) and adult psychiatry (11,3 %). The compulsory education officer was involved in almost a quarter of the school aged children (This officer works for the municipality and checks whether parents and students comply with compulsory education and qualification requirements).

3.3. Presumed somatic and psychiatric diagnoses at the start of the CACRC-investigation

At the start of the CACRC investigation, all children had one or more medical or psychological diagnoses or complaints. The most common were chronic illness and unexplained symptoms. In 30 to 40 % of the reports it was mentioned (see Table 2).

3.4. Restriction in daily functioning

The case files showed that many children were suffering from the restrictions in daily life that were imposed on them because of their treatment of their presumed illness or as a measure taken by the parent(s).

Table 3 shows an overview of the restrictions imposed on the children with measures concerning eating/feeding, mobilization, social participation and education.

The most notable factors were school absenteeism and adjustments at school, special diets or tube feeding, use of a wheelchair and social isolation of the child. It is notable that the impact of the presumed illness had many consequences for school attendance. In the Netherlands, children school is compulsory from the age of five. Among 103 children over five, 71,8 % had frequent school absenteeism. Nearly half of the school-aged children were noted by teachers to function well at school (in contrast to parental allegations). For 50 % of children using a wheelchair or buggy, professionals saw no need. Half of the tube fed children were observed by school professionals to eat normally. Children had multiple restrictions at the same time (Table 3).

3.5. The child's own point of view

The files showed no information about the child's perception of how they experienced their illness or well-being. Another observation was that in most files nothing was documented about a separate conversation with the children.

3.6. Demographic data of the parents

58 % of the parents were married, 19 % divorced. Only 2,3 % divorced after the PCF diagnosis. Most (80 %) children had siblings, and 14 % had no contact with the biological father.

3.7. Caregivers

The case files did not specify who the actual perpetrator of the child abuse was. For that reason, the files did not provide insight whether it was mother, the father, or both who were responsible. So, in all cases both parents were seen by the CACRC as the abusers.

3.8. The mother

Most mothers worked in social professions. One third of the mothers worked in health care, 20 % as doctor. While others worked in education or law.

Table 2
Presumed somatic diagnoses/illness and psychiatric diagnoses/psychological problems of the child at the start of the CACRC-investigation.

	Most frequent (30–40 %)	Highly frequent (15–20 %)	Frequent (10–15 %)	Low frequent (<10 %)
Presumed somatic diagnoses/Illness	Being chronically ill, somatically unexplained complaints	Chronically tired, food allergy, abdominal pain, assumed developmental disorder	Epilepsy, mitochondrial disorder, constipation, suspicion of intoxication	Hypermobility, motility disorder, fatal muscle disease
Presumed psychiatric diagnoses/ psychological problems			Behavioral problems, Autism Spectrum Disorder, flat affect	Angry outbursts, anxiety symptoms, ADHD, secondary attachment disorder, treated like babies by their mother, mother lied their child is going to die

Table 3
Restrictions imposed on the children in daily life.

General	Unnecessary medication		18 (12,7 %)
	Being treated like a baby		7 (4,9 %)
	Being fed with a baby bottle at the age of ten.		2 (1,4 %)
No restriction at all			26 (18,3 %)
Nutrition (142 children)	Tube feeding		21 (14,8 %)
		Nasal	11 (7,7 %)
		Jejuno/ Gastric	10 (7,0 %)
	Diet		19 (13,4 %)
	Tube feeding and parenteral feeding		6 (4,2 %)
	Only parenteral feeding		0
	Withholding food		5 (3,5 %)
	Dilute food		3 (2,1 %)
	Malone appendicostoma (an artificial access to the large intestine for colon irrigation)		2 (1,4 %)
Mobilization/social participation (142 children)	Social isolation		60 (42,3 %)
	Wheelchair/large buggy		32 (22,5 %)
	Adapted shoes/braces		1 (0,7 %)
	Bed box/harness in bed		1 (0,7 %)
	Hearing adds/deaf language		1 (0,7 %)
	Assistance dog		1 (0,7 %)
Education (103 children)	School absenteeism		74 (71,8 %)
	Rest moments in the class		20 (19,4 %)
	School change		16 (15,5 %)
	No gymnastics at school		15 (14,6 %)
	Adjusted class schedule		10 (9,7 %)
	Adapted school furniture		13 (12,6 %)
	Switch to special education		11 (10,7 %)
	Not allowed to play outside at school		10 (9,7 %)
	Mother insists on special education (not indicated)		4 (3,9 %)
	Home education		4 (3,9 %)

From data analysis, in 47 cases, mothers had extensive medical histories: unexplained complaints and unjustified immobilization (68 %), lying about diagnoses (37,5 %), unnecessary medication and adjustments (21,3 %), fibromyalgia or rheumatism (14,9 %), gastro-intestinal complaints (14,9 %), non-healing wounds or recurrent misunderstood infections (10,6 %) and chronic pain (6,4 %). More mothers might have experienced these complaints, but they were not asked about them, or the mothers did not report them.

40 files showed information about mother's psychiatric/psychological history. 32 mothers (80 %) had a problematic childhood or a history of child abuse (emotional neglect (15 %) and sexual abuse (5 %)). Other psychological problems noted were depression (17,5 %), anxiety disorder (12,5 %), remarkable behavior (not further specified) (12,5 %), panic attacks (7,5 %), stressed behavior (2,5 %). Two mothers thought themselves to be highly intelligent.

The files showed no information of possible delayed intelligence.

3.9. The father

Less was reported about fathers. Our data showed that mothers pretended that the father had an illness (1), told providers the father had no authority (3), lied to the children that their father was dead (1) or suffering from dementia (1). Also, one mother lied that the child was afraid of the father (1) and mothers falsely accused the father of abusing the child (3). Mothers gave children different surnames to hide them from fathers (2) and kept fathers distant for years (14). In 25 % of families, fathers had busy jobs. Little was known about father's medical history; for 75 % psychiatric/psychological history was unknown. Eight fathers were stated as healthy, and six as mentally healthy.

3.10. Protective measures after CACRC-investigation

In the Netherlands, assistance after reporting is voluntary. When necessary for children's acute and long-term safety and parents refuse to cooperate, a request to Child Protective Service (CPS) is made. CPS can request the Court to appoint a family guardian, with or without an out-of-home placement. CPS investigations occurred in 52.8 % of cases. For one third of children, a family guardian was requested. In some cases (4,9 %), CPS appealed against the Court's decision. CACRC asked for police investigation in 11,3 % of cases.

A quarter of all children had been placed into residential care. In two children, it is described that after returning home, the medical problems started again. Six children started to live with their father permanently, four children broke off contact with the mother completely, and three children saw their mother only under supervision.

3.11. Assistance offered after the CACRC-investigation

Following the CACRC investigation, families received various forms of assistance. Referrals were made to parental mental health care (25,6 %), family therapy (20,9 %), inpatient treatment of the whole family in a special psychiatric treatment center (5,8 %),

Table 4
Diagnoses confirmed as real after CACRC investigation.

		Number of children	%
Healthy/no diagnosis		85	62,7 %
Medical somatic diagnosis		33	23,2 %
	Uncomplicated premature birth	7	
	Grass allergy	2	
	Cardiomyopathy and asthma	2	
	Hypermobility	2	
	Tubereous sclerosis	2	
	Blood disease e.c.i.	2	
	Overweight	1	
	Status after malrotation and gallstones	1	
	Asthma	1	
	Epilepsy and mild developmental delay	1	
	Gastroesophageal reflux	1	
	Cow's milk protein allergy	1	
	Moderate hearing loss	1	
	Neurofibromatosis	1	
	IgA deficiency, underactive thyroid gland	1	
	Kabuki syndrome	1	
	Decreased c1 en c3 in fibroblast and hypertrophic cardiomyopathy	1	
	Status after ventricular septal defect	1	
	Dehydropyrimidine dehydrogenase deficiency	1	
	Celiac disease, epilepsy and malrotation	1	
	PCDH gene mutation and celiac disease	1	
	Endogene hyperinsulinism	1	
Medical somatic and psychiatric/ psychological diagnosis		2	1,4 %
	Dyslexia and lactose-intolerance	1	
	Celiac disease, Autism Spectrum Disorder and dyslexia	1	
Psychiatric/psychological diagnosis		18	12,7 %
	Dyslexia	2	
	High intelligence	2	
	Secondary attachment disorder	1	
	ADHD and oppositional defiant disorder	1	
	ADHD	1	
	ADHD and mild developmental delay	1	
	Learning disability	1	
	Conversion	1	
	Speech-language and developmental delay	1	
	Learning disabilities, mild developmental delay and dyspraxia	1	
	Asperger and developmental delay	1	
	Autism Spectrum Disorder, mild developmental delay, ADHD and multiple complex developmental disorder	1	
	Autism Spectrum Disorder	1	
	Autism Spectrum Disorder, ADHD and mild developmental delay	1	
	Autism Spectrum Disorder en ADHD	1	
	Autism Spectrum Disorder and mild developmental delay	1	

forensic psychiatric examination of the mother (3,5 %), and mandatory mental health care for a parent (2,3 %). Safety agreements involved professionals like a coordinating pediatrician (65,1 %), general practitioner (25,6 %), and child psychiatry (24,4 %). Families were monitored for 1.5 years to prevent relapses and detect falsification early. Schools (47,7 %), youth health care (25,6 %), and compulsory education (15,1 %) helped control absenteeism and identify new issues.

3.12. Outcome of the child

62,7 % of the PCF-victims became completely healthy after separation from the abusive parent and had no diagnosis at all after CACRC investigation. Children showed significant improvements in daily functioning: many returned full-time to school after frequent absenteeism, transitioned from special to regular education, phased out classroom rest periods, and participated in gymnastics again. Autism Spectrum Disorder (ASD) diagnoses were reassessed and rejected for five children due to doubts. Initially, 21 children were on tube feeding: 18 experienced complete resolution of gastrointestinal complaints after separation from the abusive parent. Of these, 17 developed excellently. Tube feeding was stopped for 11 children, with 10 resuming normal eating, and intestinal irrigation was discontinued for one child.

37,3 % of the PCF-victims had an actual medical/psychiatric/psychological diagnosis or medical history. Most common: uncomplicated premature birth in history (7) and ADHD and ASD. These children may experience some limitations as a result of their illness or condition (Table 4).

3.13. Mechanism of falsification by the perpetrator

Exaggeration and pathological lying were the most frequent mechanisms, often involving excessive healthcare use and induced disability. In over 25 % of cases, illness was actively induced through poisoning, unnecessary medication, or food manipulation. Simulation of symptoms and deliberate neglect also occurred, illustrating the broad spectrum of harmful strategies used. The Table 5 below illustrates the different mechanisms.

3.14. Other forms of child abuse

The data from the reports show that, besides PCF, other forms of CAN occurred. In addition to PCF, social emotional neglect was confirmed in 72,5 %. In twenty children, the mother had a pathological, symbiotic relationship with the victim.

There were some other notable events in the family after PCF was diagnosed. Three times, the father became a victim of sickening behavior by his partner.

3.15. Formal complaints

After the CACRC investigation, forty-eight times (33,8 %) parents took legal action and complaints against the CACRC professional involved. This happened in 24,4 % of families. Parents primarily complained about reasoning biased towards the suspicion of PCF, communication, and inaccuracies in reporting. The handling of the complaint is not recorded in the case file; as a result, there is no information available on this matter.

Table 5
Mechanism of falsification by the perpetrator.

Induction	Poisoning ($N = 36$; 25,2 %), a serious poisoning involving attempted murder ($N = 6$: 4,2 %) (Anti-epileptic drugs, laxatives, drugs causing impaired consciousness.)
	Large amounts of lactulose were administered to the child ($N = 3$; 2,1 %)
	Abdominal infection causing sepsis ($N = 2$; 1,4 %); caused by paint being lubricated in the wound, by piercing through the abdominal wall
	Unnecessary medication ($N = 26$; 18,2 %)
	Manipulation of food ($N = 11$; 7,7 %)
Simulation	Manipulation of urine and feces (N = 6; 4,2 %)
	Diarrhea was simulated by adding water to the stool (N = 2; 1,4 %)
	Maternal blood was administered to vomit/urine and feces ($N = 1$; 0,7 %)
Exaggerating/lying	Manipulative behavior of the mother ($N = 61$; 42,7 %)
	Medical overconsumption ($N = 93$; 65,1 %)
	Disability because of sickening behavior ($N = 86$; 60,2 %)
	Somatizing behavior by parents ($N = 77$; 53,9 %)
	Pathological lying ($N = 57$; 39,9 %)
	Exaggeration of the complaints of the child ($N = 45$; 31,5 %)
	Treated like a baby by the mother ($N = 8$; 5,6 %)
	The mother lies the biological father committed incest to his child ($N = 6$; 4,2 %)
	Parents incorrectly maintained the diagnosis mitochondriopathy after it was rejected (N = 8; 5,6 %)
	Lying the child is going to die (N = 1; 0,7 %)
Neglect	No help was sought although clearly necessary ($N = 14$; 9,8 %)

4. Discussion

This study is the first PCF study in the Netherlands to use data from the CACRC. The data analysis has provided several new insights: First, our data showed that although pediatricians were involved in most of the cases, they only reported in half of the cases. Other reporters such as schools, family members, or anonymous sources, were crucial for initiating investigations into PCF suspicions, emphasizing the value of anonymous reporting. Investigation by CACRC start after a report of suspected child abuse. The Dutch reporting code differs from many other countries, limiting the comparison with international literature about the reporter of child abuse and the reporting process. Usually, there is one reporter, sometimes two, although at the time of reporting, often many care providers are involved. So, having many (medical) professionals involved does not mean they recognize signals of falsification. Consistent with the literature, most PCF victims were known in several hospitals, with numerous medical professionals involved (Bass & Jones, 2011; Ali-Panzarella et al., 2017). This could mean that (medical) professionals have insufficient knowledge of PCF and therefore do not recognize signals sufficiently. School employees mostly have important information to recognize PCF. It is striking that the school could be the reporter, even though a pediatrician was involved. This means that school can be an important source of information for pediatricians. Schools have daily interaction with children, provided there is no school absenteeism. It is crucial to involve the school as an informant.

The second insight is the position of the father. Our data shed light on the position of fathers in PCF cases, with findings indicating that mothers frequently marginalized fathers by falsely portraying them as absent, deceased, lacking authority, or as perpetrators of abuse. In 14 % of cases, there was no contact with the biological father. From literature, it is known that perpetrators, often the mother, use manipulative tactics such as lying about the father's authority, falsely accusing him of abuse, or other methods to minimize his role and exclude him (Ayoub, Alexander, Beck, Bursch, et al., 2002; Bools et al., 1994; Feldman & Brown, 2002; Roesler & Jenny, 2008).

It is striking that there was very little information in the files about the fathers. It was not clear whether the fathers were spoken to. The files contained more information about mothers, for instance their own somatization or Factitious Disorder imposed on Self.

Thirdly, an important conclusion is that in the CACRC investigation there was little documented direct communication with the children. In addition to the fact that children were hardly spoken to, the perspective of children was also not included in the report.

The literature does not describe how children who are PCF victims can be spoken to.

Fourth, the study underscores the profound impact of PCF on victims, detailing restrictions in daily life such as social isolation, school absenteeism, adaptive measures at school, wheelchair dependency, and feeding difficulties requiring tube feeding.

The most common presumed somatic diagnoses/illness reported were chronic illness, somatic unexplained symptoms, chronic fatigue, food allergies, abdominal pain, development disorder or epilepsy. Common reported psychiatric/psychological complaints were behavior problems, ASD, and emotional imbalance. In literature, common presenting symptoms include food allergies, gastrointestinal complaints, assumed developmental disorders, somatically unexplained complaints, fatigue, and epilepsy (Abdurrachid & Gama Marques, 2022; Parrish & Perman, 2004; Shaw et al., 2008; Siegel & Fischer, 2001). Our most common somatic or psychiatric/psychological presenting symptoms are less clearly described in literature. Consistent with the literature, assumed developmental disorders and school absenteeism were also identified (Abdurrachid & Gama Marques, 2022).

Following intervention by CACRC, nearly two-thirds of children showed no ongoing diagnosis, even conditions like ASD being reassessed and rejected, indicating potential misdiagnoses. Often, tube feeding was discontinued.

In PCF cases, children may be misdiagnosed with ASD due to false information from the perpetrator, leading to unnecessary treatments. After intervention, these diagnoses can be reconsidered. PCF victims often face stress and isolation, causing behaviors resembling ASD. Documented cases show significant improvement in children after the perpetrator's influence stops (Ayoub, Alexander, Beck, Christian, & Daniels, 2002; Roesler & Jenny, 2008; Sanders & Bursch, 2002; Schreier, 2002).

Fifth, parents often filed formal complaints against CACRC employees.

There is no specific literature on legal proceedings against CACRC employees. The literature addresses complaints and disciplinary actions in a broader context of child abuse by falsification. It emphasizes the complexity of PCF cases and the need for careful, protocol-based approaches by medical professionals to protect themselves against unfounded complaints and disciplinary actions (Ayoub, Schreier, & Keller, 2002; Feldman & Brown, 2002; Schreier, 2002; Roesler & Jenny, 2008). During CACRC involvement, careful case file registration is essential, with attention to multidisciplinary decisions.

4.1. Limitation

This study utilizes CACRC case file system, marking a groundbreaking effort in PCF research in the Netherlands. However, its reliance on CACRC files introduces inherent limitations and potential biases. Notable, not all requested files were provided, impacting data completeness and objectivity. Critical gaps include the absence of father-related details, insufficient documentation on victims' age beyond 10 years, scant information on pregnancies, and no records of conversations with children, thus excluding the child's own point of view, or complaints against non-CACRC professionals. These omissions hinder comprehensive understanding and detection of red flags. The study underscores the need for improved data consistency and inclusion of diverse perspectives to fully grasp the complexity of PCF, its prevalence, presentation and its implications.

Significant information, such as detailed medical and psychological histories, as well as the child's own perspective, was missing in the files. There is an urgent need for improved investigations that comprehensively address the medical and psychological backgrounds of both parents, and include interviews with mothers, fathers, and children. Implementing standardized questionnaires would facilitate better data collection and enrich our understanding of PCF (Appendix A).

4.2. Implications for the future

Based on the findings of this study, we formulated the following recommendations for the CACRC and/or the physicians involved:

4.3. Recommendation 1: education of professionals

Train all (medical) professionals in recognizing red flags for PCF and the reporting code to raise awareness and ensure early intervention.

4.4. Recommendation 2: engage school

Children's functioning at school may differ from what parents' report, making school observation essential. Monitor discrepancies in children's behavior at school versus home. School staff should report such observations to the school physician, who can then consult with the pediatrician to validate parental requests for adjustments. Be vigilant about school absenteeism.

4.5. Recommendation 3: engage fathers

Engage fathers in discussions, gather their insights about family dynamics, their own history, and verify their authority. Their perspectives often differ from the mother, who is usually the (suspected) perpetrator (RCPCH, 2021).

Check mothers' information about the father with general practitioners and fathers, especially regarding health and sexual abuse allegations (Ayoub, Alexander, Beck, Bursch, et al., 2002; Bools et al., 1994; Feldman & Brown, 2002; Roesler & Jenny, 2008; RCPCH, 2021).

4.6. Recommendation 4: conversation with children

Ensure every child is spoken to without the presence of a parent, focusing on their perspective on parental role and views and their own views about their health, illness and restrictions in daily life. After PCF is diagnosed, psychological counseling for PCF victims is crucial, as mandated by the UN Convention and the Rights of the Childs (CRC).

4.7. Recommendation 5: reevaluate psychiatric diagnoses

This research shows that PCF victims diagnosis ASD was reevaluated after the child was separated from the abusive parent. Several children were no longer diagnosed with ASD. In addition to the fact that children often no longer have a medical diagnosis after separation from the perpetrator, it is recommended to reevaluate psychiatric diagnoses also.

4.8. Recommendation 6: Factitious Disorder imposed on Self (FDIoS)

Be alert if mothers show signs of FDIoS. Seek advice from CACRC and adhere to the reporting code to ensure the child's safety.

5. Conclusion

Our data reveal that while pediatricians were involved, they were not always the reporters, highlighting the importance of reports from schools, family members, or anonymous sources. Fathers were often marginalized, falsely portrayed by mothers as absent or abusive.

PCF significantly impacted victims, leading to social isolation, school absenteeism, and medical dependencies; however, CACRC intervention resulted in substantial recovery, with many children no longer needing previous diagnoses or treatments. A high percentage of complaints were filed against CACRC.

Recommendations include speaking to children, engaging fathers, monitoring school behavior, reevaluating diagnoses, educating school professionals on PCF, being alert for FDIoS, and cross-checking mothers' information with other sources. Future studies should use uniform questionnaires to improve data collection (Dutch Guideline KMDF, 2025).

We like to thank all participating CACRC locations for their collaboration.

CRediT authorship contribution statement

P.I.M. Worm: Writing – original draft, Methodology, Investigation, Conceptualization. **A.H. Teeuw:** Writing – review & editing. **M.J. Steketee:** Supervision.

Appendix A

Checklist and questions for a home visit by CACRC in case of suspected PCF

Tips prior to the home visit (Dutch Guideline Child abuse by falsification (KMdF), 2025)

Before the conversation with the family members, assess whether there are risks for one of the family members when the concerns from the report are discussed (Dutch Guideline KMd, 2025; RCPCH, 2021).

Conduct an interview with a colleague. If parents wish to record the conversation, indicate that you would also like to record it.

Conduct the interview with both parents, separately if necessary.

Check all information told about another family member.

Check authority by contacting the custody register (https://www.rechtspraak.nl/Registers/Gezagsregister).

During the home visit, note home modifications (such as stair elevator, adapted furniture, wheelchair) and ask for the reason and which professional supported the application for the aid.

Report

The conversation with the parents starts with an explanation of the tasks of the CACRC.

Explain that CACRC is initiating an investigation to refute or confirm the reported suspicion of child abuse.

Ask the opinions of all family members on the report.

Pay attention to signals that argue for and against PCF.

Has the content of the report been discussed by the reporter with the parents?

And/or the child?

If yes, in what manner?

Parents

Explanation

CACRC will talk to both authoritative parents. The starting point is to discuss the report with both parents at the same time. If only one parent is present at the meeting, or parents are divorced, then a conversation must always be held with the other parent as well. If, based on the content of the report, an assessment is made that parents cannot speak openly in each other's presence, CACRC will speak to parents separately from each other. It is possible that one parent shares information (e.g. about medical/psychological problems, behavior or custody) about the other parent. Check this information with the other parents and if necessary, with authorities or (medical) professionals.

General

Are parents married/cohabiting?

What kind of work do parents have and what are the working hours?

What is the highest education?

What do parents do as leisure activities?

What is their financial situation? Are there any debts?

Any income from personal (financial) budget?

What is parents' view of parenting (rules, important issues in the up-bringing, agreements in the family, role of the parent)

What does the day structure look like within the family?

What are strengths within the relationship?

If there is a separation: what was the reason for the separation?

What does the visitation arrangement look like?

Is there a parenting plan?

Have parents themselves experienced domestic violence/child abuse in their childhood?

Has there been any other violent event?

Have parents ever lost a child?

If so, what was the reason for her/his death?

What has been the disease history been like prior to death?

If yes, what did the death mean for the family? Parenting? The other children? Dealing with illness? Etc.?

Are there relocations?

Mother or parent 1

Medical/Psychological history

How did the pregnancy progress?

Has there been any history of miscarriage/abortion?

Wishful/unwanted pregnancy?

Do parents have any medical/psychological complaints/problems?

If yes, what diagnoses have been made/which diagnoses have been rejected?

By whom and when was the diagnosis made?

Based on what findings (history/additional examination)?

What is the medical advice?

What are possible limitations in the daily functioning of the parent?

Medication (which ones, who prescribes the medication)?

Is there any drug/alcohol use?

If yes, what is the reason for use?

Has there been any unexplained illness and/or death in the family?

Father or parent 2

Medical/Psychological history

How did the pregnancy progress?

Has there been any history of miscarriage/abortion?

Wishful/unwanted pregnancy?

Do parents have any medical/psychological complaints/problems?

If yes, what diagnoses have been made/which diagnoses have been rejected?

By whom and when was the diagnosis made?

Based on what findings (history/additional examination)?

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Checklist and questions for a home visit by CACRC in case of suspected PCF
What is medical advice?
What are possible limitations in the daily functioning of the parent?
Medication (which ones, who prescribes the medication)?
Is there any drug/alcohol use?
If yes, what is the reason for use?
Has there been any unexplained illness and/or death in the family?
Parents about health of the child
Explanation
Ask both parents about their child's medical/psychological problems. If the report describes medical/psychological problems about only one child in the family, ask about any problems of the other children. If another child also has medical/psychological problems, ask the same questions. Check parents' information with (medical)professionals. E.g. parents are asked about child functioning at school, and check functioning with the teacher.
What is a parent's view about the health of their child?
What are parents' ideas about health in general?
What do parents do to promote health (sport/nutrition?)
What are their child's complaints/medical problems/psychological problems?
Do siblings have medical/psychological problems? Tell me
What restrictions does the child experience in daily life?
Wheelchair use?
Does the child have a psychiatric diagnosis? Autism spectrum disorder?
If yes, how and by whom is the diagnosis confirmed?
School (day care/preschool)? School changes? Absence? Adapted education? Outdoor play at school? Gym? Etc.
What are observations of school regarding child's functioning?
Has the child feeding problems? Tube feeding? Parental nutrition? Oral intake? Diet? Tell me
Does the child take lunch to school? Does the child eat at school?
Medication? If yes, which ones, who prescribes the medication and why?
How do parents perceive the severity of their child's (medical) problems?
Has any medical/psychological been confirmed?
If so, which ones? By whom?
How were diagnoses confirmed? What diagnostics have there been?
What are doctors' recommendations? Advice?
Do parents follow the advice? What is the evidence of this?
If not, why?
Have diagnoses been rejected? If so, which ones?
When there is no diagnosis, but there are medical/psychological problems, what is parent's view?
What do parents think will happen if the child has fewer restrictions (e.g. less use of the wheelchair)?
How do parents view their child's health in the future?
Are parents concerned about a possible early death of their child?
Describe the impact of the child's (medical/psychological) problems? In relation to parenting/education/other children/social life/work.
What (medical) professionals have been/are involved with their child? For what purpose?
Which hospitals have been involved/are involved?
Second opinions? What reason? Outcome?
What is the role of the general practitioner?
Visiting emergency rooms?
Is youth health involved? If so, for what reason? If not, why?
Do parents agree to information sharing between all involved (medical) professionals? If yes, explain. If not, why?
Has there ever been a request to destroy information?
When there is school absenteeism: Is compulsory education involved? If yes, for what reason?
Children (Dutch Guideline KMdF (communication with the child), 2025)
General
What is important for you?
Do you have a wish?
If so, tell me about it.
What or who is important when you are sad? Angry? Happy?
What is different in your home than at a friend's house?
What does your social life look like?
What would you like to do but is not possible?
Why?
What grade do you give your quality of life?
What makes it so low/high, what is needed?
Are there things that worry you?
If so, tell me?
School
Do you attend school?
If not, why not?
If yes, which school do you attend?
Have you ever switched schools?
Tell us about it?
Are there any modifications at school?
Gym?
Class schedule?

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Checklist and questions for a home visit by CACRC in case of suspected PCF
Absenteeism?
Other adjustments?
Social isolation?
Can you do things at school that you cannot/may not do at home? Tell me?
Do you eat at school (lunch/birthday)?
What does a weekday look like?
What does a weekend day look like?
Is the youth doctor involved?
If yes what is the youth doctor's role?
If not, why not?
How is your birthday celebrated in the family?
What does the group of friends look like?
What is done with the group of friends?
Health
What do you know about your illness?
Are there things you are not allowed to do?
If yes, tell me about the things you are not allowed to do
Who told you? Do you know the reason why? Tell me
What do others say about your illness?
Mother?
Father?
Friends?
School?
Yourself?
The doctors?
How do you feel about your own illness?
Do you think you are going to die soon?
If yes, tell me about it?
Has anyone told you, you are going to die soon?
If yes, tell me about it? Who told you? What do you think?
Do you think you are sick? Tell me
Have you ever said to someone that you are not sick, or not that sick? If yes, tell me
Care providers/medical) professionals
Explanation
Questioning current or (previously deployed) care providing is important to gain insight into the family's past.
It is important to get a clear timeline for the care providers, medical professionals and the involved hospitals.
Is there any (medical) professional involved?
If yes, which professionals are involved, with which family members and why? (social work, psychology, parenting support, physiotherapy etc.)
Which professionals were involved, with which family members and why? (social work, psychology, parenting support, physiotherapy etc.)
What were positive/negative experiences with counseling in the past?
Are medical professionals/hospitals involved?
If yes, which medical professionals/hospitals are involved (second opinions)?
With which family member and why?
How and with whom is communication with the (medical) professional(s)?
Are private care providers in the family?
What does the care provide look like?
What are positive and negative experiences with caregivers/(medical)professionals involved?
Involved hospitals, previously involved hospitals and medical professionals provide insight into the medical course (also second opinions).
It is known from literature that multiple hospitals and multiple (medical) professionals are involved with the family.
At the time of reporting, the (medical) professional himself may not have any concerns.
Information about observations outside the parent's view (school) provide insight into the capabilities and limitations of the child.
Consider the child eating at school (lunch/track) or running, but tube fed and sitting in a wheelchair.
Environment and social network
Is there a support network?
What does the support look like?
Are parents active on social media, how? (check social media to see if family members share information about illness/health/restrictions or crowd founding)
Are pets present and how are they cared for?

Data availability

The authors do not have permission to share data.

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