

CHILD MORTALITY

*Preventing future child deaths
and optimizing family support*



Sandra Gijzen

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CHILD MORTALITY

PREVENTING FUTURE CHILD DEATHS AND OPTIMIZING FAMILY SUPPORT

DISSERTATION

to obtain the degree of doctor at the University of Twente
on the authority of the rector magnificus,
prof.dr. T.T.M. Palstra
on account of the decision of the graduation committee,
to be publicly defended
on Thursday the 16th of February 2017 at 12:45 hours
by

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CHAPTER 1

General introduction

Child mortality: the figures

Worldwide in 2014 6.1 million live-born children under the age of five died from natural and external causes [1]. According to the Convention on the Rights of the Child every nation must ensure that the well-being of children is promoted and children are protected from harm. Nations also are expected to take appropriate measures to diminish infant and child mortality [2]. The World Health Organization (WHO) has defined in the Millennium Development Goal 4 (MDG-4) to reduce the global mortality of children younger than 5 years with two-thirds between 1990 and 2015. To achieve MDG-4 a country needs to meet an annual reduction rate in the under-five mortality rate between 1990 and 2015 of 4.4% or higher [3]. Despite the measures taken by countries to reduce the under-five child mortality worldwide as approved, this MDG-4 has only been achieved in 62 of the 195 countries [3, 4]. The Netherlands, as a high-income country, is not included in this list of 62 countries. Between 1990 and 2015 the Netherlands achieved an annual reduction rate of 3.1%. Because MDG-4 goals have not met, world leaders have committed to continue their efforts to further reduce preventable child deaths. They renewed their goals to reduce the under-five mortality rate to 25 or fewer deaths per 1000 live born infants by 2030 or 20 or fewer deaths per 1000 live born infants by 2035 for all countries [3].

From the perspective that every nation is expected to make all efforts possible to end avoidable child deaths [2, 3], a nation needs to know which preventive measures can be taken. Therefore, it is essential to understand causes of child deaths and factors that have contributed to death [5]. A child's death is defined avoidable if a cause of death is both amendable and preventable [6]. The Office for National Statistics in the United Kingdom (UK) defines a death amendable if: "all or most deaths from that cause (subject to age limits if appropriate), in the light of medical knowledge and technology at the time of death, could be avoided through good quality healthcare." A death is defined as preventable if: "all or most deaths from that cause (subject to age limits if appropriate), in the light of understanding of the determinants of health at time of death, could be avoided by public health interventions in the broadest sense" [6].

In the Netherlands in 1950 8901 Dutch children aged 0 up to and including 19 years died from all causes (mortality rate 235.8 per 100,000 children) [7]. Information on birth and death rates of the Dutch population has been systematically collected by

the municipalities since 1840 [8, 9]. From 1901 the causes of death were compiled by Statistics Netherlands, which recorded the underlying causes of death of deceased persons in the Netherlands from that period on [9-11]. Between 1927 until 1950 the questions on the death and medical certificates and the processing of these forms have been adjusted continuously. Since 1950 the causes of death statistics were in line with the WHO recommendations in terms of the content and guidelines of completing the medical certificate of the cause of death and classification and coding of the cause of death according to the International Classification of Diseases and Related Health Problems (ICD) [9, 12]. Since then qualitatively better and universal comparable data on the cause of death are available. Statistics show that in the past two centuries child mortality has declined in the Netherlands. The observed decline is due to improvements in social circumstances, sanitation, housing, hygiene and health care, and lower birth rates [8, 13]. Although child mortality has declined to 1130 Dutch children aged 0-19 years in 2014 (mortality rate 29.4 per 100,000 children) [7], there are still child deaths that are avoidable. Insight in the causes of child deaths and the factors that have contributed to death can provide suggestions to further reduce child mortality.

Understanding the causes of child deaths

The death of a child is an enormous tragedy not only for the parents and their family members [14, 15], but also for the wider community [5]. When a child dies, a comprehensive analysis of the causes and factors that contributed to death should be carried out in order to provide parents information about why their child has died and to improve vital statistics data [14, 16]. In addition to this, support after the death of a child that meets the needs of the parents should be provided to help them to cope with the loss of their child and to prevent physical and psychosocial problems [14, 17]. Furthermore, identified factors that contributed to death should be translated in (public) health and legislative strategies in order to prevent future child deaths [16].

In the Netherlands professionals from several organizations may be involved when a child dies. These professionals have different responsibilities and tasks and approach the death of a child from different perspectives. Efforts have been made with regard to the identification of causes of child deaths and circumstantial factors

that have contributed to certain child deaths in the Netherlands in the past decades. First, since 1996 the National Cot Death Study Group reviews cases of Sudden and Unexpected Death in Infants (SUDI) and gives support to their families when needed [18, 19]. Second, perinatal deaths are analyzed by obstetric care professionals since 2009 on a local level to identify substandard factors in perinatal care with the objective to reduce mortality and morbidity. The implementation of these perinatal audits is supported by Perined, previously called Dutch Perinatal Audit Foundation [20]. Reviews of term perinatal deaths have resulted in effective identification of substandard factors that generate recommendations to improve the quality of perinatal care [21]. Third, the Institute for Road Safety Research carries out high quality fundamental and anticipatory research in order to improve road safety and prevent transport-related deaths [22]. For road safety analyses information from the national road crash register, called in Dutch Bestand geRegistreerde Ongevallen in Nederland (BRON), is used. All road traffic crashes in the Netherlands that are recorded by the police in reports or registration sets are included in BRON. For analysis of transport-related child deaths information registered in BRON is linked with the Dutch causes of death statistics [23]. Finally, between October 2012 and January 2014 unexplained deaths in minors were systematically examined in a Dutch pilot. This so-called NODO-procedure (Further Examination of the Causes of Death, in Dutch Nader Onderzoek DoodsOorzaak) included further investigation of the child's death in order to clarify the primary cause of death [24, 25]. After an initial national pilot period, the Ministry of Health, Welfare and Sport concluded that further examination into the causes of death should be organized regionally in a less extensive procedure. In order to achieve this, organizations involved in child deaths developed a multidisciplinary guideline that describes the procedure in case of unexplained death in minors [26]. This procedure, titled NODOK (Further Examination of the Causes of child Death, in Dutch Nader Onderzoek naar de DoodsOorzaak van Kinderen), is in use since August 1, 2016 [27].

The analysis of SUDI cases, perinatal deaths and transport-related deaths in the Netherlands resulted in the identification of factors that have contributed to these child deaths [21, 23, 28]. In cases of Sudden Infant Death Syndrome (SIDS) it proved to be valuable to analyze the causes and circumstances under which the death occurred. The translation of avoidable factors that have contributed to SIDS into preventive interventions has led to a remarkable decline of SIDS cases from more than 200 in 1984 to 10-15 cases nowadays [28]. It might therefore be desirable to

extent the scope of systematic analysis to other categories of child deaths in the Netherlands in order to prevent future deaths.

A comprehensive approach

In the United States of America (USA), Canada, Australia, New Zealand and the United Kingdom (UK) every child's death is systematically analyzed. This method is called Child Death Review (CDR) [29, 30]. The overall objective of CDR is to prevent future child deaths and to improve relatives' coping with bereavement [5, 31]. A multidisciplinary team analyses the circumstances surrounding every child's death in a systematic way in order to 1. improve the quality of the procedure with regard to the determination of the cause of death as well as the death statistics; 2. identify avoidable factors that give directions for prevention; 3. translate the results into possible interventions, and 4. support the family [5, 16, 31]. Support to the family is an essential part of the method to enhance understanding and acceptance of the child's death, which improves bereavement [5, 14].

CDR has its origin in the USA, where in the late seventies of the twentieth century the first CDR teams in the Los Angeles County reviewed suspicious child deaths as a response to the assumed underestimation of fatal child abuse [32]. However, Child Fatality Reviews conducted in Arizona in 1995-1999 found that less than 3% of all preventable child deaths in Arizona are the result of child abuse [33]. Therefore, the focus has expanded towards reviewing all child deaths since then. This is the case in nearly half of the states of America. The extended approach of reviewing all child deaths could reduce avoidable deaths and improve the accuracy of vital statistics data [16].

Over time CDR has been implemented in other countries, as mentioned above [30, 34, 35]. It turned out that in the USA 38% of all child deaths that occurred after the first month of life could have been prevented [32, 33]. Research in the UK, where CDR is implemented since 2006, shows that as many as 29% of child deaths could have been prevented because potentially avoidable factors were involved [5, 35]. In 20% of the completed reviews in England in 2010 to 2011 modifiable factors in child deaths were identified [30]. In another study the Victorian Child Death Review Committee (VCDRC) in Australia reviewed 38 child deaths known to the child

protection service in 2011 to 2012. A lack in collaborative practice and insufficient information sharing were identified next to familial and social characteristics, such as substance use, family violence and mental illness [36]. Thus, CDR potentially identifies avoidable factors that give directions for prevention and might contribute to prevent future child deaths.

Aim and outline of the thesis

The aim of this thesis is to investigate how to prevent future child deaths and optimize family support in the Netherlands. This thesis consists of three parts in order to achieve this aim.

In part A of this thesis, 'Epidemiology', trends and patterns of child death from natural and external causes are presented. Chapter 2 describes the pattern of natural causes of child deaths in the Netherlands in the past decades. Mortality data due to natural causes from all deceased Dutch children aged 0 up to and including 19 (0-19) years for the period 1950-2014 are analyzed using the electronic database of Statistics Netherlands in order to answer the next research questions:

- a. Which trends can be observed in child mortality due to natural causes in children aged 0 up to and including 19 years in the Netherlands in the past decades?
- b. What has contributed to these trends?

In chapter 3 changes in the pattern of external causes of child mortality in the Netherlands are described in groups classified by age and sex in deceased Dutch children aged 0-19 years from 1969 to 2011 using the electronic database of Statistics Netherlands. Possible explanations for the low Dutch child mortality rates from external causes are given. Categories of deaths from different external causes in the period 1996–2011 are described in detail.

Part B, 'Responding to child deaths', presents the way professionals involved in the child (health) care in the Netherlands respond to a child's death. Chapter 4 describes the results of a study that investigates to what extent the existing procedures of organizations involved in the child (health) care in the Netherlands cover four CDR

objectives in responding to a child's death. Protocols, guidelines and other working agreements that describe the responsibilities and activities in case of a child's death of participating organizations with an operative range in the Eastern part of the Netherlands and some directed at a national level, are analyzed by means of scorecards for each of the four CDR objectives.

As family support offered by professionals is part of their response to a child's death, the experiences of Dutch parents with support are explored in a study of which the results are described in chapter 5. Four asynchronous online focus group interviews with parents of deceased children under the age of 2 years regarding the bereavement care offered by professionals are conducted. The following research questions are answered in this part of the study:

- a. What bereavement care did parents in the Netherlands receive after the death of their child?
- b. Did this care meet their needs?

In part C, 'Implementation of Child Death Review', the results of an implementation study of the CDR method in the Netherlands are presented. Chapter 6 describes the results of a study that examines the opinions of stakeholders about the implementation of CDR in the Netherlands. Four face-to-face focus groups are held with professionals and parents of a deceased child under the age of two years. The facilitating and impeding factors are identified using the Measurement Instrument for Determinants of Innovations (MIDI), developed by Fleuren et al. [37, 38]. The research question is twofold:

- a. What are the stakeholders' opinions on the facilitating and impeding factors in the implementation of CDR in the Netherlands?
- b. Which recommendations do stakeholders give for the implementation of CDR in the Netherlands?

Knowledge on facilitating factors and of solutions that are found for the observed impeding factors are used for designing the CDR procedure in the pilot implementation. Chapter 7 describes the results of a study on a pilot implementation, which is conducted in order to determine to what extent the chosen implementation strategy was effective. The SWOT (Strengths, Weaknesses, Opportunities, Threats) –

framework is used to analyze eighteen logs and seven transcribed records of the CDR meetings that are held in the pilot study concerning six deceased children to answer the following research questions:

- a. Which strengths, weaknesses, opportunities and threats in the pilot implementation of CDR can be identified?
- b. Which recommendations can be made for future development of the CDR method in the Netherlands?

The thesis is completed with chapter 8 in which the main findings are discussed, strengths and weaknesses related to the study are considered and recommendations for further research and policy recommendations are provided in order to prevent future child deaths and optimize family support.

CHAPTER 2

Child mortality in the Netherlands in the past decades: an overview of natural causes

THIS CHAPTER HAS BEEN SUBMITTED AS:

Gijzen S, L'Hoir MP, Boere-Boonekamp MM, Need A.

Child mortality in the Netherlands in the past decades: an overview of natural causes

Abstract

BACKGROUND Worldwide child mortality under the age of five has declined to 6.1 million live-born children in 2014. Understanding the causes of child death and contributing factors is essential to direct preventive measures. We present an overview of child mortality due to natural causes in the Netherlands and discuss possible explanations.

METHODS We analyzed mortality data of deceased Dutch children aged 0-19 for the period 1950 - 2014 using the electronic database of Statistics Netherlands.

RESULTS Child mortality has declined from 167.5/100,000 in 1950 to 24.1/100,000 in 2014 (age-standardized mortality rate). Most child deaths were due to conditions originating in the perinatal period and congenital abnormalities. Infectious diseases and diseases of the respiratory and digestive system were frequent causes in 1950 (18.3/100,000, 13.9/100,000 and 7.6/100,000 respectively), but were rare in 2014 (< 1.0/100,000). The incidence rate of Sudden Infant Death Syndrome increased from 1973 until 1987 (111.9/100,000) and then decreased to 6.4/100,000 in 2014.

CONCLUSION Increased standard of living, improvements in sanitation, hygiene, housing and health care and the introduction of preventive measures have resulted in the decline. Systematic analysis for more categories of child deaths can contribute to the identification of avoidable factors that give direction for prevention.

Introduction

Child mortality is an important indicator of the health status of the population of a country. The World Health Organization (WHO) employs the infant mortality rate and the under-five child mortality rate as Core Health Indicators [39]. According to the Convention on the Rights of the Child appropriate measures should be taken by State Parties to ensure the survival and development of children to a maximum extent and to diminish infant and child mortality [2]. From this perspective, nations are responsible to monitor child mortality and to analyze each child death in order to translate the conclusions into preventive measures [5, 40, 41].

Worldwide 6.1 million live-born children under the age of five died from natural or external causes in 2014 [1]. According to the Dutch Health Care Inspectorate, a natural cause of death is “due to an illness or old age, including compliance with established principles of contemporary medical treatment”. An external cause of death, popularly often called ‘unnatural death’, is defined as “death due to a factor outside the body (chemical or physical), including medical errors and death due to criminal intent” [42].

Next to the manner of death, which can be natural or external, a distinction is made between the primary and secondary cause of death. The WHO defines the ‘primary’ or ‘underlying cause of death’ as “the disease or injury which initiated the sequence of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury” [43]. Consequences or complications of disease or injury, and other diseases present at the time of death that may have contributed, are considered as ‘secondary causes’ of death [44].

Worldwide, the likelihood that a child dies is highest in the neonatal period (0 till 27 days after birth). In 2013 the global leading causes of death in the neonatal period were prematurity (15%), intra-partum related complications (11%) and neonatal sepsis (7%). From the age of one month until five year the leading causes of death were pneumonia (13%), diarrhea (9%) and malaria (7%) [4, 45]. For older children injury-related deaths predominate. In the age group 15-19 years road injuries (18.7%), followed by interpersonal violence (7.8%) and self-harm (7.4%) were the global leading causes of death in 2013 [46]. Most child deaths occurred in underdeveloped countries, particularly in Sub-Saharan Africa and Southern Asia

[3, 4]. Since 1955 global all-cause child mortality has declined [47], mainly due to governmental measures, like the implementation of effective interventions such as vaccinations, and the use of medical technology [46] and the road safety measures taken in developed countries [47]. Child mortality has declined globally, particularly in developed countries [47].

In the Netherlands, a decline in child mortality has been observed as well [4]. In a previous publication (Chapter 3) we provided an overview of external causes of deaths in children aged 0 up to and including 19 years in the Netherlands from 1969 till 2013. We concluded that mortality due to external causes has declined in the Netherlands, particularly due to decreases in road traffic accidents and other external causes of accidental injury in all age groups. Interventions taken by Dutch government, the Consumer Safety Institute, and the Institute for Road Safety Research have contributed to this decline. Death due to intentional self-harm increased and assault and events of undetermined intent remained constant [48]. In this paper we describe the trends in child mortality due to natural causes in the Netherlands as a developed country from a historical perspective in order to determine the focus for further prevention. To direct preventive policy an understanding of the causes of child deaths that are still frequent and of the causes in which a decline is observed to a low level, is essential. The research questions of this paper are: (1) Which trends can be observed in child mortality due to natural causes in children aged 0 up to and including 19 years (0-19) in the Netherlands in the past decades?; and (2) What has contributed to these trends?

Since qualitatively better and universal comparable data on the cause of death in the Netherlands are available from 1950 onwards, we focus in this paper on child mortality in the period between 1950 and 2014. This paper builds on an article published in a national journal (in Dutch) in which child mortality data from natural and external causes in the period 1969 until 2008 was highlighted [49]. In the present study we focus on natural deaths in a bigger time frame.

Materials and methods

Study design

We have analyzed existing historical data of Statistics Netherlands. Before answering the above mentioned research questions, we first describe the organization of the causes of death statistics in the Netherlands.

Setting

In the Netherlands only the medical doctor and municipal coroner are allowed to certify death. They do this by signing a death certificate. In cases of deceased minors the medical doctor is obliged to consult the municipal coroner, but only since January 2010 [25]. During this consultation it should be determined whether the death is convincingly explained by the medical history of the child and whether the death was expected [24]. Before 2010, medical doctors completed the death certificate on the basis of the medical history of the child and postmortem examination. In circumstances where a natural cause of death is doubted or where an external cause is evident, the municipal coroner is responsible for certifying the death, which has been a standard procedure in the Netherlands. In all other cases the medical doctor is permitted to sign the death certificate [42]. For statistical purposes the medical doctor or municipal coroner completes a medical certificate on the cause of death, which contains only anonymous data of the deceased stating the primary and secondary cause of death. Furthermore, the name of the municipal coroner or medical doctor is added on the certificate. This medical certificate on the cause of death is sent in a sealed envelope through the municipal authority of the city where the death occurred to the medical officer of Statistics Netherlands. The information on the cause of death is then linked with mortality data in the municipal personal record database. Statistics Netherlands as the official registrar in the country records the primary cause of death of citizens in the Netherlands using codes according to the International Statistical Classification of Diseases and Related Health Problems (ICD) of the World Health Organization (WHO) [50]. The secondary causes of death are not registered by Statistics Netherlands. Mortality data, available since 1950, are published annually in an electronic database, called Statline [7]. From 1950 Statline relied on ICD versions 6, 7, 8, 9 and 10, in compliance with revisions made by WHO every ten years [11, 51, 52]. In the Netherlands ICD version 6 was in use from 1950-

1957, version 7 from 1958-1968, version 8 from 1969-1978, version 9 from 1979-1995 and version 10 from 1996 until now [9]. Citizens from foreign countries are not included in the Dutch cause of death statistics before naturalization [11].

Study population

The study population consists of the dynamic population of Dutch children from 0-19 years of age in consecutive years in the period 1950-2014. The size of this population increased from 3,774,058 in 1950 to 4,692,976 in 1972. A decrease occurred to 3,748,812 in 1993 followed by a slight increase to 3,987,757 in 2004. From 2004 a slight decrease is observed to 3,837,050 in 2014 [7].

Data analysis

We used data obtained from Statline [7] for analyzing the mortality data of natural causes of death of Dutch children aged 0 - 19 years in the period 1950-2014. We first arranged the mortality by cause of death in the age groups 0, 1-4, 5-9, 10-14 and 15-19 year. Then we calculated cause-specific mortality rates per year (per 100,000 children) by dividing the total number of cause-specific deaths in the age 0, 1-4, 5-9, 10-14 and 15-19 year in one year by the midyear population of children in the age category in that specific year. The midyear population for each year was calculated by summing up the population at the end and beginning of the year divided by two. To control for different age distributions among populations over time we applied age standardization using the European standard population of 2013 [53].

We chose to present the course of mortality in time 1) for all natural causes, divided into three age groups and for the three age groups together, 2) for the three highest incidence cause-of-death groups in 2014, 3) for the three low incidence cause-of-death groups ($< 1.0/100,000$) in 2014 that were rather highly represented in 1950 ($> 7.0/100,000$), and 4) for Sudden Infant Death Syndrome (SIDS) (only children aged 0 year and from 1969-2014). The patterns in the cause-of-death groups are presented in Figure 2-4.

Results

Child mortality due to natural causes in Dutch children aged 0 – 19 years has declined from an absolute number of 7,823 cases in 1950 to 906 cases in 2014, which means a decline of the age-standardized mortality rate of 167.5/100,000 to 24.1/100,000. Figure 1 presents an overview of age-standardized death rates per 100,000 Dutch children due to natural causes for three age groups (0 year, 1-4 year, 5-19 year) and for the three age groups together in the period 1950-2014. Since 1950 most deaths occurred before children reached their first birthday.

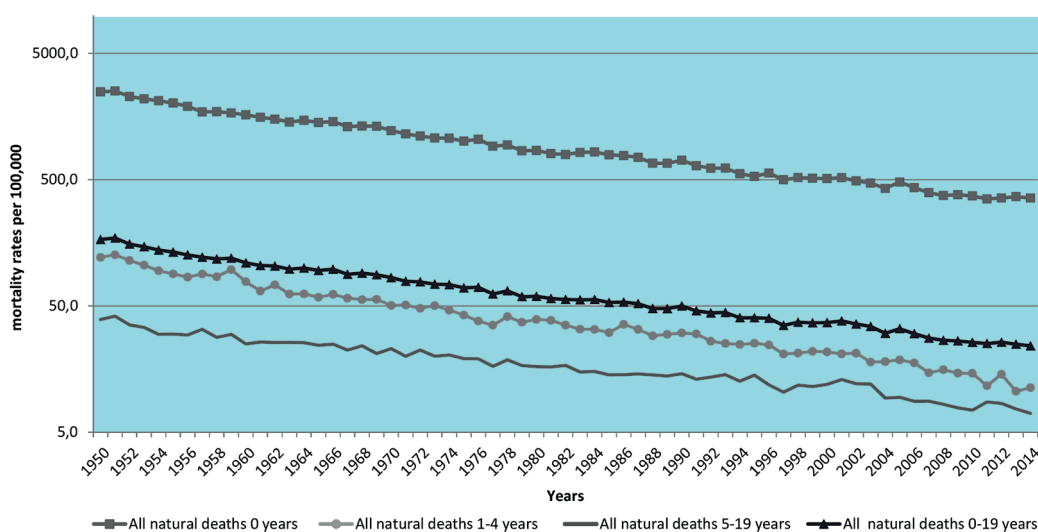


FIGURE 1. Death due to natural causes in Dutch children aged 0-19 (per 100,000 in a logarithmic scale) divided into four age groups from 1950 – 2014, age-standardized using the European standard population of 2013

Natural causes of death with a high incidence in 2014

Age-standardized cause-specific mortality rates for 14 natural cause-of-death groups per 100,000 Dutch children (0-19 year) in the period 1950-2014 are shown in Table 1.

Figure 2 presents cause-specific mortality rates per 100,000 Dutch children (0-19 year) in the period 1950-2014 for those natural cause-of-death groups that are still highly represented in 2014 statistics (age-standardized rates). These cause-of-

death groups are certain conditions originating in the perinatal period, congenital malformations and chromosomal abnormalities, and neoplasms (Table 1).

TABLE 1. Age-standardized cause-specific mortality rates for 14 natural cause-of-death groups per 100,000 Dutch children (0-19 year) in the period 1950-2014. For corresponding ICD-codes version 6-10 see Appendix 2.1

	Certain infectious and parasitic diseases	Neoplasms	Diseases of blood/ blood forming organs/ disorders immune mechanism	Endocrine/nutritional/metabolic diseases	Mental and behavioural disorders	Diseases of nervous system	Diseases of circulatory system	Diseases of respiratory system	Diseases of the digestive system	Diseases of the skin and subcutaneous tissue	Diseases of the genitourinary system	Certain conditions originating in the perinatal period	Congenital malformations, deformations and chromosomal abnormalities	Symptoms, signs and abnormal clinical/ laboratory findings
1950	18.3	8.2	0.7	1.1	2.8	6.5	3.7	13.9	7.6	1.6	2.1	61.1	26.8	13.0
1951	19.8	8.4	0.9	1.0	2.3	6.7	4.7	15.6	6.1	1.1	1.8	63.1	29.0	11.8
1952	14.0	8.7	0.7	1.0	2.6	6.7	3.1	13.6	4.8	1.2	1.6	57.4	28.3	10.4
1953	12.3	8.4	0.5	1.1	2.8	6.2	3.2	13.3	5.0	1.4	1.3	54.7	27.7	8.7
1954	7.5	8.2	0.8	0.9	2.5	6.9	3.5	11.0	4.4	1.2	1.4	52.9	28.8	8.3
1955	6.7	8.1	0.7	1.1	2.6	7.4	2.7	11.7	3.8	1.0	1.5	50.0	28.9	7.2
1956	7.0	8.8	0.6	0.8	2.4	6.4	2.4	10.1	3.8	1.5	1.4	47.1	27.6	6.5
1957	4.6	9.2	0.5	0.9	2.5	7.2	1.5	13.1	4.3	1.0	1.6	42.6	27.0	5.4
1958	4.7	8.9	0.5	0.9	2.3	6.9	2.4	9.2	4.2	1.0	1.2	41.7	27.9	5.8
1959	4.8	8.6	0.7	0.9	2.2	6.9	1.8	10.7	5.4	1.1	1.4	42.9	26.5	5.2
1960	3.0	9.1	0.2	0.9	1.7	6.2	2.1	7.2	4.0	0.9	1.0	42.5	25.9	4.7
1961	2.3	8.7	0.3	0.7	1.0	6.4	2.0	5.6	3.6	1.1	1.0	39.8	26.6	5.2
1962	2.6	9.3	0.4	1.1	0.7	6.2	1.6	6.3	4.2	1.0	0.9	37.9	27.3	3.8
1963	2.0	8.6	0.3	0.9	0.7	6.5	1.9	5.5	3.8	1.2	1.1	36.4	24.4	4.3
1964	2.0	8.9	0.2	0.6	0.7	6.2	1.8	4.1	4.0	1.3	1.1	41.0	24.2	3.7
1965	1.7	8.6	0.4	0.8	0.5	6.2	1.8	5.0	3.2	1.1	0.8	40.2	21.2	3.7
1966	2.0	8.6	0.4	0.8	0.4	6.8	1.6	6.2	4.0	1.0	0.9	38.9	22.1	3.6
1967	1.6	8.3	0.4	0.9	0.7	5.1	1.4	3.9	3.9	1.0	0.9	36.5	20.8	3.5
1968	2.0	9.0	0.4	0.9	0.7	6.0	1.8	4.3	3.7	1.1	0.8	35.2	21.4	3.4
1969	3.9	7.3	0.5	1.9	0.4	5.5	2.0	4.2	2.4	0.2	0.6	33.2	23.2	2.7
1970	3.9	7.7	0.5	1.7	0.5	4.4	2.2	4.0	2.3	0.4	0.4	30.1	22.2	3.5

	Certain infectious and parasitic diseases	Neoplasms	Diseases of blood/ blood forming organs/ disorders immune mechanism	Endocrine/nutritional/metabolic diseases	Mental and behavioural disorders	Diseases of nervous system	Diseases of circulatory system	Diseases of respiratory system	Diseases of the digestive system	Diseases of the skin and subcutaneous tissue	Diseases of the genitourinary system	Certain conditions originating in the perinatal period	Congenital malformations, deformations and chromosomal abnormalities	Symptoms, signs and abnormal clinical/ laboratory findings
1971	3.6	6.8	0.5	1.7	0.5	4.7	1.8	3.5	2.1	0.2	0.5	28.2	20.3	3.7
1972	3.5	8.0	0.5	1.7	0.5	4.8	1.9	4.1	2.3	0.2	0.4	28.4	17.2	3.9
1973	3.6	7.3	0.4	1.5	0.3	4.5	1.9	4.0	1.5	0.2	0.2	26.8	17.9	4.0
1974	3.4	6.9	0.4	1.7	0.6	4.3	2.3	4.1	1.8	0.3	0.7	26.1	16.6	4.5
1975	2.7	6.2	0.5	1.5	0.7	4.3	1.8	2.9	1.6	0.3	0.3	23.4	16.5	6.9
1976	2.7	5.9	0.5	1.6	0.2	4.9	1.9	2.7	1.0	0.3	0.3	22.8	19.2	6.1
1977	2.6	5.5	0.2	1.5	0.2	4.2	1.2	2.3	0.8	0.1	0.2	18.8	16.7	7.7
1978	2.6	6.4	0.4	1.8	0.1	4.8	1.3	2.4	1.7	0.2	0.3	17.8	18.0	8.0
1979	1.5	5.8	0.6	1.5	0.0	3.5	1.2	1.8	1.1	0.1	0.2	17.5	16.7	7.6
1980	1.6	5.6	0.6	1.5	0.1	3.9	1.4	2.2	1.3	0.0	0.1	17.2	15.1	8.8
1981	1.2	5.3	0.6	1.5	0.0	3.7	1.5	2.5	1.1	0.2	0.1	15.4	16.0	7.9
1982	1.2	5.4	0.5	1.3	0.1	3.8	1.4	2.0	0.9	0.1	0.1	14.7	16.3	8.4
1983	1.0	4.8	0.4	1.4	0.0	3.6	1.5	1.6	0.8	0.1	0.1	15.2	15.7	9.3
1984	1.0	5.1	0.6	1.4	0.0	3.4	1.5	1.6	0.8	0.2	0.2	15.0	16.0	9.2
1985	1.2	4.8	0.3	1.8	0.1	3.7	1.6	2.4	0.7	0.1	0.0	13.7	15.3	7.6
1986	1.6	4.3	0.5	1.3	0.0	3.7	1.3	2.5	0.8	0.0	0.2	13.9	15.1	8.3
1987	1.7	4.4	0.4	1.4	0.1	3.9	1.2	2.0	0.6	0.1	0.1	13.2	15.3	7.5
1988	1.6	4.6	0.5	1.0	0.1	3.7	1.6	1.2	0.4	0.1	0.2	13.7	13.4	5.5
1989	1.7	4.3	0.3	1.1	0.1	2.8	1.3	1.4	0.5	0.1	0.1	14.5	12.6	6.6
1990	1.7	4.4	0.7	1.7	0.1	4.0	1.1	1.0	0.7	0.2	0.1	14.4	13.7	6.2
1991	2.0	4.3	0.4	1.4	0.1	2.8	0.9	1.2	0.4	0.2	0.1	13.6	13.4	4.9
1992	1.6	3.9	0.5	1.3	0.1	2.8	1.0	1.0	0.5	0.1	0.2	12.4	13.8	5.0

	Certain infectious and parasitic diseases	Neoplasms	Diseases of blood/ blood forming organs/ disorders immune mechanism	Endocrine/nutritional/metabolic diseases	Mental and behavioural disorders	Diseases of nervous system	Diseases of circulatory system	Diseases of respiratory system	Diseases of the digestive system	Diseases of the skin and subcutaneous tissue	Diseases of the genitourinary system	Certain conditions originating in the perinatal period	Congenital malformations, deformations and chromosomal abnormalities	Symptoms, signs and abnormal clinical/ laboratory findings
1993	1.7	4.3	0.4	1.3	0.2	2.6	1.0	1.3	0.7	0.0	0.1	13.0	12.9	4.7
1994	1.7	4.1	0.2	1.0	0.1	2.6	1.1	1.1	0.3	0.1	0.1	12.0	12.4	3.3
1995	1.7	4.3	0.3	1.0	0.1	3.1	1.1	1.2	0.4	0.1	0.1	12.1	11.0	3.7
1996	1.9	4.5	0.4	1.3	0.3	2.0	1.7	0.9	0.7	0.1	0.1	12.6	10.4	3.0
1997	1.7	3.7	0.2	1.2	0.2	1.6	1.3	0.8	0.3	0.2	0.0	10.1	11.0	2.6
1998	2.2	3.3	0.3	1.0	0.3	2.1	1.5	1.0	0.4	0.1	0.2	11.9	10.1	2.9
1999	1.7	3.3	0.2	1.2	0.3	2.0	1.3	0.8	0.5	0.1	0.2	12.0	9.7	3.3
2000	1.5	3.8	0.3	1.1	0.4	1.9	1.5	1.2	0.5	0.1	0.1	12.1	9.3	3.0
2001	2.1	3.9	0.3	1.1	0.2	2.3	1.4	1.0	0.5	0.1	0.1	11.9	9.2	3.8
2002	1.6	3.5	0.4	1.2	0.1	2.3	1.4	1.0	0.5	0.2	0.1	12.5	8.3	3.1
2003	1.2	3.3	0.3	1.0	0.3	2.5	1.3	1.0	0.5	0.1	0.1	11.0	8.9	2.8
2004	0.8	3.4	0.2	0.9	0.2	1.7	1.5	1.0	0.3	0.1	0.0	10.3	8.0	1.9
2005	0.9	3.6	0.1	0.8	0.1	2.0	1.2	0.9	0.4	0.2	0.1	12.4	8.0	2.2
2006	0.8	3.6	0.4	1.0	0.1	2.1	1.0	0.8	0.2	0.2	0.1	10.2	8.0	1.6
2007	0.5	2.9	0.3	0.8	0.1	1.8	1.0	0.8	0.5	0.2	0.1	10.9	6.4	1.4
2008	0.8	3.2	0.3	1.0	0.2	1.7	1.2	0.6	0.4	0.0	0.1	9.6	5.8	1.7
2009	0.3	2.7	0.3	0.7	0.2	2.2	1.3	1.2	0.2	0.2	0.0	9.7	6.1	1.3
2010	0.6	2.7	0.3	1.2	0.3	1.7	0.8	0.8	0.4	0.2	0.1	9.0	6.4	1.5
2011	0.6	3.0	0.1	0.9	0.2	2.0	0.9	0.8	0.2	0.1	0.0	8.9	6.0	1.4
2012	0.4	3.2	0.4	0.9	0.2	2.1	0.9	0.7	0.2	0.2	0.1	9.4	5.8	1.2
2013	0.6	2.6	0.2	1.2	0.2	1.9	0.6	0.5	0.1	0.2	0.1	10.2	5.1	1.3
2014	0.5	2.7	0.2	1.0	0.3	1.5	0.8	0.2	0.1	0.1	0.1	10.2	5.0	1.4

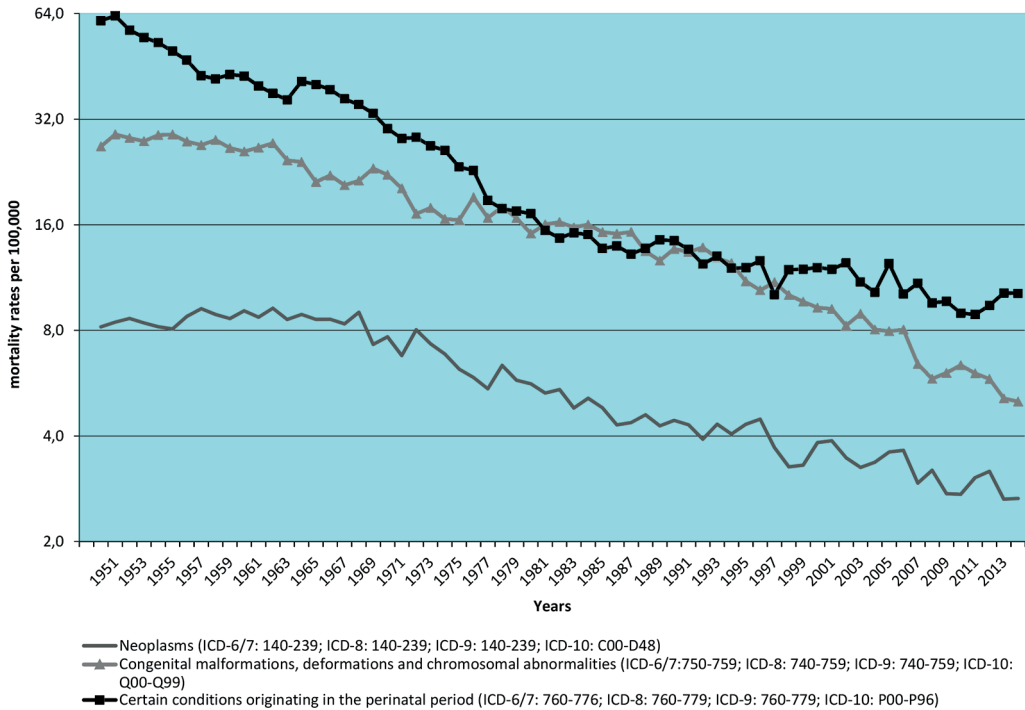


FIGURE 2. Cause-specific mortality rates per 100,000 Dutch children aged 0-19 in a logarithmic scale from 1950 – 2014 of high incidence natural causes-of-death groups, age-standardized using the European standard population of 2013

Certain conditions originating in the perinatal period

Death rates due to conditions originating in the perinatal period have declined from 61.1/100,000 in 1950 to 10.2/100,000 in 2014. Since 1980 the decline in perinatal mortality has levelled to a plateau phase (Figure 2). Deaths are mainly in children under the age of one year.

Congenital malformations and chromosomal abnormalities

Death rates due to congenital malformations and chromosomal abnormalities have declined from 26.8/100,000 in 1950 to 5.0/100,000 in 2014 (Figure 2). Most children died under the age of one year. Death rates due to congenital malformations of the nervous system have shown the largest decline from 9.6/100,000 to 0.6/100,000 in 2014. Until 1979 children were mainly dying from congenital malformations of the

circulatory system. After 1979 other congenital malformations are particularly the cause of death in this category.

Neoplasms

From 1950 to 1968 death rates due to neoplasms show a slight increase from 8.2/100,000 to 9.0/100,000. Since 1968 mortality has declined to 2.7/100,000 in 2014 (Figure 2). Most children died in the age group 0-4 years mainly from malignant neoplasms of lymphoid, haematopoietic and related tissues or other neoplasms.

Natural causes of death with a low incidence in 2014

Figure 3 presents cause-specific mortality rates per 100,000 Dutch children (0-19 year) in the period 1950-2014 for those natural cause-of-death groups that were rather highly represented in 1950 ($> 7.0/100,000$) and are almost not represented anymore in 2014 statistics ($< 1.0/100,000$) (age-standardized rates). These cause-of-deaths groups are certain infectious and parasitic diseases, diseases of the respiratory system and diseases of the digestive system.

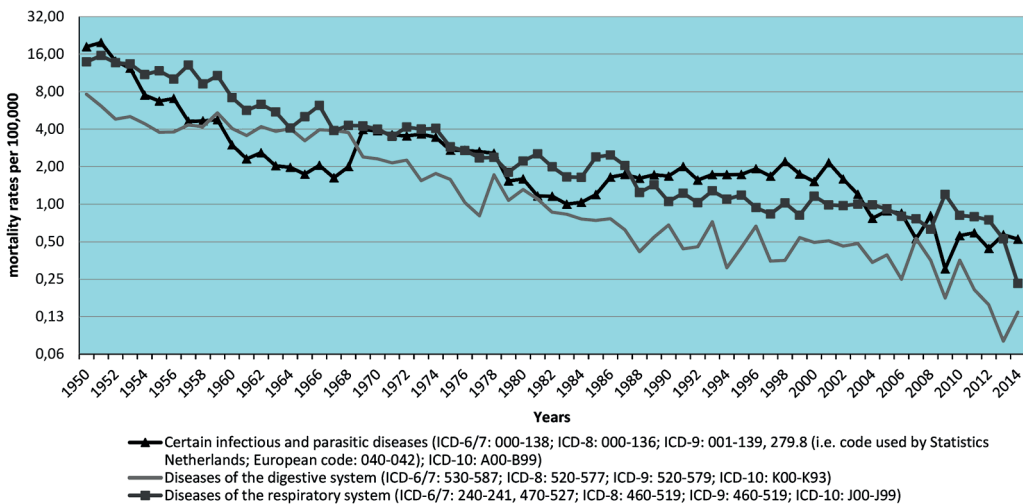


FIGURE 3. Cause-specific mortality rates per 100,000 Dutch children aged 0-19 in a logarithmic scale from 1950 – 2014 of low incidence natural causes-of-death groups, age-standardized using the European standard population of 2013

In figure 4 the incidence of Sudden Infant Death Syndrome (SIDS) in the period 1969-2014 is presented as incidence rate per 100,000 children aged 0 year.

Certain infectious and parasitic diseases

Death rates due to certain infectious and parasitic diseases have declined from 18.3/100,000 in 1950 to 0.5/100,000 in 1967 (Figure 3). The decline is particularly caused by a decrease in deaths due to causes in the category 'other infectious and parasitic diseases', that includes all infectious and parasitic diseases, except tuberculosis, viral hepatitis and Human immunodeficiency virus (HIV) disease. Since 1967 death rates have slightly increased to 3.9/100,000 in 1969, mainly due to other infectious and parasitic diseases. From 1969 a decline is seen to 1.0/100,000 in 1983. After a slight increase from 1983 to 2.1/100,000 in 2001, mainly due to meningococcal infection, a further decline is seen to 0.5/100,000 in 2014 (Figure 3).

Diseases of the respiratory system

Death rates due to diseases of the respiratory system have declined from 13.9/100,000 in 1950 to 0.2/100,000 in 2014 (Figure 3). The decline is mainly caused by a decrease in deaths due to pneumonia, which occurred particularly in the age group 0 and 1-4 years.

Diseases of the digestive system

Since 1950 death rate due to diseases of the digestive system has declined from 7.6/100,000 to 0.1/100,000 in 2014 (Figure 3), mainly due to a decrease in deaths due to causes in the category 'other diseases of the digestive system'. This category includes all diseases of the digestive system, except gastric, duodenal, peptic and gastrojejunal ulcer, alcohol liver disease, chronic hepatitis not elsewhere classified and liver fibrosis and cirrhosis. The largest decrease has occurred in the age group 0-4 years.

Sudden Infant Death Syndrome

Death rates due to Sudden Infant Death Syndrome (SIDS) have increased since 1973 from 4.9/100,000 to 111.9/100,000 in 1986, after which a decline has occurred to

6.4/100,000 in 2014 (Figure 4). Of the children that died from SIDS almost two-thirds were boys.

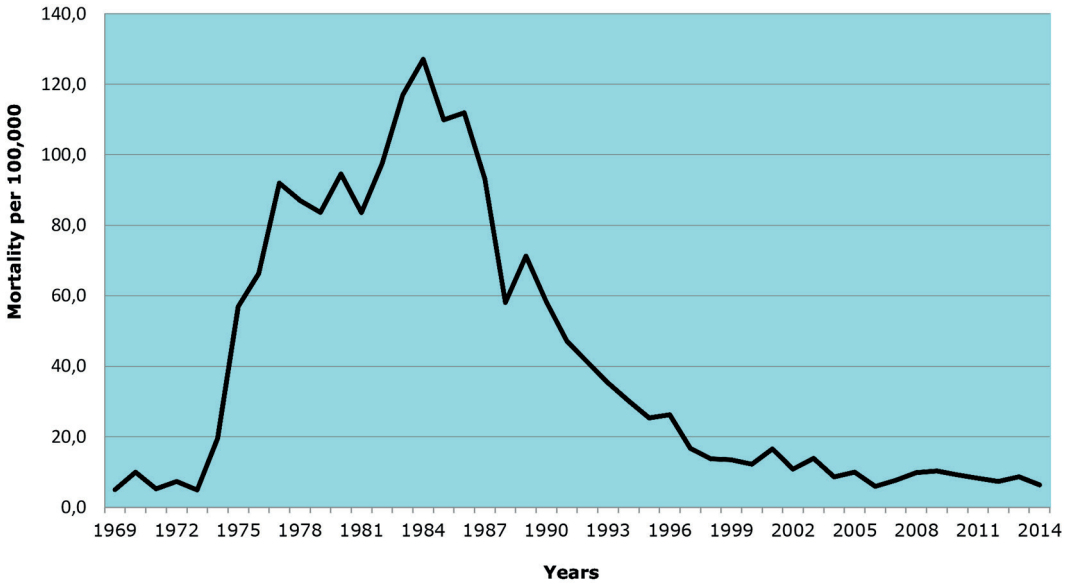


FIGURE 4. Mortality rate (per 100,000) of deaths due to Sudden Infant Death Syndrome (SIDS) in Dutch children aged 0 year from 1969-2014 (ICD-codes: ICD-6+7: --; ICD-8: 795 children aged < 1 yr; ICD-9: 798.0 children aged < 1 yr; ICD-10: R95).

Discussion

Child mortality due to natural causes has declined in the Netherlands since 1950. Certain conditions originating in the perinatal period, congenital anomalies and cancer are natural causes of child death that still have a high incidence in 2014. Since 1980 the decline in perinatal deaths has leveled to a plateau phase, while deaths due to congenital anomalies and cancer have declined further. Infectious diseases and diseases of the respiratory and digestive system were rather prevalent in the causes of death statistics of 1950, but are rare causes of child deaths in 2014. The incidence of Sudden Infant Death Syndrome (SIDS) has increased from 1973 until 1987, after which a decrease is observed until a very low incidence in 2014. The observed shift in cause-of-death rates from deaths due to infectious diseases towards deaths due to cancer parallels the epidemiological transition that can be seen in the adult population as well [54].

The downward trend in child mortality due to natural causes has also been observed globally [47]. The increased standard of living and the improvements in sanitation, hygiene, housing and access to health care, have contributed to the decrease in several causes of child deaths [13]. Next to this, other factors might be present to provide a possible explanation for the declining trend in the Netherlands.

The decrease of certain conditions originating in the perinatal period occurred together with an improvement in antenatal and perinatal care and the introduction of anti-D immunoglobuline around 1970. Next to this, the proportion of high-risk pregnancies has been reduced due to a declining birth-rate, which is associated with a decrease in perinatal deaths [55]. The downward trend in perinatal deaths is also observed in other high income countries since 1950 [56]. From 1980 the decline in perinatal deaths in the Netherlands has levelled to a plateau phase, which can be explained by several reasons [57, 58]. First of all four important risk factors related to perinatal mortality have increased in the Netherlands in the past decades: 1. higher ages of mothers of first born children, 2. the increase of mothers with an immigrant background, in whom the prevalence of socio-cultural and lifestyle risk factors are higher, 3. multiple births mainly caused by fertility treatment, and 4. smoking during pregnancy [57-59]. Maternal smoking was on a stable high level in the period 1967-1975 and has declined afterwards [60]. The exposure of nicotine during pregnancy and after birth is related to mortality (i.e. perinatal deaths and SIDS) and morbidity [61, 62]. In addition to these risk factors the reserved use of antenatal diagnostics and of the most modern medical techniques in case of extremely prematurely born children, has also resulted in a less rapid decrease in perinatal deaths in the Netherlands. The restraint to use these technologies by Dutch pediatricians and gynecologists is seen by the authors of a study into the perinatal mortality in the Netherlands as an explanation for a further decline failing to occur in perinatal mortality compared to other West-European countries [57]. This has led to political preventive measures in order to further reduce perinatal mortality by renewing perinatal health care policy. This includes among others conducting perinatal audits on a regional and national level, supported by Perined, to translate the conclusions into preventive measures with the objective to improve the quality of perinatal health care [20, 63]. In addition to this, ten regional consortia have been installed that form the knowledge network Perinatal Care, are conducting research in order to reduce perinatal and maternal death [64].

We observed a downward trend in death rates due to congenital malformations and chromosomal abnormalities. This decline is also seen in wealthier countries since 1950, but to a lesser extent [56]. The introduction of prenatal screening programs for the detection of congenital anomalies in many Western countries, like the Netherlands, has resulted in an increase in child survival. With the early detection of congenital anomalies expectant parents can make an informed decision on either continuing the pregnancy and starting appropriate, timely treatment after birth, or terminating the pregnancy [65, 66]. With regard to deaths due to congenital malformations of the nervous system the use of folic acid supplementation during the periconceptional period, which was introduced in Dutch governmental policy in 1993, resulted in a reduction of the prevalence of neural tube defects in infants [67]. Other research has supported the effect of folic acid consumption not only on the prevention of neural tube defects [68], but also on the prevention of congenital heart disease when used in the recommended period 4 weeks prior to conception to 8 weeks afterwards [67]. The decline in deaths due to congenital heart disease that we observed, might also be associated with the improvement of diagnostics, such as echocardiography, ultrasound screening performed around 20 weeks of gestation and screening at Preventive Child Health Care centers, and treatment [65, 69-71].

The downward trend in deaths due to neoplasms in the Netherlands since 1968 occurred together with an improvement in cancer treatment around 1970 [55]. As concluded in other studies improvement in diagnostics and treatment has increased survival of children with cancer and therefore has resulted in a reduction in mortality [72, 73]. Of the most common tumor types in children in Europe, which are leukemia, central nervous system tumors and lymphomas [72], the greatest reduction in mortality over time in Europe was observed for leukemia and lymphomas (more than 50%) and to a lesser extent for central nervous system tumors (around 30%) [73].

The introduction of antibiotics in 1947 and mass vaccination in the Netherlands in 1952 [55] after which the Nationwide Immunization Program (NIP) was implemented from 1957 [74], has contributed to a declining trend in deaths due to infectious diseases since 1951 and pneumonia [13, 55]. Routine vaccination against childhood diseases has been identified as one of the most cost-effective strategies to prevent death from pneumonia [75]. The decrease in infectious diseases has also been observed in two Dutch studies that provided data from 1969-2006 and from 1903-2012 respectively [13, 76]. The further decline in infectious diseases since 2001 can

probably be associated with the introduction of the Meningococcal C-vaccination at the age of 14 months in 2002 and the vaccine against pneumococcal disease in 2006 in the NIP [77, 78]. As other studies have concluded [79, 80], the use of conjugate vaccines, like the Hib and pneumococcal conjugate vaccines in the NIP [78], might have resulted in a further decline of death due to pneumonia in the Netherlands.

We observed a downward trend in death due to mainly other diseases of the digestive system that occurred together with an improvement of medical and surgical treatment of those diseases [55]. As the category 'other diseases of the digestive system' includes a broad range of diseases, it is difficult to compare with other literature. Therefore, we leave out the comparison.

The increase in SIDS in the Netherlands from 1973 to 1987 might be explained by the increase of several risk factors, such as prone sleeping following the promotion of this sleeping position in order to stimulate infant motor development at the 13th International Paediatric Congress in Vienna in 1971 [81], overheating by the use of central heating and duvets, and smoking during pregnancy and after birth [60]. In addition to this, the composition of the Dutch population in terms of ethnicity changed in the 70s and 80s [82]. The incidence of SIDS used to be higher in the Turkish population compared to Maroccans, which is related to cultural care practices, such as use of pillows in bed and maternal smoking [82, 83]. From 1987 parents were advised by the health care professionals not to put their baby's prone to sleep. This resulted in a decrease in the incidence of SIDS [84]. Since the advice was given to place an infant on the back to sleep in 1992 together with the education on other risk factors, as discouragement of duvet and pillow use and bed-sharing, but also the recommendation of protective factors, as the use of a sleeping bag and dummy [85], the incidence of SIDS has further declined [86, 87]. In the Netherlands the guideline '*Prevention of Cot Death*' developed by the Dutch Pediatric Association in collaboration with the Association of Preventive Child Health care physicians, is used to prevent SIDS. As a result of new insights into the pathogenesis of cot death the guideline is revised in 2007 with additional advices for a safe sleeping environment of the infant [28, 88].

Strengths and weaknesses

This study describes the pattern of natural causes of child deaths in the Netherlands in the past decades. It provides insight into the causes of child deaths that are still frequent and what has possibly contributed to a decline in order to direct future preventive measures.

In this study we used existing data on the primary causes of death of Statistics Netherlands. The quality of these data largely determines the validity of the trends described. Ascertaining the cause and manner of death might be difficult for attending physicians. Therefore, in some cases the death of children may have been classified incorrectly. The mandatory consultation of a municipal coroner in case of deceased minors since 2010 might help attending physicians in correctly classifying the cause of death. Specific trend deviations after 2010, which might be explained by a shift in the classification of deaths, have however not occurred.

Next to this, the use of five different versions of the ICD in the causes of death statistics impedes comparisons over time. As each ICD version has a different set of codes, the conversion of codes into ICD version 10 is prone to errors or miscoding. Furthermore, the causes of death were coded manually up until 2012 by the medical coders of Statistics Netherlands. Bias can be reduced by using software for coding and selecting the cause of death [10]. Since 2013 causes of death are partly coded automatically [44].

Finally, it should be noted that the absence of the secondary causes of deaths in the Dutch causes of death statistics creates a gap in understanding the death of a child completely. Information on the secondary causes of death might identify additional risk factors that can be translated in suggestions for prevention.

Conclusion

Child mortality due to natural causes has declined enormously in the Netherlands in the past decades due to the increased standard of living and improvements in sanitation, hygiene, housing and access to health care. In addition to this, improvements in diagnostics, medical treatment and surgery, and the introduction of preventive measures, like mass vaccination [55] and informing parents about

the risk factors for SIDS [89], have contributed to a further decline. Despite those improvements and preventive measures there are still causes of child deaths that are frequent and avoidable.

In the Netherlands perinatal deaths and cases of Sudden and Unexpected Deaths in Infants are systematically reviewed by perinatal audits and the National Cot Death Study Group respectively in order to reduce those deaths. Also, when a child dies in the hospital, the death is reviewed by the involved medical professionals in order to improve health care delivery.

A further decline of child mortality due to natural causes is achievable when systematic analysis of child deaths has become a standard procedure for more categories of child deaths. This might result in the identification of avoidable factors for which preventive measures can be implemented.

APPENDIX 2.1 Natural cause-of-death groups with corresponding International Classification of Diseases (ICD) codes version 6, 7, 8, 9 and 10.

	ICD-6+7	ICD-8	ICD-9	ICD-10
	Version 6 in use from 1950-1957; version 7 In use from 1958-1968	In use from 1969-1978	In use from 1979-1995	In use from 1996 until now
Certain infectious and parasitic diseases	000-138	000-136	001-139, 279.8 (CBS code. European code: 040-042)	A00-B99
Neoplasms	140-239	140-239	140-239	C00-D48
Diseases of blood/ blood forming organs/disorders immune mechanism	290-299	280-289	279-289 excl. 279.8	D50-D89
Endocrine/nutritional/ metabolic diseases	250-289	240-279	240-278	E00-E90
Mental and behavioural disorders	300-326	290-315	290-319	F00-F99
Diseases of nervous system	340-398	320-389	320-389	G00-H95
Diseases of circulatory system	330-334, 400-468	390-458	390-459	I00-I99
Diseases of respiratory system	240-241, 470-527	460-519	460-519	J00-J99
Diseases of the digestive system	530-587	520-577	520-579	K00-K93
Diseases of the skin and subcutaneous tissue	242-244, 690-716	680-709	680-709	L00-L99
Diseases of the genitourinary system	590-637, 792	580-629, 792	580-629	N00-N99
Certain conditions originating in the perinatal period	760-776	760-779	760-779	P00-P96
Congenital malformations, deformations and chromosomal abnormalities	750-759	740-759	740-759	Q00-Q99
Symptoms, signs and abnormal clinical/laboratory findings	780-791, 793-795	780-791, 793-796	780-799	R00-R99

CHAPTER 3

Child mortality in the Netherlands in the past decades: an overview of external causes and the role of public health policy

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Abstract

Among European countries, the Netherlands has the second lowest child mortality rate from external causes. We present an overview, discuss possible explanations, and suggest prevention measures. We analyzed mortality data from all deceased children aged 0–19 years for the period 1969–2011. Child mortality declined in the past decades, largely from decreases in road traffic accidents that followed government action on traffic safety. Accidental drowning also showed a downward trend. Although intentional self-harm showed a significant increase, other external causes of mortality, including assault and fatal child abuse, remained constant. Securing existing preventive measures and analyzing the circumstances of each child's death systematically through Child Death Review may guide further reduction in child mortality.

Introduction

Child mortality is an important indicator of overall health. If subdivided into age-specific categories, it also indicates whether health risks are higher for particular age groups. Understanding the causes of death through Child Death Review (CDR – see a discussion of the term in our conclusion) can help health-care professionals and policy makers act to reduce preventable deaths [16].

We define child mortality consistent with the target group of Dutch youth health care – every live-born child who dies under the age of 20 [90]. There is more than one way, or set of rules, for attributing ‘cause of death’. The World Health Organization (WHO) defines the ‘primary’ or ‘underlying cause of death’ in a manner similar to the International Classification of Diseases (ICD): ‘the disease or injury which initiated the sequence of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury’ [43, 44]. Consequences or complications of disease or injury, and other diseases present at the time of death that may have contributed, are considered as ‘secondary causes’ of death. Where the cause of death is external (see definition below), the primary cause is the underlying event and the injury is considered as the secondary cause of death [44]. When a person dies of a cerebral hemorrhage due to an accidental fall, for example, the primary cause of death is the accidental fall and the cerebral hemorrhage the secondary cause.

Worldwide, injuries are the leading cause of death among children aged 10–19 years [91-94]. Each year approximately 950 000 children under 18 years of age die as a result of injury or violence. ‘Accidental’ or ‘unintentional’ deaths account for nearly 90 per cent of all external causes of mortality. The highest rates of unintentional injury occur in low- and middle-income countries [91, 92]. In European countries the highest child mortality rates from external causes are found in Eastern Europe and the lowest in Western Europe. Sweden has the lowest child mortality rate (due to a societal approach of safety promotion) [95, 96], followed by the Netherlands. The difference between Eastern and Western Europe can be explained by regional inequalities in public policy (such as safety legislation) and problems with accuracy and availability of mortality data [97].

We looked for the explanation for the low Dutch child mortality rates from external causes. We analyzed changes in the external causes of child mortality in the Netherlands in groups classified by age and sex from 1969 to 2011. We also discuss the data quality and measures taken to reduce the number of external causes of child deaths.

Methods

Setting and Methods

In the Netherlands only the attending physician and the municipal coroner are permitted to certify death; they do so by signing a death certificate. Since January 2010, the attending physician is legally obliged to consult a municipal coroner in case of deceased minors [25].

During the post-mortem examination the physician must determine the cause and manner of death, distinguishing between 'natural' and 'external' causes. According to the Dutch Health Care Inspectorate, a natural cause of death is 'due to an illness or old age, including compliance with established principles of contemporary medical treatment'. Dutch authorities define an external cause of death as one originating outside the body by chemical or physical means, including medical errors and death due to criminal intent [42]. In circumstances where a natural cause of death is doubted, or external cause of death is evident, the attending physician is not permitted to issue a certificate of death. Instead, the municipal coroner is notified to conduct a post-mortem examination and is responsible to determine the cause of death [98].

For statistical purposes, the attending physician or municipal coroner completes a medical certificate on the cause of death containing only anonymous data, then sends it in a sealed envelope through the local municipal authority of the city where the death occurred to the medical officer of Statistics Netherlands. Subsequently the information on the cause of death can be linked with mortality data from the municipal personal records database. Compilation of these data results in tables on cause of death for every deceased Dutch citizen who is buried or cremated in the Netherlands or abroad. Citizens of foreign countries are not included in national statistics before naturalization [11, 25].

Statistics Netherlands as the official registrar in the country records only the primary cause of death of citizens of the Netherlands using the rules of the ICD of the WHO in a statutory computer-based register, that is continuously updated. These data, available since 1969, are published annually in an electronic database, Statline. From 1969 to 2011 Statline relied on ICD versions 8, 9, and 10, in compliance with revisions made by WHO once every 10 years [11, 51, 99]. The differences between ICD-8, ICD-9, and ICD-10 for classifying external causes of death can be followed in Table 1, a part of the conversion table used by Statistics Netherlands.

TABLE 1: Corresponding codes of external causes of death between ICD-8, ICD-9, and ICD-10

Description of cause of death	ICD-10	ICD-9	ICD-8
External causes of mortality	V01-Y89	E800-E999	E800-E999
Accidents	V01-X59	E800-E929	E800-E929,
	—	—	E940-E949
Transport accidents	V01-V99	E800-E848	E800-E845
Road traffic accidents	—	E810-E819,	E810-E819,
	—	E826-E829	E825-E827
Accidental fall	W00-W19,X59	E880-E888	E880-E887
Accidental drowning	W65-W74	E910	E910
Accidental poisoning	X40-X49	E850-E869	E850-E877
Intentional self-harm	X60-X84	E950-E959	E950-E959
Assault	X85-Y09	E960-E969	E960-E969
Event of undetermined intent	Y10-Y34	E980-E989	E980-E989

Study population

Our study population consists of the dynamic population of Dutch children from 0 to 19 years of age in the Netherlands in consecutive years in the period 1969–2011. The average size of this population decreased from 4 647 616 in 1969 to 3 779 487 in 1996. A slight increase occurred from 1996 to 3 987 757 in 2004, followed by a decrease to 3 901 958 in 2011 [100].

Analysis

We analyzed mortality data of external causes of death in Dutch children aged 0–19 years in the period 1969–2011. The numbers and incidences of deaths are not

cohort-based estimates, but true results of the entire population and, therefore, this study does not use statistical analyses with probability values as would be required in cohort or sample-based estimations. Then we calculated cause-specific mortality rates per year (per 100 000 children) by dividing the total number of cause-specific deaths in this age in one year by the sum of the population of children in the age category at the end and beginning of the year divided by two, thus finding the midyear population for each year.

To establish age-specific rates for selected age groups (under 1, 1–4, 5–9, 10–14, 15–19), we divided the actual annual numbers of deaths by the midyear population for each age and gender group. We present annual midyear population numbers for each year between 1969 and 2011 and death rates as the number of deaths per 100 000 persons per year by gender and age group. In some categories of deaths the selected age groups are combined. We used linear regression for trend analysis in mortality due to intentional self-harm. To describe the external causes of death after 1996 in detail, we assembled and analyzed categories of deaths from different external causes in the period 1996–2011.

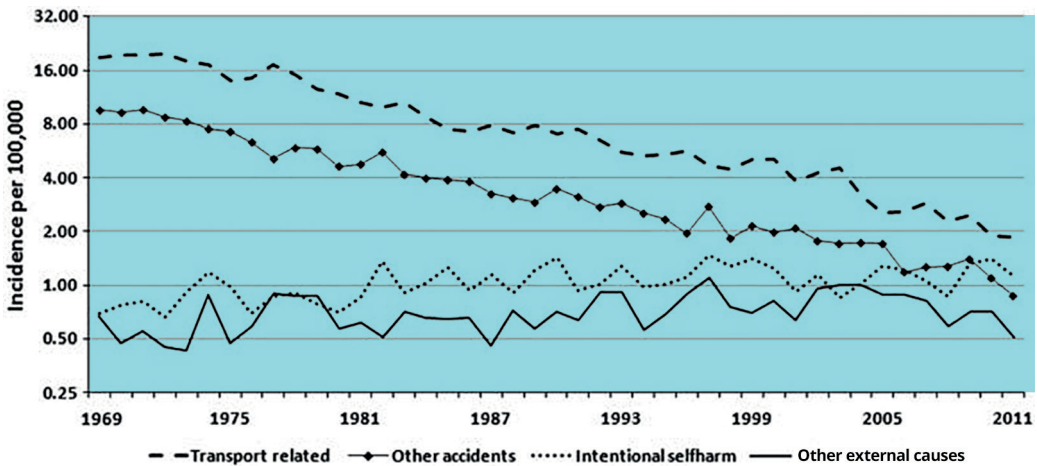


FIGURE 1: Death due to external causes in Dutch children aged 0–19 (crude rate per 100,000) from 1969–2011.

Results

Child mortality due to external causes in the period 1969–2011

Figure 1 presents child mortality per 100 000 Dutch children due to external causes for ages 0–19 in the period 1969–2011. Death from external causes has declined since 1969. Most children die from transport-related accidents.

Fatal transport-related accidents (ICD-8: E800-E845; ICD-9: E800-E848; ICD-10: V01-V99)

Since 1973, death due to transport-related accidents decreased enormously, especially in the age category 15–19 years, from 20/100 000 in 1973 to 1.9/100 000 in 2011. The peak in 1977 can be explained by an airplane crash in Tenerife with many Dutch victims [101]. Boys are overrepresented in all age categories, but the difference in mortality between boys and girls decreased over time (Figure 2).

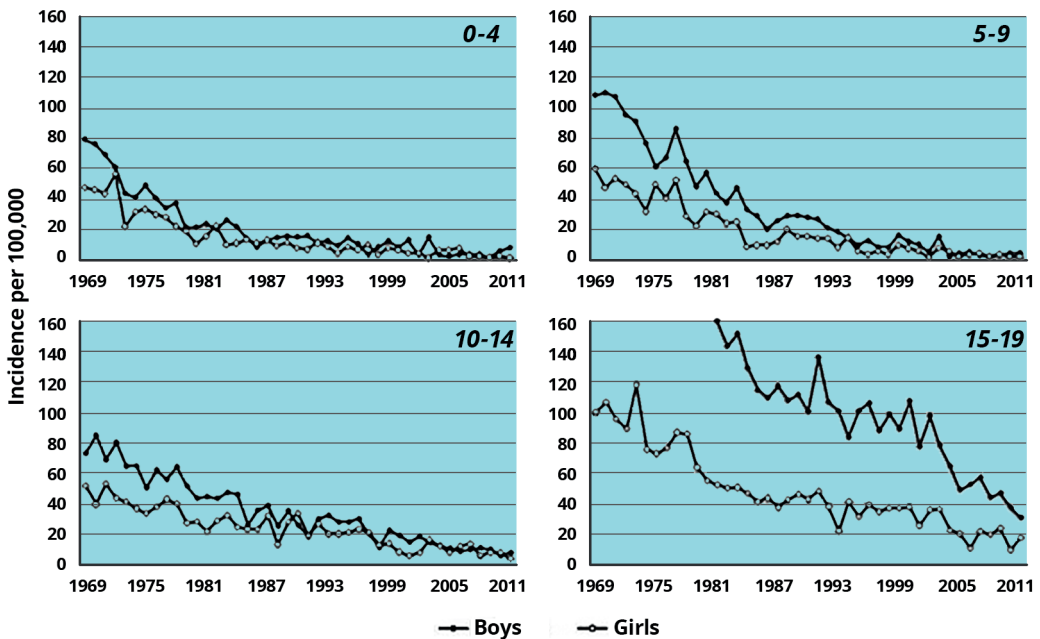


FIGURE 2: Annual incidence (per 100,000 in a logarithmic scale) of transport-related accidental deaths in the Netherlands in four age categories (0–19 years) from 1969–2011.

Other fatal accidents (ICD-8: E850-E877, E880-E887, E890-E929, E942-E946; ICD-9: E850-E888, E890-E929; ICD-10: W00-X59)

Death due to other accidents, such as ‘accidental fall’ and ‘accidental drowning’, also declined from 10/100 000 in 1971 to 0.9/100 000 in 2011. Accidental fall is the most common cause of death in boys aged 0–4 years and 15–19 years; girls are at risk especially from ages 0 to 4. Accidental drowning occurs in both boys and girls, most often those 0–4 years (Figure 3).

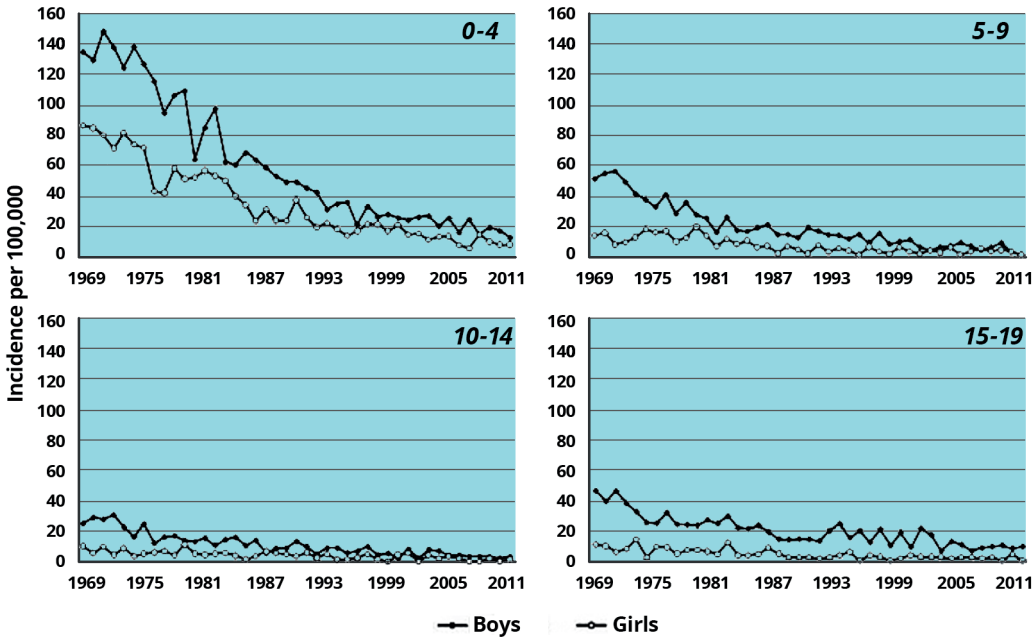


FIGURE 3: Annual incidence (per 100,000) of other accidental deaths in the Netherlands in four age categories (0–19 years) from 1969–2011.

Intentional self-harm (ICD-8: E950-E959; ICD-9: E950-E959; ICD-10: X60-X84) and other external causes of mortality (ICD-8: E930-E949, E960-E978, E980-E999; ICD-9: E930-E949, E960-E978, E980-E999; ICD-10: X85-Y89)

‘Intentional self-harm’ is observed from the age of 10 years. The total number of deaths in this category shows a significant increase ($P \leq 0.0001$) from 1969 to 2011.

Analysis by age and sex shows a significant increase for boys ($P = 0.0001$) and girls ($P = 0.0008$) 15–19 years of age, and for girls 10–14 years of age ($P = 0.002$), but no such increase for boys 10–14 years ($P = 0.894$) (Figure 4).

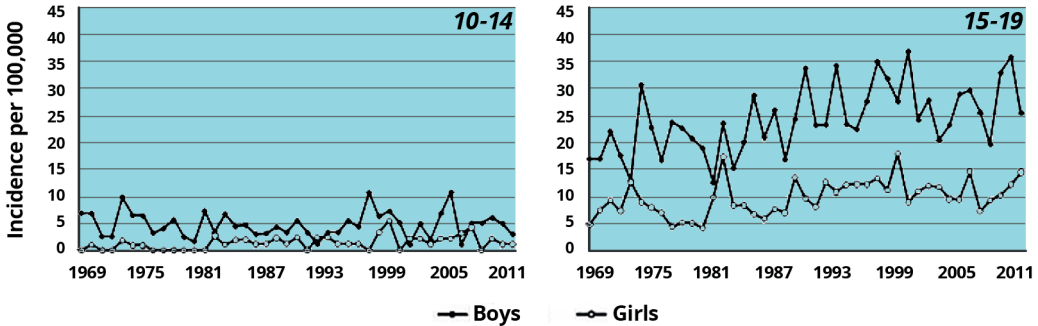


FIGURE 4: Annual incidence (per 100,000) of fatal intentional self-harm among 10-19 year old Dutch boys and girls from 1969–2011.

Death from other external causes of mortality, including assault and events of undetermined intent, remain fairly stable from 1969 to 2011.

The period 1996–2011 in detail

Over the past 16 years, external causes account for about 20 per cent of child mortality with external causes having declined from 9.7/100 000 in 1996 ($n = 365$) to 4.4/100 000 in 2011 ($n = 171$), largely reflecting a decline in transport-related accidents. We discuss below the main external causes of death, expressed as the crude rate per 100 000 children and represented in Table 2.

Fatal transport-related accidents (ICD-10: V00-V99)

Death due to transport-related accidents, mostly road traffic accidents, declined from 5.7/100 000 in 1996 ($n = 215$) to 1.9/100 000 in 2011 ($n = 73$). Most fatal transport-related accidents killed children aged 15–19 years (about 67 per cent of all transport-related accidents) with boys overrepresented. Most of these deaths involve motorcyclists (including moped riders) who collided with a car or delivery van (ICD-10: V23), or an occupant of a car that collided with a fixed or stationary object (ICD-10: V46). Cyclists from the age of 10 died most often from collision with a truck (ICD-10: V14).

Other fatal accidents (ICD-10: W00-X59)

Within the category 'other external causes of accidental injury', accidental drowning is prominent. There seems to be a decrease of accidental drowning from 0.9/100 000 in 1996 (n = 35) to 0.5/100 000 in 2010 (n = 19), but absolute numbers are small. In 2011 only 0.1/100 000 children died (n = 5); for most the cause of death was recorded as 'unspecified drowning or submersion'. Drowning killed mostly children aged 1–4 years and almost half of the drowning accidents occurred in or around the house. Two-thirds were boys [102].

TABLE 2: External causes of death in children aged 0–19 years in the Netherlands (crude rate per 100 000)

	Transport accidents (ICD-10: V00-V99) of which:	Road traffic accidents	Other (transport)	Other external causes of accidental injury (ICD-10: W00-X59) of which:	Accidental fall	Accidental drowning	Accidental poisoning	Other accidents	Intentional self-harm (ICD-10: X60-X84)
1996	5.7	5.2	0.5	2.0	0.3	0.9	0.0	0.7	1.1
1997	4.7	4.6	0.1	2.8	0.4	1.1	0.1	1.1	1.5
1998	4.5	4.3	0.2	1.8	0.3	0.7	0.0	0.8	1.3
1999	5.1	4.9	0.2	2.2	0.3	0.9	0.1	0.8	1.4
2000	5.0	4.8	0.2	2.0	0.2	0.7	0.0	1.1	1.2
2001	3.8	3.6	0.2	2.1	0.1	0.6	0.1	1.2	0.9
2002	4.2	4.1	0.1	1.8	0.2	0.9	0.1	0.6	1.1
2003	4.5	4.2	0.3	1.7	0.2	0.5	0.1	0.9	0.9
2004	3.2	3.0	0.2	1.7	0.3	0.7	0.1	0.7	1.0
2005	2.5	2.4	0.2	1.7	0.3	0.6	0.1	0.7	1.3
2006	2.6	2.4	0.2	1.2	0.1	0.4	0.1	0.6	1.2
2007	2.9	2.8	0.1	1.3	0.1	0.4	0.1	0.8	1.1
2008	2.3	2.2	0.1	1.3	0.2	0.4	0.1	0.6	0.9
2009	2.5	2.3	0.2	1.4	0.1	0.4	0.1	0.9	1.3
2010	1.9	1.7	0.2	1.1	0.1	0.5	0.1	0.4	1.4
2011	1.9	1.7	0.2	0.9	0.1	0.1	0.1	0.6	1.1

TABLE 2: *Continued*

	Other external causes of mortality (ICD-10: X85-Y89) of which:	— Assault	— Events of undetermined intent	— Other external causes of mortality	Total external causes of mortality	Midyear population (millions)
1996	0.9	0.7	0.1	0.0	9.66	378
1997	1.1	0.9	0.1	0.2	10.00	380
1998	0.8	0.6	0.1	0.1	8.34	382
1999	0.7	0.6	0.0	0.1	9.34	386
2000	0.8	0.6	0.1	0.2	9.07	389
2001	0.6	0.5	0.1	0.1	7.47	392
2002	1.0	0.7	0.2	0.1	8.12	395
2003	1.0	0.7	0.3	0.0	8.09	398
2004	1.0	0.6	0.3	0.2	6.92	399
2005	0.9	0.7	0.1	0.1	6.40	398
2006	0.9	0.6	0.2	0.1	5.85	397
2007	0.8	0.6	0.1	0.1	6.03	395
2008	0.6	0.4	0.1	0.1	5.00	394
2009	0.7	0.6	0.0	0.1	5.90	393
2010	0.7	0.6	0.1	0.1	5.10	392
2011	0.5	0.5	0.0	0.0	4.38	390

Source: Statline CBS, June 2012.

Fatal intentional self-harm (ICD-10: X60-X84)

The number of children who died from 'intentional self-harm' increased from 1996 to 2011 ($n =$ between 34 and 56 per year). Intentional self-harm, coded from the age of 10, occurred mostly among those 15–19 years of age. The rate for boys was about 2.5 times that for girls. Most of these deaths involved hanging or strangulation; less frequently the cause involved jumping in front of a train or subway (especially boys).

Other external causes of mortality (ICD-10: X85-Y89)

The number of deaths due to 'other external causes' remained constant from 1996 to 2011 (n = between 20 and 42 per year). This group includes 'assault' (ICD-10: X85-Y09), events of 'undetermined intent' (ICD-10: Y10-Y34), and 'fatal child abuse' (ICD-10: Y05-Y07). The data include 62 children so registered from 1996 to 2011, 61 were 0–9 years of age (0.19/100 000). Reported assaults occurred mostly after the age of 15 years, including assault by 'other and unspecified means' (ICD-10: X93 (n = 4), X94 (n = 1), and X-95 (n = 43)). Young men are overrepresented here as victims of fatal violence [103]. In most cases, the motive of assault is unknown and a public area is the place of death.

Discussion

Mortality due to external causes has declined in the Netherlands, particularly due to decreases in road traffic accidents and other external causes of accidental injury in all age groups. Death due to intentional self-harm increased significantly, and assault and events of undetermined intent remained constant. Researchers in other high-income countries observe the same trends [91, 92, 95]. For almost all external causes, boys from 15 to 19 years are most commonly involved, with the exception of accidental falls and drowning which occur mainly among 0–4-year olds.

Decrease in road traffic accidents probably results from government traffic safety interventions implemented to protect particular types of accident victims. Other high-income countries explain their declines in these accidents similarly [93, 94, 96]. From 1973 to 1985, construction of motorways and separate cycle paths, plus safety engineering in vehicles have surely contributed to saving children's lives in the Netherlands. In the 1970s, government promoted safety nationwide with an obligation to wear seat belts in cars and helmets for motorcyclists, speed limits outside urban areas, a legal alcohol limit, and the introduction of speed limits in residential areas. From 1998, the government supported a safe traffic system, by developing 30 km/h and 60 km/h zones, shifting mopeds from the cycling path to the main road, and replacing crossroads with roundabouts. From 2000, certain measures aimed to reduce high accidental risk among road users aged 15–19 years: introduction of a driver's license for beginners with a demerit system (from 2002)

and a lower alcohol limit of 0.2 parts per thousand for novice drivers (from January 2006) [104]. Also, the Netherlands introduced a new element in the driving-test in March 2009: to visualize and recognize hazards in traffic [105].

Introduction of a 'blind-spot' mirror in 2003 did not, however, result in a measurable decline in deaths among cyclists who collide with right- turning trucks. The Institute for Road Safety Research has suggested other safety measures, such as stopping trucks at a considerable distance before the stop line, a code of conduct for cyclists, and the use of mirrors or a camera when a truck is turning right. These should help to reduce accidents [106]. As elsewhere, in the past 16 years, transport-related accidents remain the greatest of all external causes of death in children [91]. Overrepresentation of boys probably reflects lack of driving experience, plus age- and gender-related risk-taking behaviour [105]. The Netherlands permits 16-year olds to drive mopeds. Seventeen-year olds may obtain a car driver's license, but until their 18th birthday they can drive only under supervision.

Further reduction of mortality and morbidity will require continuous attention to prevention at the level of the traffic participant, vehicle safety improvements, and infrastructure improvements. These same measures can reduce health-care expenditures and the societal burden for the care of the victims [107, 108].

A downward trend in accidental drowning from 1996 to 2010 occurred in a country with many lakes, rivers, canals, and ponds. The small number of cases in 2011 is in sharp contrast to previous years and may be a one-off observation (again 15 cases in 2012). The decreased risk of drowning does not apply to children of non-Western immigrants. Children of recently immigrated parents of non-Western ethnicity, most 3–10 years, are most often the drowning victims and as foreign nationals not included in statistics. The risk for these children is about 4–8 times higher than for native Dutch children [109, 110].

Possible reasons for the decline in drowning accidents include socio-cultural factors (higher education level of parents, smaller families, increased supervision) and effective prevention, such as swimming lessons and the dissemination of safety cards by the Consumer and Safety Foundation, and by youth health-care organizations targeting accident prevention [102, 111]. Prevention involves education about safety precautions for children when near open water, and swimming lessons [109, 110].

Among Dutch teenagers, especially those 15 and older, deaths from intentional self-harm increased in the past 16 years, despite preventive efforts of youth health-care professionals. As in other high-income countries this trend is extremely worrying [94, 96, 112]. The suicidal process in adolescence is related to behavioral and emotional (family) problems [113], and the overall risk of suicide increases when underlying factors, which contribute to the deliberate self-harm, are silently present [114]. Early detection of adolescents at risk is required to reduce suicide. The Dutch government recently allotted additional resources for individual counseling sessions for adolescents in youth health care [115]. An instrument to detect suicidal tendencies is yet to be developed.

Assault as a cause of death, including fatal child abuse, remained remarkably stable in the past 16 years. The very restrictive Dutch Weapon and Ammunition legislation probably accounts for the small number of assaults [116]. The number of children dying from fatal child abuse in the period 1996–2011, as registered in the causes of death statistics, does not match the numbers sometimes mentioned in popular media. The way data are gathered and differing definitions of child abuse could explain this [117-119]. Attention to violent and criminal behavior of adolescents and prevention of domestic violence are crucial to ensure that children grow up in a safe and healthy environment. Preventing and identifying child abuse are the tasks of (public) health professionals, the Child Protection Service, and police [120, 121].

Limitations

Because the death of a child is a rare event, attending physicians and municipal coroners may have little experience in determining correctly the primary cause of death and whether the cause of death is natural or external. Since January 2010, attending physicians are obliged to consult the municipal coroner in case of a deceased minor, and the municipal coroners are obliged to be registered as forensic physicians. Although external causes of death are generally well documented because police, municipal coroner, and justice officials investigate thoroughly, the use of three different versions of the ICD in the causes of death statistics impedes comparisons over time. Finally, a more detailed description of the main external causes of death from 1996 to 2011 is made difficult by the small numbers of deceased children in the subcategories of the ICD-10.

Conclusion

The number of children who die from external causes declined in the past decades, especially due to efforts of the Dutch Government, the Consumer and Safety Foundation, and the Institute for Road Safety Research. The number of deaths due to intentional self-harm shows an alarming increase.

A further reduction of these deaths is achievable. The circumstances of each child's death should be examined in a systematic and multidisciplinary way to clarify the cause of death and produce accurate mortality data plus directions for prevention. This methodology, called CDR, has its origin in the United States in the late 1970s and has spread through Canada, New Zealand, and Australia to the United Kingdom, where it was implemented in 2006 and embedded in legislation in 2008 [5, 34]. In the past decade in the United States, CDR has come to constitute a model to identify public health and legislative strategies for reducing preventable child fatalities [16].

Dutch public health professionals and policy makers can contribute to preventing avoidable deaths and improving vital statistics data by paying constant attention to education and by introducing CDR in the Netherlands.

CHAPTER 4

Procedures in child deaths in the Netherlands: a comparison with Child Death Review

THIS CHAPTER HAS BEEN SUBMITTED AS:

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Procedures in child deaths in the Netherlands: a comparison with Child Death Review

Abstract

AIM Child Death Review (CDR) is a method in which every child death is systematically and multidisciplinary examined to 1) improve death statistics, 2) identify factors that give direction for prevention, 3) translate the results into possible interventions, and 4) support families. The aim of this study was to determine to what extent procedures of organizations involved in the (health) care for children in the Netherlands cover these four objectives of CDR.

SUBJECT AND METHODS Organizations in the Eastern part of the Netherlands and Dutch umbrella organizations involved in child (health) care were asked to provide their protocols, guidelines or other working agreements that describe their activities and responsibilities in case of a child's death. Eighteen documents and nine interview reports became available. For the analyses we used scorecards for each CDR objective.

RESULTS The procedures of Perined, National Cot Death Study Group, Dutch Cot Death Foundation and Child Protection Service cover the largest part of the objectives of CDR. Organizations pay most attention to the translation of results into possible interventions. Family support gets the least attention in the protocols, guidelines and other working agreements.

CONCLUSION Dutch organizations separately cover parts of CDR. When the procedures of organizations are combined, all CDR objectives are covered in the response to only specific groups of child deaths, i.e. perinatal deaths, Sudden Unexpected Deaths in Infants and fatal child abuse cases. Further research into the conditions that are needed for an optimal implementation of CDR in the Netherlands is necessary.

Introduction

In the Netherlands 992 children aged 0-19 (mortality rate 25.9/100,000) died in 2015, of which 84% due to a natural cause [7]. Most children (56%) died under the age of one year mainly due to conditions originating in the perinatal period and congenital malformations, deformations and chromosomal abnormalities [7]. Almost half of the children aged 0-19 die in the hospital [122]. Although child mortality in the Netherlands has declined in the past decades [7, 48], each deceased child is one too much. Therefore, it is of great importance to learn from these deaths and to implement interventions preventing future deaths [5].

In the United States of America (USA), Canada, Australia, New Zealand and the United Kingdom (UK) the death of every child is examined in a systematic way by a multidisciplinary team. This method is called Child Death Review (CDR) [32, 34, 35]. A team of professionals collaborates according to a specific protocol. The kind of professionals who participate in the team, differ between the countries where CDR is implemented [30]. The CDR objectives are to (1) improve the quality of the procedure with regard to the determination of the cause of death as well as the death statistics; (2) identify avoidable factors that give directions for prevention; (3) translate the results into possible interventions; and (4) support the family [5, 16, 31, 123]. Each country using the CDR has a different review process [29]. However, all countries share the four objectives of CDR that is considered to be the *golden standard* in the management of child deaths by the American Academy of Pediatrics [16].

It has been argued that there are many benefits of CDR, and that a formal Child Death Review should be provided in all countries to understand how and why children die in order to prevent future child deaths [30]. Next to this, according to the Convention on the Rights of the Child, every nation should take appropriate measures to diminish infant and child mortality [2]. From this point of view, there seems to be a need to also implement CDR in the Netherlands. Parents in the first place, but also the Dutch government and local authorities are responsible for the wellbeing and safe development of every child. When a child dies, professionals from several organizations are involved. These professionals have different roles, tasks and responsibilities and approach the death of a child from different perspectives. Until 2016, professionals systematically review only cases of Sudden Unexpected Deaths in Infants (SUDI) and perinatal deaths in a multidisciplinary way in order

to further prevent those deaths. Dutch local authorities play a marginal role in the reduction of child deaths.

In the Eastern part of the Netherlands, a pilot implementation of CDR was conducted [124]. Within the framework of this pilot implementation, we performed a baseline measurement in which we inventoried how Dutch organizations involved in the (health) care for children respond to a child's death. We compared the characteristics of the organizations' procedures with the objectives of CDR. In this context we answered the research question to what extent the existing procedures of organizations involved in the (health) care for children in the Netherlands cover the four CDR objectives in responding to a child's death.

Methods

Study design

We used a qualitative, descriptive design to answer the above mentioned research question.

Identification of stakeholders

An inventory of organizations that are involved in the (health) care for children in the eastern part of the Netherlands was made on the basis of the type of organizations in the UK that are working with children and are responsible for their safety and development [125]. The identified 22 Dutch stakeholder organizations are outlined in Table 1, of which one is the hospital (department of pediatrics). Eight hospitals are identified in the pilot region, including one top clinical hospital with a Neonatal Intensive Care Unit. Six stakeholders are organized on a national level only (Table 1). In case of a child's death (part of) the listed organizations in Table 1 use a protocol, guideline or other type of working agreement.

Identification of CDR characteristics

We used the UK CDR method, as described in the document 'Working Together to Safeguard Children' [125] to identify a list of objectives to analyze in our study. CDR in

the UK is a standardized process that is described clearly and in detail, and includes all child deaths [30]. It consists of two interrelated parts: 1) the Rapid Response (RR), undertaken by a special team immediately after a sudden and unexpected death of a child, and 2) the Child Death Overview (CDO) undertaken by a panel, a few months after a child death, including the RR cases. The RR-team is directed at determining the cause of death, identifying any contributory factors and ensuring ongoing support of the family [5]. CDO-panels' main targets are systematic analysis of the information provided by the professionals who were involved before and around the time of death in order to identify modifiable factors, making recommendations for prevention and signaling patterns or trends in child deaths.

The different characteristics mentioned in the description of the RR and CDO [125] were used as criteria to determine the extent to which the procedures of Dutch organizations cover the four CDR objectives. The characteristics of RR and CDO were identified by the second author (JP) and arranged according to the four CDR objectives. In the final list of characteristics (Table 2a and 2b) the number of characteristics varies by CDR objective. The whole procedure of making the list of characteristics was checked by the first (SG) and fourth author (MB) independently from each other and differences were discussed until consensus was reached. Prerequisites like working agreements directed at communication were not included in the set of characteristics.

TABLE 1. Overview of Dutch organizations involved in a child's death, their protocols, guidelines and other working agreements that were included for analysis. In brackets the number of professionals who have been approached for providing documents

Organization	Title of document available for analysis	Description of the tasks/activities
1. Hospital - Department of Pediatrics [10]	a. Dutch Association for Pediatrics – Action protocol after Cot death	Procedures are aimed at determining the cause of death and avoiding false suspicion of parents.
	b. Death of a Child (on emergency dept.)	Attention is paid to nearness to the dying child, spiritual care and aftercare for parents. Supporting parents is most important in this protocol.
	c. Emergency Baptism to an Infant's Death	This protocol provides for an emergency baptism when a child is dying and the parents want their child baptized. Parents' wishes are central.
	d. Deceasing or Dying	The aim is taking leave of the dying one and providing spiritual care.
	e. Procedures in External Cause of Death	A few points of interests are briefly described, e.g. the execution of the autopsy and informing the family. It is hard to classify this protocol.
2. General Practice [1]	Dutch Association for Pediatrics – Action protocol after Cot death (<i>same as organization 1</i>)	Procedures are aimed at determining the cause of death and avoiding false suspicion of parents.
3. Forensic Medical Service – part of the Municipal Health Service [2]	a. Work Instruction 'Reporting Deceased Minors'	According to a flowchart the municipal forensic physician draws a conclusion about the manner and cause of death.
	b. Guideline Forensic Postmortem Examination	The protocol describes the responsibilities of the municipal forensic physician, what to determine (e.g. cause of death), who to inform about the death and how to report.
4. Ambulance Service [2]	National Protocol Ambulance Care	The main aim of this guideline is providing for acute assistance. Some attention is paid to (determining) SUDI and to the grieving process.
5. Preventive Child Healthcare [1]	Guideline Counseling Families in Child Death	When a child dies Preventive Child Healthcare contacts the parents to condole them and to inform them about aftercare regarding the grieving process.
6. Municipal Health Services [1]	a. Guideline Counseling Families in Child Death (<i>same as organization 5</i>)	When a child dies Preventive Child Healthcare contacts the parents to condole them and inform them about aftercare regarding the grieving process.
	b. Protocol Large scale Sexual Abuse	This protocol could be used to prevent social tumult in the context of child mortality. Relief and assistance are part of it.

7. Hospital Social Work [1]	Interview report	A memorial day for deceased children is organized in the hospital without guidelines, so no protocol could be analyzed.
8. General Social Work [1]	No usable protocols	The protocol retrieved was not aimed at child mortality.
9. Mental Health Trust [3]	a. Suicide and External Cause of Death	The main aim is informing the right professionals and organizations and reporting about the death. None of the four objectives is central, therefore this protocol has not been classified.
	b. External Cause of Death in Admitted Patient Inside of the Clinic	Responsibilities of the professionals involved in the context of determining the cause of death and grief counseling are described.
	c. External Cause of Death in Admitted Patient Outside of the Clinic	Responsibilities of the professionals involved in the context of determining the cause of death and grief counseling are described.
	d. External Cause of Death in Ambulatory Patient Outside of the Clinic	Administrative tasks of the professionals involved aimed at determining the cause of death are central.
10. MEE[1]	Interview report	This organization does not use protocols in case of child death.
11. Child Welfare Agency [1]	Guidelines Death of a Juvenile Client	This protocol is a practical description of informing the right professionals and organizations. Some attention is paid to supporting the professionals involved and the family.
12. Child Protection Service [1]	Interview report	The protocol retrieved was not aimed at child mortality.
13. Police [1]	Interview report	Procedures are performed to determine cause of death.
14. Public Prosecutor [1]	Interview report	Procedures are performed to determine cause of death.
15. School / Daycare / Playgroup [4]	Protocol in Case of Death	This protocol is a general guideline how to deal with practical aspects of providing information, organizational adjustments and grief counseling in case of a child's death.
16. Perined* [1]	Local Audit	Professionals analyze the provided care in a structured way to improve the quality of care. Getting insight in avoidable factors in perinatal deaths is important.
17. National Cot Death Study Group* [1]	Dutch Cot Death Foundation	Professionals analyze the provided care in a structured way to investigate whether SIDS was the cause of death. Preventing SIDS and inform and advise parents are the main goals.
18. Dutch Cot Death Foundation* [1]	Interview report	This organization delivers evidence-based information for professionals and parents by means of a web site

19. Association for Parents of a Deceased Child* [2]	No protocols	No protocols retrieved because of no response.
20. Dutch Safety First Association [1]	Interview report	This organization focuses on developing interventions in the context of child mortality.
21. Consumer Safety Institute* [1]	Interview report	This organization focuses on developing interventions in the context of child mortality.
22. Dutch Safety Board* [1]	Interview report	This organization focuses on developing interventions in the context of child mortality.

* Organized on a national level

Data collection

In April 2011 all inventoried organizations were asked to provide information on procedures, laid down in protocols, guidelines or other working agreements (referred to below as 'guidelines'), that describe their responsibilities and activities in case of a child's death. If written guidelines were not available, information was obtained by means of semi-structured interviews with professionals as representatives of their organizations. These interviews were written out. Main characteristics of the procedures concerning the responsibilities and activities of that organization in responding to child deaths were identified. Subsequently it was determined what CDR objective(s) correspond(s) with regard to these characteristics.

One out of 22 organizations (Table 1) did not respond to our request (parents' association). Of the remaining 21 organizations, 12 organizations provided a total of 18 guidelines that were relevant for answering our research question.

Of the 21 organizations, 9 did not have any written guideline that describes how to act in case of a child's death. Representatives of those 9 organizations (Hospital Social Work; MEE, an organization that provides support to people with intellectual disabilities or chronic illness; Child Protection Service; Police; Public Prosecutor; National Cot Death Study Group; Dutch Safety First Association; Dutch Consumer and Safety Institute; and Dutch Safety Board) were asked for an interview. Eighteen written guidelines and 9 interview reports were available for analysis (Table 1).

Data analysis

To measure the extent to which the procedures of organizations involved in the (health) care for children in the Netherlands cover the four CDR objectives, scorecards were used with the characteristics arranged by CDR objective. For each of the 18 retrieved written guidelines and 9 interview reports a scorecard was filled in. The question whether the description of responsibilities and activities in the guidelines and interview reports corresponded with the characteristics of CDR on the scorecard, could be answered with 'yes', 'to a limited extent' or 'no'. In case of uncertainty the guideline or interview report was scored again by the second author (JP) and discussed with the fourth author (MB) after which a definitive decision was made. Finally, for each of the guidelines and interview reports the second author completed the scorecards.

Results

The extent to which the procedures of organizations involved in the (health) care for children in the Netherlands cover the four CDR objectives is shown in Table 2a-2b, and Appendix 4.1-4.4. Below, for each of the CDR objective, we summarize the findings.

'Improve the quality of the procedure of determining the cause of death as well as the quality of the causes of death statistics'

The CDR objective directed at the improvement of the quality of the procedure with regard to the determination of the cause of death as well as the death statistics is mainly found in the 'Action protocol after cot death' of the Dutch Association for Pediatrics and the procedures of the Public Prosecutor, the Child Protection Service and the National Cot Death Study Group (Table 2a and Appendix 4.1).

Half of the participating organizations describe in their procedures, which professionals have to be involved in the investigation in determining the cause of death shortly after the death of a child. Only two organizations, i.e. the Forensic Medical Service and the National Cot Death Study Group, pay (some) attention to define how the collaboration between physicians and the municipal forensic physician could be constituted (Table 2a and Appendix 4.1).

Eight organizations describe in their procedures that results of the review need to be passed on to a national institution a few months after the death of a child. No organization focuses in their procedures on the need to analyze the actions of professionals in determining the cause of death and to provide feedback on this to improve the quality of the procedure with regard to the determination of the cause of death (Table 2a and Appendix 4.1).

TABLE 2A. Characteristics of the Rapid Response (RR) and Child Death Overview (CDO), arranged according to Child Death Review objective, and organizations that have these characteristics as a major or minor focus. The (a,b,c,d) refers to the documents available for analysis mentioned in Table 1.

		Organizations with procedures with	
		major focus (+ in the appendix)	minor focus (+/- in the appendix)
RR	Objective 'Improve the quality of the procedure with regard to the determination of the cause of death as well as the death statistics'		
	Rapid response actions exist in cases of unexplained death.	Dept. ¹ of Pediatrics (a), GP ² , Forensic Med. ³ Service (a), Cot Death Found. ⁴	Child Welfare Agency, Child Protection Service, Publ. ⁵ Prosecutor, National Cot Death Study Group
	It has been defined who will lead the investigation to determine the cause of death.	Forensic Med. Service (a), Mental Health Services (b) Mental Health Trust (b,c,d), Child Protection Service, Police, Publ. Prosecutor, Perined, National Cot Death Study Group, Cot Death Found.	Dept. of Pediatrics (a), GP, Social Work in Hosp. ⁶
	It has been defined which professionals have to be involved in the investigation to determine the cause of death.	Dept. of Pediatrics (a), GP, Forensic Med. Service (a), Mental Health Trust (b,c,d), Child Protection Service, Police, Publ. Prosecutor, Perined, Cot Death Found.	Forensic Med. Service (b), Ambulance Service, Mental Health Trust (a), Child Welfare Agency, Cot Death Comm.
	It has been defined what has to be investigated. This includes: data collection from relevant institutions and professionals, postmortem investigation and investigation at the place of death and circumstances of the death.	Dept. of Pediatrics (a), GP, National Cot Death Study Group	Dept. of Pediatrics (e), Forensic Med. Service (a,b), Mental Health Trust (b,c,d), Child Protection Service, Police, Publ. Prosecutor
	Results are collected and represented according to national criteria.	Dept. of Pediatrics (a), GP, Child Protection Service, Police, Publ. Prosecutor, Perined	Forensic Med. Service (a), Mental Health Trust (b,c,d), Cot Death Found.
	It has been defined how the relationship between physicians and the forensic physician could be constituted.	Forensic Med. Service (a)	Cot Death Found.
	It has been defined how often and when the involved professionals have to discuss the results of the investigation to determine the cause of death.	Forensic Med. Service (a), Police, Publ. Prosecutor	Dept. of Pediatrics (a), GP, Forensic Med. Service (b), Munic. ⁷ Health Services (b), National Cot Death Study Group
	Relevant institutions and professionals, such as school and GP, are consulted to get relevant information about the possible cause of death.	Child Protection Service, Police, Publ. Prosecutor, National Cot Death Study Group	Forensic Med. Service (b), Munic. Health Services (b)

¹ Dept. = Department

³ Med. = Medical

⁵ Publ. = Public

⁷ Munic. = Municipal

² GP = General Practitioner

⁴ Found. = Foundation

⁶ Hosp. = Hospital

CDO	The results of the review are passed on to a national institution.	Dept. of Pediatrics (a), GP, Mental Health Trust (b,c,d), Perined, National Cot Death Study Group	Child Protection Service, Publ. Prosecutor, Cot Death Found.
	A format to get specific data about a particular cause of death is used.	Dept. of Pediatrics (a), GP, National Cot Death Study Group	Perined, Cot Death Found.
	The actions of professionals involved in determining the cause of death are analyzed.	-	-
	Feedback is given to professionals on their actions in determining the cause of death.	-	-
	New relevant information regarding the cause of death and factors contributed to the death, that is obtained in the long run, is provided to all professionals involved in the death.	Child Protection Service, Publ. Prosecutor, Perined	Police, Cot Death Found.
Objective 'Identify avoidable factors that give directions for prevention'			
RR	Relevant institutions and professionals, such as school and GP, are consulted to get more information about the child, his/her social circumstances and environment in the context of avoidable factors of child mortality.	Child Protection Service, Cot Death Found., Safety Board	Forensic Med. Service (b), Munic. Health Services (b), Publ. Prosecutor, Perined, National Cot Death Study Group, Consumer Safety Inst. ⁸
	During data collection from relevant institutions and professionals, postmortem examination and investigation at the place of death and circumstances of the death, attention is paid to (new) avoidable factors of child mortality.	Dept. of Pediatrics (a), GP, Child Protection Service, Cot Death Found.	Publ. Prosecutor, National Cot Death Study Group
CDO	Avoidable factors of child mortality and lessons learned are identified.	Dept. of Pediatrics (a), GP, Child Protection Service, Perined, National Cot Death Study Group, Cot Death Found.	Mental Health Trust (a), Police, Publ. Prosecutor, Safety First Assoc. ⁹ , Consumer Safety Inst., Safety Board
	A distinction is made in factors intrinsic to the child, family and environmental factors, parenting capacity, and service provision.	-	Child Protection Service, Perined, Consumer Safety Inst., Safety Board
	Professionals involved work together with regional and national institutions to identify lessons learned.	Dept. of Pediatrics (a), GP, Child Protection Service, Perined, National Cot Death Study Group, Cot Death Found.	Social Work in Hosp., Publ. Prosecutor, Safety First Assoc., Consumer Safety Inst., Safety Board
	After identifying avoidable factors of child mortality, the extent of the problem is determined and (groups of) people most affected by the problem are sorted out.	Perined, National Cot Death Study Group, Cot Death Found., Safety Board	Child Protection Service, Publ. Prosecutor, Safety First Assoc., Consumer Safety Inst.

⁸ Inst. = Institute

⁹ Assoc. = Association

TABLE 2B. Characteristics of the Rapid Response (RR) and Child Death Overview (CDO), arranged according to Child Death Review objective, and organizations that have these characteristics as a major or minor focus. The (a,b,c,d) refers to the documents available for analysis mentioned in Table 1.

		Organizations with procedures with	
		major focus (+ in the appendix)	minor focus (+/- in the appendix)
Objective 'Translate the results into possible interventions'			
RR	Information relevant for immediate prevention (e.g. protection of other children in the family) is discussed by the rapid response team. It has been defined which immediate preventive measures have to be taken, when necessary.	Munic. Health Services (b), Mental Health Protection Service Mental Health Trust (b,c), Child Protection Service	Ambulance Service, Police Child Welfare Agency
CDO	Research ends with a discussion how such a death can be avoided in the future. Recommendations, actions to be performed and lessons learned are passed on to relevant authorities or individuals. Recommendations, actions to be performed and lessons learned are passed on to governmental institutions to improve Publ. health. It has been defined who is responsible for (taking care of) carrying out the improvements.	Perined, National Cot Death Study Group, Cot Death Found. Mental Health Trust (b,c), Child Protection Service, Perined, National Cot Death Study Group, Cot Death Found., Safety First Found., Consumer Safety Inst., Safety Board National Cot Death Study Group, Cot Death Found., Safety First Found., Consumer Safety Inst., Safety Board Perined, Safety First Found., Consumer Safety Inst., Safety Board	Mental Health Trust (b,c), Child Protection Service, Safety Board Munic. Health Services (b), Mental Health Trust (a,d), Publ. Prosecutor Child Protection Service, Publ. Prosecutor, Perined Mental Health Trust (b,c)
Objective 'Support to the family'			
RR	The potential needs of relatives are identified. When a child died in the hospital, parents are supported by a designated professional of the hospital. When conditions permit, parents get the opportunity to be alone with their deceased child to take leave of their child. Parents are informed about up-to-date findings of the research, unless this obstructs the research.	Dept. of Pediatrics (b,d), Preventive Child Healthcare, Munic. Health Services (a,b.), Social Work in Hosp., Child Welfare Agency, School Dept. of Pediatrics (b), Social Work in Hosp. Dept. of Pediatrics (b,d)	Dept. of Pediatrics (a,c), GP, Mental Health Trust (b,c), Publ. Prosecutor, National Cot Death Study Group, Cot Death Found. Dept. of Pediatrics (d), Munic. Health Services (b) Dept. of Pediatrics (d), Mental Health Trust (b,c)

	It has been defined how to act when parents and the deceased child do not live in the same country.	-	-
	After completion of the rapid response, further (psychological) assistance is rendered to the relatives.	Dept. of Pediatrics (b), Preventive Child Healthcare, Munic. Health Services (a,b), Social Work in Hosp., Mental Health Trust (a,b,c,d), Cot Death Found.	Child Welfare Agency, School
CDO	The actions of professionals in supporting grief counseling to relatives are analyzed.	Dept. of Pediatrics (b), Munic. Health Services (b)	Social Work in Hosp., Mental Health Trust (a)
	Relatives are kept in touch in the long run, whereby feedback is given on research of (factors contributed to) the death and grief counseling.	Dept. of Pediatrics (b), Munic. Health Services (b), National Cot Death Study Group, Cot Death Found.	Dept. of Pediatrics (a), GP, Preventive Child Healthcare, Munic. Health Services (b), Social Work in Hosp., Child Protection Service, School, Perined
	The given support to relatives is monitored.	Preventive Child Healthcare, Munic. Health Services (a,b), Social Work in Hosp.	Dept. of Pediatrics (c), Mental Health Trust (a), Cot Death Found.

'Identify avoidable factors that give directions for prevention'

In general the CDR objective directed at the identification of avoidable factors that give directions for prevention is most recognizable in the procedure of the Child Protection Service, Perined, the National Cot Death Study Group and the Dutch Cot Death Foundation (Table 2a and Appendix 4.2).

Only three organizations specifically describe in their procedures that relevant institutions and professionals should be consulted in order to register possible avoidable factors shortly after the death of the child. Also, four organizations have their major focus on recording (new) avoidable factors of child deaths during the investigation (Table 2a and Appendix 4.2).

Six organizations have a major focus on the identification of avoidable factors and learned lessons as well as on working together with regional and national institutes to identify learned lessons a few months after the death of a child. None of the organizations has a major focus in their procedures on the categorization in factors intrinsic to the child, the family and environment, the parenting skills and service provision. Of the four organizations that have a minor focus in their procedures on this characteristic, only the Consumer Safety Institute distinguishes between behavioral, product and physical factors (Table 2a and Appendix 4.2).

'Translate the results into possible interventions'

The CDR objective directed at the translation of identified factors into possible interventions is mainly displayed in the procedures of the institutes for mental health care directed at external causes of death in- and outside the clinic and the procedure of the Child Protection Service (Table 2b and Appendix 4.3).

In the procedures of four organizations specific attention is paid to discuss information for immediate prevention shortly after the death of a child. Only three organizations have defined in their procedures which preventive actions should be taken (Table 2b and Appendix 4.3).

Eight organizations particularly focus in their procedures on the aspect of informing relevant authorities and individuals a few months after the death of a child about the

recommendations, actions to be performed and lessons learned. In the procedures of only three organizations it is specifically described that an investigation ends with a discussion how to prevent such a death in the future (Table 2b and Appendix 4.3).

'Support of the family'

The CDR objective directed at the support of the family is mainly included in the procedures of the Department of Pediatrics described in 'Death of a child', of the Hospital Social Work, and of the Municipal Health Services, directed at prevention of social anxiety in serious traumatic incidents, for example in case of child abuse and child deaths, (Table 2b and Appendix 4.4).

Half of the participating organizations pay attention to the potential needs of relatives shortly after the death of a child, for example needs concerning washing and dressing the deceased child and farewell rituals. No organization except the department of pediatrics in the hospital describes that parents get the opportunity to be alone with their deceased child to take leave of their child. In addition to this, no organization describes in their procedures how to act in the rare situation that the parents and the deceased child do not live in the same country (Table 2b and Appendix 4.4).

Almost half of the participating organizations describe in their procedures the follow-up of relatives a few months after the death of a child, where feedback is given about the circumstances of and factors that contributed to the death and grief counseling is provided. The analysis of the actions of professionals in supporting grief counseling to relatives is described in the procedures of only four organizations (Table 2b and Appendix 4.4).

Discussion

Quite a few organizations are involved in child deaths in the Netherlands. The procedures of these organizations, laid down in protocols, guidelines, and working agreements, were systematically compared to the objectives of CDR. In the analysis it was determined to what extent the procedures cover the four objectives of CDR used in the UK, namely the (1) improvement of the quality of the procedure with

regard to the determination of the cause of death as well as the causes of death statistics, (2) identification of avoidable factors that give directions for prevention, (3) translation of results into possible interventions, and (4) support of the family.

When all procedures of Dutch organizations in responding to child deaths are combined, the four CDR objectives are largely covered in the response of these organizations, but only for specific groups of child deaths, namely for perinatal deaths (Perined), SUDI cases (National Cot Death Study Group and Dutch Cot Death Foundation) and fatal child abuse cases (Child Protection Service). It is indisputable that all organizations (should) devote attention to support involved relatives.

These results imply that the different procedures are fragmented in relation to the objectives of CDR and that not all groups of child deaths are covered, such as natural causes of child death other than perinatal deaths and SUDI and death due to intentional self-harm. We consider the insufficient coverage as a shortcoming, because it provides us an incomplete overview of avoidable factors in child deaths which hinders targeted preventive measures. With regard to fragmentation this is not necessarily disadvantageous as long as organizations are aware of their tasks and the tasks of other organizations in case of a child's death, and communicate and share information with each other [32, 125, 126]. Reviews on child's death and serious injury in different countries have stressed the importance of inter-agency working [127]. In order to take adequate actions to prevent a child's death and to support the family, clear local arrangements for collaboration between organizations are needed.

Strengths and weaknesses of this study

One of the strengths of this study is the broad scope that is used to identify the organizations and to analyze their procedures. Another strength is the high response rate of the organizations that have been approached. Only one organization, the parents' association, did not react to our request to participate in this study. Although all hospitals in our pilot region have been approached and gave insight in their procedures, the procedures of the academic hospitals located outside our study region were not obtained. Therefore, some caution is required in the interpretation of the results as some of the children die in an academic hospital. Apart from this limitation, the quantity of retrieved procedures provides us an almost complete

overview of the procedures in responding to child deaths in the Eastern part of the Netherlands and of some organizations involved at a national level.

A weakness in this study is the fact that we did not examine whether and to what extent the organizations actually act in case of a child's death according to these procedures. Professionals within these organizations may provide other care as described. We also did not examine to what extent organizations have a multidisciplinary case discussion within their own organization after a child has died. Further research could give insight in the adherence to protocols, guidelines or other working agreements by professionals.

Conclusions

Where CDR examines all child deaths, the procedures of the organizations in this study that cover parts of the four CDR objectives, focus on a particular part of child mortality only. Consequently, a complete overview of avoidable factors that give directions for prevention of child deaths is lacking. Another conclusion is that support of the family should be more systematically included in the procedures of organizations.

Further research into the conditions that are needed for an optimal implementation of CDR in the Netherlands is necessary. In case the responsibilities and activities are better coordinated among organizations involved, the four objectives of CDR could be better achieved in the majority of (natural) child deaths. CDR might then only be indicated for particular groups of child deaths, e.g. in unexpected, unexplained child deaths, to achieve its objectives.

APPENDIX 4.1. Extent to which procedures of Dutch organizations covered CDR objective 'Improve the quality of the procedure with regard to the determination of the cause of death as well as the death statistics' (yes + ; to a limited extent = +/- ; no = -)

Organization/ professional	Title of document available for analysis	RR1.1	RR1.2	RR1.3	RR1.4	RR1.5	RR1.6	RR1.7	RR1.8	CD01.1	CD01.2	CD01.3	CD01.4	CD01.5
Department of Pediatrics and GP	Dutch Association for Pediatrics – Actionprotocol after Cot death	+	+/-	+	+	+	-	+/-	-	+	+	-	-	-
	Death of a Child	-	-	-	-	-	-	-	-	-	-	-	-	-
	Emergency Baptism	-	-	-	-	-	-	-	-	-	-	-	-	-
	Deceasing or Dying	-	-	-	-	-	-	-	-	-	-	-	-	-
	Procedures in External Cause of Death	-	-	-	+/-	-	-	-	-	-	-	-	-	-
Forensic Medical Service	Work Instruction 'Reporting Deceased Minors'	+	+	+	+/-	+/-	+	+	-	-	-	-	-	-
	Guideline Forensic Postmortem Examination	-	-	+/-	+/-	-	-	+/-	+/-	-	-	-	-	-
Ambulance Service	National Protocol Ambulance Care	-	-	+/-	-	-	-	-	-	-	-	-	-	-
Preventive Child Healthcare / Municipal Health Services	Guideline Counseling Families in Child Death	-	-	-	-	-	-	-	-	-	-	-	-	-
	Protocol Large scale Sexual Abuse	-	+	-	-	-	-	+/-	+/-	-	-	-	-	-
Hospital Social worker Mental health trust	Interview report	-	+/-	-	-	-	-	-	-	-	-	-	-	-
	Suicide and External Cause of Death	-	-	+/-	-	-	-	-	-	-	-	-	-	-
	External Cause of Death inside of the Clinic	-	+	+	+/-	+/-	-	-	-	+	-	-	-	-
	External Cause of Death outside of the Clinic	-	+	+	+/-	+/-	-	-	-	+	-	-	-	-
	External Cause of Death in Ambulatory Patient Outside of the Clinic	-	+	+	+/-	+/-	-	-	-	+	-	-	-	-
Child Welfare Agency Child Protection Service	Guidelines Death of a Juvenile Client	+/-	-	+/-	-	-	-	-	-	-	-	-	-	-
	Interview report	+/-	+	+	+/-	+	-	-	+	+/-	-	-	-	+

Organization/ professional	Title of document available for analysis	RR1.1	RR1.2	RR1.3	RR1.4	RR1.5	RR1.6	RR1.7	RR1.8	CD01.1	CD01.2	CD01.3	CD01.4	CD01.5
Police	Interview report	-	+	+	+/-	+	-	+	+	-	-	-	-	+/-
Public Prosecutor	Interview report	+/-	+	+	+/-	+	-	+	+	+/-	-	-	-	+
School	Protocol in Case of Death	-	-	-	-	-	-	-	-	-	-	-	-	-
Perined	Perined	-	+	+	-	+	-	-	-	+	+/-	-	-	+
National Cot Death Study Group	Dutch Cot Death Foundation	+/-	+	+/-	+	-	-	+/-	+	+	+	-	-	-
Dutch Cot Death Foundation	Interview report	+	+	+	-	+/-	+/-	-	-	+/-	+/-	-	-	+/-
Dutch Safety First Association	Interview report	-	-	-	-	-	-	-	-	-	-	-	-	-
Consumer Safety Institute	Interview report	-	-	-	-	-	-	-	-	-	-	-	-	-
Dutch Safety Board	Interview report	-	-	-	-	-	-	-	-	-	-	-	-	-

RR1.1 Rapid response actions exist in cases of unexplained death.

RR1.2 It has been defined who will lead the investigation to determine the cause of death.

RR1.3 It has been defined which professionals have to be involved in the investigation to determine the cause of death.

RR1.4 It has been defined what has to be investigated. This includes: data collection from relevant institutions and professionals, postmortem examination and investigation at the place of death and circumstances of the death.

RR1.5 Results are collected and represented according to national criteria.

RR1.6 It has been defined how the collaboration between physicians and the municipal forensic physician could be constituted.

RR1.7 It has been defined how often and when the involved professionals have to discuss the results of the investigation to determine the cause of death.

RR1.8 Relevant institutions and professionals, such as school and GP, are consulted to get relevant information about the possible cause of death.

CD01.1 The results of the review are passed on to a national institution.

CD01.2 A format to get specific data about a particular cause of death is used.

CD01.3 The actions of professionals involved in determining the cause of death are analyzed.

CD01.4 Feedback is given to professionals on their actions in determining the cause of death.

CD01.5 New relevant information regarding the cause of death and factors contributed to the death, that is obtained in the long run, is provided to all professionals involved around the death.

APPENDIX 4.2. Extent to which procedures of Dutch organizations covered CDR objective 'Identify avoidable factors that give directions for prevention' (yes = +; to a limited extent = +/-; no = -)

Organization / professional	Title of document available for analysis	RR2.1	RR2.2	CD02.1	CD02.2	CD02.3	CD02.4
Department of Pediatrics and GP	Dutch Association for Pediatrics – Action protocol after Cot death	-	+	+	-	+	-
	Death of a Child	-	-	-	-	-	-
	Emergency Baptism	-	-	-	-	-	-
	Deceasing or Dying	-	-	-	-	-	-
Forensic Medical Service	Procedures in External Cause of Death	-	-	-	-	-	-
	Work Instruction 'Reporting Deceased Minors'	-	-	-	-	-	-
	Guideline Forensic Postmortem Examination	+/-	-	-	-	-	-
Ambulance Service	National Protocol Ambulance Care	-	-	-	-	-	
Preventive Child Healthcare / Municipal Health Services	Guideline Counseling Families in Child Death	-	-	-	-	-	-
	Protocol Large scale Sexual Abuse	+/-	-	-	-	-	-
	Interview report	-	-	-	-	+/-	-
Hospital Social worker Mental health trust	Suicide and External Cause of Death	-	-	+/-	-	-	-
	External Cause of Death inside of the Clinic	-	-	-	-	-	-
	External Cause of Death outside of the Clinic	-	-	-	-	-	-
	External Cause of Death in Ambulatory Patient Outside of the Clinic	-	-	-	-	-	-
MEE	Interview report	-	-	-	-	-	-
Child Welfare Agency	Guidelines Death of a Juvenile Client	-	-	-	-	-	-
Child Protection Service	Interview report	+	+	+	+/-	+	+/-
Police	Interview report	-	-	+/-	-	-	-
Public Prosecutor	Interview report	+/-	+/-	+/-	-	+/-	+/-

Organization / professional	Title of document available for analysis	RR2.1	RR2.2	CD02.1	CD02.2	CD02.3	CD02.4
School	Protocol in Case of Death	-	-	-	-	-	-
Perined	Perined	+/-	-	+	+/-	+	+
National Cot Death Study Group	Dutch Cot Death Foundation	+/-	+/-	+	-	+	+
Dutch Cot Death Foundation	Interview report	+	+	+	-	+	+
Dutch Safety First Association	Interview report	-	-	+/-	-	+/-	+/-
Consumer Safety Institute	Interview report	+/-	-	+/-	+/-	+/-	+/-
Dutch Safety Board	Interview report	+	-	+/-	+/-	+/-	+
RR2.1	Relevant institutions and professionals, such as school and GP, are consulted to get more information about the child, his/her social circumstances and environment in the context of avoidable factors of child mortality.						
RR2.2	During data collection from relevant institutions and professionals, postmortem examination and investigation at the place of death and circumstances of the death, attention is paid to (new) avoidable factors of child mortality.						
CD02.1	Avoidable factors of child mortality and lessons learned are identified.						
CD02.2	A distinction is made in factors intrinsic to the child, family and environmental factors, parenting capacity, and service provision.						
CD02.3	Professionals involved work together with regional and national institutions to identify lessons learned.						
CD02.4	After identifying avoidable factors of child mortality, the extent of the problem is determined and (groups of) people most affected by the problem are sorted out.						

APPENDIX 4.3. Extent to which procedures of Dutch organizations covered CDR objective 'Translate the results into possible interventions'

(yes = + ; to a limited extent = +/- ; no = -)

Organization / professional	Title of document available for analysis	RR3.1	RR3.2	CD03.1	CD03.2	CD03.3	CD03.4
Department of Pediatrics and GP	Dutch Association for Pediatrics – Actionprotocol after Cot death	-	-	-	-	-	-
	Death of a Child	-	-	-	-	-	-
	Emergency Baptism	-	-	-	-	-	-
	Deceasing or Dying	-	-	-	-	-	-
	Procedures in External Cause of Death	-	-	-	-	-	-
Forensic Medical Service	Work Instruction 'Reporting Deceased Minors'	-	-	-	-	-	-
	Guideline Forensic Postmortem Examination	-	-	-	-	-	-
Ambulance Service	National Protocol Ambulance Care	+/-	-	-	-	-	-
Preventive Child Healthcare / Municipal Health Services	Guideline Counseling Families in Child Death	-	-	-	-	-	-
	Protocol Large scale Sexual Abuse	+	-	-	+/-	-	-
Hospital Social worker	Interview report	-	-	-	-	-	-
Mental health trust	Suicide and External Cause of Death	-	-	-	+/-	-	-
	External Cause of Death inside of the Clinic	+	+	+/-	+	-	+/-
	External Cause of Death outside of the Clinic	+	+	+/-	+	-	+/-
	External Cause of Death in Ambulatory Patient Outside of the Clinic	-	-	-	+/-	-	-
MEE	Interview report	-	-	-	-	-	-
Child Welfare Agency	Guidelines Death of a Juvenile Client	+	+/-	-	-	-	-
Child Protection Service	Interview report	+	+	+/-	+	+/-	-
	Interview report	+/-	-	-	-	-	-

Organization / professional	Title of document available for analysis	RR3.1	RR3.2	CD03.1	CD03.2	CD03.3	CD03.4
Public Prosecutor	Interview report	-	-	-	+/-	+/-	-
School	Protocol in Case of Death	-	-	-	-	-	-
Perined	Perined	-	-	+	+	+/-	+
National Cot Death Study Group	Dutch Cot Death Foundation	-	-	+	+	+	-
Dutch Cot Death Foundation	Interview report	-	-	+	+	+	-
Dutch Safety First Association	Interview report	-	-	-	+	+	+
Consumer Safety Institute	Interview report	-	-	-	+	+	+
Dutch Safety Board	Interview report	-	-	+/-	+	+	+

RR3.1 Information relevant for immediate prevention (e.g. protection of other children in the family) is discussed by the rapid response team.

RR3.2 It has been defined which immediate preventive measures have to be taken, when necessary.

CD03.1 Research ends with a discussion how such a death can be avoided in the future.

CD03.2 Recommendations, actions to be performed and lessons learned are passed on to relevant authorities or individuals.

CD03.3 Recommendations, actions to be performed and lessons learned are passed on to governmental institutions to improve public health.

CD03.4 It has been defined who is responsible for (taking care of) carrying out the improvements.

Organization / professional	Title of document available for analysis	RR4.1	RR4.2	RR4.3	RR4.4	RR4.5	RR4.6	CD04.1	CD04.2	CD04.3
School	Protocol in Case of Death	+	-	-	-	-	+/-	-	+/-	-
Perined	Perined	-	-	-	-	-	-	-	+/-	-
National Cot Death Study Group	Dutch Cot Death Foundation	+/-	-	-	-	-	-	-	+	-
Dutch Cot Death Foundation	Interview report	+/-	-	-	-	-	+	-	+	+/-
Dutch Safety First Association	Interview report	-	-	-	-	-	-	-	-	-
Consumer Safety Institute	Interview report	-	-	-	-	-	-	-	-	-
Dutch Safety Board	Interview report	-	-	-	-	-	-	-	-	-
RR4.1	The potential needs of relatives are identified.									
RR4.2	When a child died in the hospital, parents are supported by a designated professional of the hospital.									
RR4.3	When conditions permit, parents get the opportunity to be alone with their deceased child to take leave of their child.									
RR4.4	Parents are informed about up-to-date findings of the investigation, unless this obstructs the investigation.									
RR4.5	It has been defined how to act when parents and the deceased child do not live in the same country.									
RR4.6	After completion of the rapid response, further (psychological) assistance is rendered to the relatives.									
CD04.1	The actions of professionals in supporting grief counseling to relatives are analyzed.									
CD04.2	Relatives are kept in touch in the long run, whereby feedback is given about the circumstances of and factors contributed to the death and grief counseling.									
CD04.3	The given support to relatives is monitored.									

CHAPTER 5

How do parents experience support after the death of their child?

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How do parents experience support after the death of their child?

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Abstract

BACKGROUND A child's death is an enormous tragedy for both the parents and other family members. Support for the parents can be important in helping them to cope with the loss of their child. In the Netherlands little is known about parents' experiences of the support they receive after the death of their child.

The purpose of this study is to determine what support parents in the Netherlands receive after the death of their child and whether the type of care they receive meets their needs.

METHOD Parents who lost a child during pregnancy, labour or after birth (up to the age of two) were eligible for participation. They were recruited from three parents' associations. Sixty-four parents participated in four online focus group discussions. Data on background characteristics were gathered through an online questionnaire. SPSS was used to analyse the questionnaires and Atlas ti. was used for the focus group discussions.

RESULTS Of the 64 participating parents, 97% mentioned the emotional support they received after the death of their child. This kind of support was generally provided by family, primary care professionals and their social network. Instrumental and informational support, which respectively 80% and 61% of the parents reported receiving, was mainly provided by secondary care professionals. Fifty-two per cent of the parents in this study reported having received insufficient emotional support. Shortcomings in instrumental and informational support were experienced by 25% and 19% of the parents respectively. Parental recommendations were directed at ongoing support and the provision of more information.

CONCLUSION To optimise the way Dutch professionals respond to a child's death, support initiated by the professional should be provided repeatedly after the death of a child. Parents appreciated follow-up contacts with professionals at key moments in which they were asked whether they needed support and what kind of support they would like to receive.

Introduction

The death of a child is an enormous tragedy for both the parents and other family members. Parents experience intense feelings of loss after their child's death [128]. The death of the child influences not only the family system, which is internally disrupted [15, 129], but also others: neighbours, friends, relatives (i.e. the social network) and other acquaintances. Everyone needs to deal with his or her own grief. While parents try to pick up the pieces, support that meets their needs is important for them to cope with the loss of the child [15].

The period of mourning and the way people mourn differ from person to person. There is no "right" way of grieving [130, 131]. Some authors describe different stages in the grieving process, which may overlap each other [130]. Others state that grief is a complex process which has no stages and consider it to be more like a fingerprint: unique and erratic [132]. The dual process model [133], in which an effective way of mourning is finding a balance between 'loss orientation' and 'restoration orientation', fits well with this view. Although people mourn in their own way, on different levels of intensity and time course, complicated forms of grief have been reported [134]. As many as 58% of parents who lost a child suddenly and unexpectedly, show 18 months after the death of their child, "complicated grief reactions" if the definition of Prigerson & Jacobs is used [135]. But given the nature of the parent-child relationship, this may not necessarily indicate pathological processes. Bereavement outcome depends on a complex interaction between situational, personal and coping factors [136]. It is known that grief rumination [137] leads to more symptoms of depression and complicated mourning [136]. Complicated grief then, like yearning existing longer than six months post-loss [138, 139], increases the risk of psychosocial and psychiatric problems and death from natural and external causes [17, 140, 141]. To prevent psychosocial and psychiatric problems after the death of a child it is important that professionals understand the complex emotional grieving process and identify symptoms of possible complicated grief in parents and other family members at an early stage, in order to provide adequate family support.

The intensity of parental grief is related to a number of factors, such as gender and coping strategies of parents, the child's age, and circumstances surrounding the death. Cultural and ethnic differences must be taken into account in assessing

the extent of expressions of grief and mourning. What is considered normal in one culture may not be in another [142]. Mothers experience intensive grief reactions more often than fathers [17, 143-145]. Gender differences are also observed in the use of coping strategies in relation to death. It seems that women confront their emotions, while men use avoidance coping strategies more often. The intensity of grief among parents generally increases when the child dies at an older age [17]. Furthermore, parents experience more grief reactions when the death is due to an external cause and is unexpected. Features of grief and coping styles differ between individuals, different ethnic groups and cultural backgrounds [136]. This implies that the need for support also varies.

When their child has died, parents receive support from family, friends, colleagues and other people, for example from day care, school or sport clubs, and from (health) professionals. There are different types of support described in literature [146, 147], which can be divided into emotional, instrumental and informational support. Emotional support is any behaviour in which empathy, love, trust and care is provided to parents. Instrumental support is the provision of tangible assistance or services that directly help parents. Informational support is the provision of advice and information, which empowers parents to make informed decisions about the care offered to their child, such as withdrawal of treatment, as well as other issues pertaining to family life [146]. Health professionals and others involved in a child's death are confronted with their own emotions and fears. This may influence the way they approach the parents of a deceased child [148]. The care, or the lack of care, that parents receive around the time of death has a great impact on the adjustment process and well-being of the parents in the long-term [149]. In case of a sudden and unexpected death in particular, the initial care largely determines the course of bereavement. In this context professionals should realise that parents want to say goodbye to their child, receive information about the cause of death and feel supported by professionals [14]. Parents value health professionals and others who approach them with empathy, kindness and respect. They also value professionals when they listen and communicate well and offer support before and after the death of a child [14, 140, 149, 150]. According to parents, support should be offered on an individual basis and may vary in intensity depending on the family needs [140]. Support should not be focused solely on parents but also on any surviving siblings [148].

In the Netherlands, professionals from different organisations are involved when children die. In protocols, guidelines or other working agreements, supporting the family after a child's death receives relatively little attention [151]. The Dutch Preventive Child Healthcare has a guideline particularly directed at counselling families after the death of a child [152]. For professionals in palliative care, a national guideline, 'Grief', is available and it describes how surviving relatives can be supported [153]. The Dutch Association of Pediatrics developed a guideline in collaboration with the Dutch College of General Practitioners specifically directed at the organisation of care for children in the palliative phase [154]. Other professionals have generic aspects of family support included in their guidelines.

Although there is a lot of knowledge on bereavement and increasing interest in the support of the family, information is lacking about parents' experiences of the support they received after the death of their child. In this study we answer the research question: what bereavement care did parents in the Netherlands receive after the death of their child and did this care meet their needs? The answers to these questions can help professionals to optimise the support they offer after a child's death.

Methods

Study design

Online focus groups and a questionnaire were used to explore what bereavement care parents in the Netherlands received after the death of their child. The METC Twente (Medisch Ethische Toetsingscommissie Twente) reviewed the project plan for ethical permission, but decided the study was not subject to the Medical Research Involving Human Subjects Act (WMO) (METC/11011.boe)[155].

Study sample

The target population consisted of parents who have lost their child during pregnancy and labour or after birth, up to the age of two. To recruit these parents we contacted the chairs of three parents' associations by email: the Association of Parents of Cot Death Children (in Dutch: Vereniging Ouders van Wiegendoodkinderen), the

Association of Parents of a Deceased Child (in Dutch: Vereniging van Ouders van een Overleden Kind) and the online Sweet Angel Foundation (in Dutch: Stichting Lieve Engeltjes). The Association of Parents of Cot Death Children is a support group that consists of fellow sufferers. Its aim is “to support parents and others who are closely involved, to give information, to gather knowledge on cot death and to stimulate research to optimally support families and to put research to prevent Sudden Infant Death Syndrome (SIDS) on the agenda” [156]. The Association of Parents of a Deceased Child is an organisation which consists of parents of a deceased child (of any age) that aims “to offer understanding and compassion to fellow sufferers” [157]. The Sweet Angel Foundation is an association for parents of a child that died during pregnancy, birth or at an older age, and other persons who are confronted with a child’s death in or outside the family. This association “provides fellow sufferers the opportunity to get in touch with each other by email”[158].

The chairs of the three parents’ associations agreed to invite their members to participate in the study by means of an invitation letter, which contained information about the objectives and procedure of the study. The 256 members of the Association of Parents of Cot Death Children received the invitation letter by post. The Association of Parents of a Deceased Child published the invitation letter in their newsletter, which is delivered to all members including the 200 who lost their child when he or she was under two. The Sweet Angel Foundation placed the invitation letter in their newsletter, which all members received by email. Respectively 33, 1 and 38 parents signed-up via e-mail.

Data collection

Data were gathered through four asynchronous online focus group discussions in February and March 2013. Participating parents from the Association of Cot Death Children were divided into two focus groups of 16 and 17 persons. Participating parents from the Association of Parents of a Deceased Child and the Sweet Angel Foundation were divided into two focus groups of 20 and 19 persons.

Background characteristics of the participating parents were gathered by means of a questionnaire. A semi-structured questionnaire was used to guide the focus group discussions. To conduct these online group discussions a secure forum licensed by TNO Child Health [159] was used. Each session was guided by two moderators (first

and second authors; SG and MLH). Parents gave their consent to participate at the beginning of the online focus group discussion, after they received a document by email that described the procedure of logging in on the secure forum. This document also contained communication rules. Anonymity for participants was ensured through the use of nicknames. The secure forum was accessible to the participants for one week. Each day, the first moderator posted a question on the forum, to which participants could respond at any time of day. Participants could also respond to each other if they wished. In total, seven questions were posted about the support parents had received in the period around and after the death of their child, and whether this care met their needs. Parents were asked to describe who was involved around the time of death of their child and whether they had received support from professionals or other people. If parents reported receiving support, they were asked to describe who supported them, what kind of support they had received and what their experiences were in relation to the support (see Appendix 5.1). The two moderators followed the discussion on a daily basis, in order to stimulate the exchange of information and experiences by answering participants' questions when something was unclear. The second author (MLH), a psychotherapist, also referred some parents to a form of trauma therapy or a website for information when she felt this was appropriate.

Data analysis

First, the background characteristics of the participants were categorised. Second, the input given in the online focus groups, saved on the secure forum, was analysed using Atlas ti.[160]. A codebook was created based on the time period of support in relation to the death, the type of support (emotional, instrumental or informational) parents had received or lacked from a certain person, and wishes or recommendations from parents with regard to support. Support that was in line with the parents' needs or expectations was identified as good practice when parents valued this explicitly with words. The first author (SG) coded all four online focus groups and the third (MB) and fourth author (AN) each independently coded two of the four online focus groups, to minimise the introduction of researcher selection bias into the results. Relevant text fragments related to the topics of the seven questions in this study were selected and given codes. The codes and the corresponding fragments coded by the different coders were compared. The differences were discussed between the three researchers. Ultimately, consensus

was reached about the definitive set of codes and the fragments that corresponded to these codes. Next, the first author (SG) removed duplicates in codes and sorted the remaining codes by the kind of support that parents reported that they had received or lacked after their child's death.

Results

Background characteristics of the participants

Of the 72 parents who had signed up for participation, 29 from the Association of Parents of Cot death Children, one from the Association of Parents of a Deceased child and 34 from the Sweet Angel Foundation actually participated in the online focus group discussions. Fifty-seven of these 64 participants completed the questionnaire on background characteristics (Table 1).

TABLE 1. Background characteristics of 64 parents¹ participating in the online focus group discussions and of their deceased children.

Characteristics	Participants N=64	
	Number	%
Participating parent		
Mother	53	83
Father	4	6
Unknown	7	11
Ethnicity		
Dutch	57	89
Unknown	7	11
Church membership		
No	35	55
Yes	22	34
Unknown	7	11
Year of death of the child		
1970-1999	22	34
2000-2012	35	55
Unknown	7	11
Age of the child at time of death		
Stillbirth	10	16
First month	15	23
2nd -12th month	25	39
Second year	7	11
Unknown	7	11
Expected /unexpected death		
Expected	16	25
Unexpected	41	64
Unknown	7	11
Cause of death		
Pregnancy and childbirth related conditions	13	20
Congenital malformations, deformations and chromosomal abnormalities	10	16
Sudden infant death syndrome	26	41
Other	8	12
Unknown	7	11
Place of death		
Stillbirth	10	16
At home	24	38
In hospital	15	23
Other	8	12
Unknown	7	11

¹ Seven parents who participated in the online focus group discussions did not fill out the questionnaire (answer category: 'unknown')

Most of the 64 participants were mothers (83%). Their mean age was 42.4 years, ranging from 24 to 65 years. All of them were Dutch. Their children died between 1970 and 2012; more than half of the children died after the year 2000. Sixteen per cent of the children died during pregnancy; 39% died between the ages of two months and twelve months. Sixty-four per cent of all deaths were unexpected. Forty-one per cent of the deaths were categorised as Sudden Infant Death Syndrome (SIDS); other causes of death were pregnancy and childbirth related conditions and congenital malformations, deformations and chromosomal abnormalities. Most children died at home (38%) or in the hospital (23%); eight children died elsewhere: three with family, friends or neighbours; four at the crèche, nursery or child-minder's and one in a car seat.

Parents' experiences with support

The kind of support parents reported having received or lacked after their child's death is shown in Table 2. An overview of the professionals who did or did not provide support, for each type of support, as reported by parents is given in Table 3a and 3b.

TABLE 2. Number of focus group participants who reported receiving or lacking support after the death of their child. The total number of participants in the focus groups was 64.

Type of support	Number of participants who reported receiving support	Number of participants who reported lacking support
Emotional*	62	33
Instrumental**	51	16
Informational***	39	12
Unspecified	0	9

* Emotional support: any behaviour in which empathy, love, trust and care is provided to parents.

** Instrumental support: provision of tangible assistance or services that directly help parents.

*** Informational support: provision of advice and information, which empowers parents to make informed decisions about the care offered to their child as well as other issues pertaining to wider family life.

TABLE 3A: Specification of the persons/organisations who/that gave support to the parents after the death of their child, as reported by the 64 focus group participants

Person/organisation who/that gave support	Number of participants who reported receiving support after the death of their child		
	Emotional	Instrumental	Informational
Health care professionals			
Preventive health care	7	5	1
Primary care ¹	43	23	9
Secondary care ²	33	35	29
Maternity care outside the hospital	15	9	5
Acute care outside the hospital	5	2	2
Mental health care	28	4	3
Other professionals			
Funeral service	10	20	12
(Pre)school-related care	3	0	1
Work-related care	8	8	0
Informal network			
Partner	17	1	0
Family	49	22	5
Social network	38	18	2
Support groups	18	6	7
Other ³	7	10	6

¹ Primary care: general practitioner, social worker and home care nurse.

² Secondary care: paediatrician, gynaecologist, other medical specialist, nurse, personnel of the Accident and Emergency department.

³ Other: media, photographer and people not specified by parents.

TABLE 3B: Specification of the people/organisations who/that did not give support to the parents after the death of their child, as reported by the focus group participants

Person/organisation who/that did not give support as perceived by the respondents	Number of participants who reported lack of support after the death of their child		
	Emotional	Instrumental	Informational
Health professionals			
Preventive health care	2	1	0
Primary care ¹	5	1	0
Secondary care ²	6	2	5
Maternity care outside the hospital	1	2	1
Acute care outside the hospital	0	0	0
Mental health care	5	0	0
Other professionals			
Funeral service	1	1	1
(Pre)school-related care	1	0	0
Work-related care	3	1	0
Informal network			
Partner	0	0	0
Family	8	0	0
Social network	4	0	0
Support groups	0	0	1
Other ³	11	9	7

¹ Primary care: general practitioner, social worker and home care nurse.

² Secondary care: paediatrician, gynaecologist, other medical specialist, nurse, personnel of the Accident and Emergency department.

³ Other: media, photographer and persons not specified by parents.

Emotional support

Of the 64 parents, 62 (97%) mentioned the emotional support they received after their child's death (Table 2). Emotional support was mainly provided by family, primary care professionals (i.e. general practitioner, social worker and home care professional) and the parents' social network (Table 3a). Examples of good practices are illustrated in the following quotes:

"We were very satisfied with the support of the general practitioner who did everything for us to sort out everything around the death of our child." (Year of death, 1997)

“The general practitioner often visited us or called us sometimes to see how we coped. We knew that we could always contact her for questions and that thought was comforting.” (Year of death, 2010)

“Our parents and the rest of the family were there for us to provide a shoulder to cry on, to listen to us and ask how we were coping. This kind of support is priceless and has been very crucial for us.” (Year of death, 2010)

Despite the fact that most parents received emotional support, 33 out of the 64 parents (52%) reported lacking this kind of support (Table 2). Parents reported a lack of emotional support in particular from other (not specified) persons and family (Table 3b). The following quotes illustrate the kind of emotional support two parents had missed:

“Like my mother-in-law subtly noted after 6 weeks “Are you still crying? You have to stop doing that now, because for us it is very annoying”. And yet she was a very sweet woman who did not know better.” (Year of death, 1985)

“Although we received a lot of support from our family, they do not know how it feels when you have lost a child. They completely miss the point in giving well-intentioned advice.” (Year of death, 1997)

5

Instrumental support

Fifty-one of the 64 parents (80%) mentioned the instrumental support they received after their child’s death (Table 2). Instrumental support was particularly provided by primary and secondary care professionals (paediatrician, gynaecologist, other medical specialist, nurse, personnel of the Accident and Emergency department) and family (Table 3a). Examples of instrumental support are reflected in the following quotes:

“We received a lot of support from our family, who took over our household and made dinner for us. I have experienced this as pleasant.” (Year of death, 1999)

“The forensic physician allowed us to bring our daughter to the hospital ourselves without police or hearse. The hospital was informed about our arrival. A special

room was prepared for us where we could stay. They offered us the opportunity to be present during the first examination, which we did not want to. After the examination we could take our daughter in our arms until she was taken away for the complete autopsy. Afterwards we put her in her own bed underneath a blanket as if she was going to sleep. We experienced this as a very warm gesture to our daughter and ourselves.” (Year of death, 2005)

“The hospital had organised a memorial service 5 months after the death of our daughter for all the parents of children that died at the neonatology department that year. The memorial service was followed by a get together with fellow sufferers. I am positive about this kind of support (as far as you could speak in those terms).” (Year of death, 2005)

Sixteen of the 64 parents (25%) mentioned a lack of instrumental support after the death of their child (Table 2). Parents reported a lack of instrumental support in particular from other (not specified) persons (Table 3b). The following quote illustrates the kind of instrumental support one parent reported lacking:

“After the death of our child we have had to struggle to get the help we needed. A psychologist with experience in bereavement was hard to find.” (Year of death, 2011)

Informational support

Of the 64 parents, 39 (61%) mentioned the informational support they received after the death of their child (Table 2). Informational support was particularly provided by secondary care professionals (Table 3a). The following quotes illustrate the informational support received from secondary care professionals:

“We experienced the counseling for a future pregnancy in the hospital as very valuable. You are no longer the ‘unconcerned’ parent.” (Year of death, 1993)

“Both hospitals where I stayed were very supportive, especially one physician: the gynaecologist. The talks, the time, the personal advice. It was all well meant and direct. Although I did not want to hear it, he gave advice anyway. But I appreciated (and I still do appreciate) the support, the honesty and sincerity of this man.” (Year of death, 2012)

Twelve out of 64 (19%) mentioned a lack of informational support after their child's death (Table 2). Parents reported a lack of informational support in particular from other (not specified) persons and secondary care professionals (Table 3b). The informational support that parents lacked is reflected in the following quotes:

"At a follow up check the gynecologist told me that I should be pregnant again as soon as possible. This would not happen the next time. I did not get any further information." (Year of death, 1970)

"For advice and information you have to look on the Internet." (Year of death, 2012)

Recommendations of parents

Twenty of the 64 parents (31%) responded to the question about the ways in which support could be improved and what kind of support they had appreciated from which person. The recommendations they provided are directed at emotional, instrumental and informational support after the death of a child, as presented in Table 4.

TABLE 4 Recommendations reported by parents per type of support

Type of support	Recommendations
Emotional	Create possibility to share grief and experiences and get support not only after the death of a child but in the next pregnancy as well [1] [year of death 1986] [realized by the Care of Next Infant program (CONI)]
	Close relatives or friends should let the parents know that support could be provided anytime [1] [year of death 2005]
	Professionals should realise that parents want to hold and cuddle their deceased child [1] [year of death 2005]
	A physician (e.g. the GP), midwife or social worker should offer a consultation 6-12 months after the death of a child to check whether there are questions or whether parents need support [3] [year of death 2005, 2011, 2012]
	The GP or Preventive Child Health nurse should contact (phone, home visit) parents as a 'safety net' [1] [year of death 2012] several times after the death of their child to pay attention to the loss, listen to them [4] [year of death 2000, 2010] and signal problems in the grieving process at a very early stage [1] [year of death 2010]
	A hospital professional, like the gynaecologist or nurse, should contact parents uninvited to evaluate [2] [year of death 2008, 2012]
	Professionals should take into account the mental situation of the mother when she gives birth to a deceased child [1] [year of death 2012]
Instrumental	The GP should offer support and discuss his/her options for giving after care shortly after the death of a child [3] [year of death 1985, 1997, 2000]
	Professionals should structurally draw the parents' attention to contact with fellow sufferers [2] [year of death 2005] [still does not happen always]
	Support should be offered repeatedly by a professional from the hospital, midwife, preventive child health care professional or GP, especially when support from social network has stopped [2] [year of death 2005, 2012]
	Hospitals should organise a memorial service for all deceased children [1] [year of death 2008] [happens in many hospitals, nowadays]
	Offer a form of maternity care once a week for 6 to 12 months [1] or help in the household for 1 year after the death of a child, to be reimbursed by the insurance company [1] [year of death 2011]
Informational	Professionals should draw parents' attention to books, websites, documents [3] [year of death 1997, 2005]. A brochure that contains different kinds of support with contact information of professionals should be offered as a standard procedure shortly after the death of a child [1] [year of death 2010]
	The undertaker should provide parents with information about options for a funeral or cremation, including examples of grave covers and sample texts for cards [2] [year of death 1997, 2005] [Is realized nowadays]
Unspecified	Lay down rules for bereavement leave for the duration that is needed [1] [year of death 2011]
	The hospital should offer a return visit to the department of the hospital where the child is born to speak the nursing staff [1] [year of death 2012]

Discussion

When a child has died, many people are involved and provide some form of support to parents. Through the use of online focus group discussions we explored parents' experiences with support after the death of their child aged two or younger.

Most parents mentioned the emotional support they received after the death of their child. This kind of support was particularly provided by family, primary care professionals and the parents' social network. Instrumental and informational support was mainly provided by secondary care professionals. As described in other research, physicians arrange follow-up meetings, usually after 6 weeks, with parents to inform them about the autopsy findings, cause of death and genetic risk, to answer questions and to offer and provide support in the following pregnancy if needed [161].

An important finding is that slightly more than half of the parents reported a lack of emotional support, particularly from family. Furthermore, informational support from secondary care professionals was evaluated as insufficient and many parents experienced shortcomings in the instrumental and informational support of other, non-professionals.

Bereavement care has changed over time. In the post-war years parents were not allowed to talk about their deceased child, to see their child after death or to show their grief [162, 163]. Nowadays, there is a greater understanding of the loss and pain parents experience after the death of their child. Although this has changed the way in which support is provided to the family, parents in this study have made some recommendations to optimise family support. Parents emphasise that they would like to be approached with empathy and be acknowledged in their bereavement. Alongside this, health care workers should offer support repeatedly and provide parents with information about the grieving process and options for support. Parents appreciate contact with professionals six to twelve months after their child's death, to check whether the family needs any extra care or support. This contact should be initiated by the professional. In line with the results of other studies, parents indicate that they would appreciate the provision of more support and follow-up appointments or contacts with a professional after the death of their child [14, 150].

Strengths and weaknesses of this study

For our target population, the use of online group forums proved to be a comfortable form of group discussion. This may have helped with recruitment, because participants were confident that anonymity was guaranteed and they could decide when and where they wanted to answer the questions. We were able to recruit 64 respondents living throughout the country, of whom 57 provided information about the time, place and cause of death, the extent to which the death was expected, and the age of the child. However, parents were only recruited from support groups, which creates bias. It could be that parents who are members of support groups experience less support from family or have less or more coping skills than bereaved parents who do not participate in such a group. Recruitment through an invitation letter in the organisation's newsletter seemed to be less effective than a letter sent by post. The low participation rate for parents from the Association of Parents of a Deceased Child might relate to the fact that this association includes parents of children who died at any age, while this study focusses only on young children. Furthermore, in the interpretation of the number of members of the parents' associations it should be taken into account that membership lists usually include many dormant members. The distribution of the background characteristics of participants (mostly mothers of Dutch ethnicity) limits the generalisability of the results to fathers or other ethnicities. In addition, we also were not able to observe gender differences in grief reactions and the way professionals should respond to this. With regard to church membership, the numbers are not remarkably different from the current Dutch population [164, 165].

The number of participants prohibits analysing subgroups according to the circumstances of the child's death or parents' characteristics. In addition to the small number of participants, the heterogeneity of time and circumstances of loss as well as the range of professionals likely to be involved in providing support, make it difficult to assess the internal validity of conclusions drawn from parents' reports. The findings of this study shed light on Dutch practice over decades and do not provide a clear picture of current practice. Although participants provided valuable recommendations with regard to the way in which support should be improved, some of these have already been implemented in practice. We therefore recommend repeating this study with a larger sample size covering a short time span, for example the past five years, arranged by age of the deceased child and manner of death.

An advantage of online focus groups is that data do not need to be transcribed. This improves the accuracy of data and eliminates transcript bias, thereby increasing the quality of data [166]. A limitation of the online method is the varying response rate and length of responses to each individual question posted on the forum. Not every participant answered every question and was specific enough, which is understandable because it calls for a high degree of discipline. If we had been able to ask each parent to respond to each question posted on the forum, this would probably have resulted in a higher response rate and a more complete overview of the support parents received or lacked after the death of their child.

Conclusion and recommendations

Different types of support are provided to parents after the death of their child. Although increasing attention has been paid to supporting families after the loss of a child, one-fifth to slightly more than half of the parents in this study lacked some sort of support or experienced support that was not in line with their needs or wishes. According to the results of this study, support initiated by professional should always include listening to parents and asking them at key moments after their child's death whether they need (extra) support and what kind of support they would like to receive. Parents should also be asked specifically about the emotional support they receive from their family and their social network. When they lack this type of support, caregivers should explore with them how to reach out and receive more support. Furthermore, adequate communication skills and a respectful attitude are necessary in approaching the parents of a deceased child. The results of this study may not apply to every parent who has lost a child, because participants were a selected, self-admitted group. Future study is necessary in which parents are contacted through hospitals or government registries of death in order to compare the responses of those who participate in support groups and those that do not. Next to this, further research with the use of online focus groups is desirable, because the scope to reach parents and to include them in research seems so much wider than traditional focus groups.

APPENDIX 5.1. *Seven questions that are posted in the online focus groups*

Question 1
Who were involved in the care before and after the death of your child?
Question 2
Who offered you support in the period around and shortly after the death of your child?
Question 3
Could you specify what kind of support (emotional, instrumental, informational) you received after the death of your child and from whom?
Question 4
Did professionals take into account the specific situation of your child or your cultural background? Did you know if professionals tuned in the support with each other?
Question 5
Were members of the direct or extended family involved in the support?
Question 6
At what moment started professional support and how long did it take? What kind of support did you receive and how often took this kind of support place?
Question 7
If you look back, what went well or could have been better with regard to the support you have received? What did you appreciate the most about the support and from whom?

CHAPTER 6

Stakeholders' opinions on the implementation of Child Death Review in the Netherlands

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Abstract

BACKGROUND The death of a child is an enormous tragedy for both the family and others involved. A child's death appeals to everyone's responsibility to take measures to prevent similar deaths in the future. Child Death Review (CDR) is an interagency approach in which a child's death is systematically analyzed by a multidisciplinary team. The aim of CDR is to identify avoidable factors that give direction to prevention and to improve death statistics. CDR is not yet implemented in the Netherlands. The purpose of this study is to determine Dutch stakeholders' opinions regarding the facilitating and impeding factors in the implementation of CDR in the Netherlands.

METHODS Four focus groups were conducted: three with professionals who are involved in children's deaths and one with parents who have lost a child under the age of 2 years. The recorded discussions were transcribed and analyzed using Atlas ti. The facilitating and impeding factors were measured using the measurement instrument for determinants of innovations (MIDI). The MIDI identifies facilitating and impeding determinants associated with the innovation, user, organization and social-political context.

RESULTS Improvement of the quality of (health) care and obtaining a clear explanation for the child's death (user and innovation) were identified as benefits of CDR. The emotional burden for professionals and parents and the time implications were considered to be drawbacks of CDR (user and innovation). The multidisciplinary approach (innovation), parental consent and the use of anonymized data (user) were considered as facilitators to implementation. Insufficient information (innovation), potential legal consequences for professionals and organizations (user), insufficient ratification by organizations (organization) and confidentiality (social-political context) were identified as impeding implementation.

CONCLUSIONS The determinants identified as facilitating and the recommendations provided to overcome the barriers can be used as input for the strategy for implementation of CDR. A pilot study is necessary to determine to what extent the chosen implementation strategy is effective.

Background

Children are expected to grow into adulthood in a safe and healthy environment. It is the responsibility of every state to promote the welfare of children and protect them from harm [2, 125]. When a child dies, it is a great tragedy for both the family and relatives, friends, neighbors, and other acquaintances [15, 167].

Concerted efforts remain necessary to avoid child deaths in the coming years and to accelerate further progress in improving child survival [3].

In the United States of America (USA), Canada, Australia, New Zealand and the United Kingdom (UK), a structured approach is being used where different agencies work together in order to understand why children die and how future deaths can be prevented. This approach is called Child Death Review (CDR). The objectives of CDR are to identify avoidable factors in child deaths, to translate the results in recommendations which may prevent future deaths and improve child health and welfare, and to improve cause of death statistics [30, 31] and the support to the family [5]. In the USA and UK, CDR consists of two interrelated parts: a rapid response investigation in cases of unexpected deaths and a retrospective panel review of all child deaths by a multidisciplinary team. This multidisciplinary team consists of core members [29-31]. Studies have shown that CDR has identified modifiable factors in child deaths [5, 30, 33, 168]. Implementation of recommendations based on the CDR method locally, regionally and nationally have resulted in the prevention of child deaths [16, 30].

In the Netherlands CDR is not implemented yet. If the CDR were to be introduced, it would require support and involvement of the parents of a deceased child and professionals in child and family (health) care. A bottom-up approach is desirable in developing an implementation strategy, because it may increase the motivation of professionals to integrate the CDR-procedure in their own (clinical) practice [169]. For the successful implementation of an innovation in current (health) care structures, ideally, all stages of the process of change, i.e. dissemination, adoption, implementation and continuation, should be passed. At each stage different factors may facilitate or impede the process of change [37, 169]. It is important to get insight in which impeding and facilitating factors might influence the different stages of the implementation of CDR in the Netherlands.

In this study, started from February 2010 till January 2011, we examined the opinions of stakeholders about the implementation of CDR in the Netherlands. We focused on the creation of support among stakeholders (adoption), the actual implementation and securing CDR in existing practice (continuation). Important stakeholders were asked for their opinions regarding the facilitating and impeding factors in the implementation of CDR. The research question of this study is twofold: (1) what are the stakeholders' opinions regarding the facilitating and impeding factors in the implementation of CDR in the Netherlands; and (2) which recommendations do stakeholders give for the implementation of CDR in the Netherlands? We planned to use the results of this study to design a pilot implementation.

Methods

Study design

To answer our research question we used a qualitative, descriptive design. We held focus group discussions to identify stakeholders' opinions regarding facilitating and impeding factors in the implementation of CDR in the Netherlands. We used the Measurement Instrument for Determinants of Innovations (MIDI), developed by Fleuren et al. [37]. This is a qualitative coding framework consisting of four domains, each of which contains a number of determinants associated with the innovation; with the adopting person (user); with the organisation; and with the socio-political context. A description of all 29 determinants [38] is provided in Appendix 6.1. The MIDI identifies facilitating and impeding factors in the four domains [37]. We consider CDR as an innovation because it concerns a working method that is new to the Netherlands [170], even though it has been implemented elsewhere previously. According to the criteria of Dutch Medical Research Involving Human Subjects Act, this study did not need to be submitted for ethical approval by a Medical Ethical Committee [19]. Therefore the study was reviewed by the institutional Ethical Committee of the University of Twente (Ethical Committee (EC) of the faculty of Behavioral Sciences, reference number 16039) and approved.

Study sample

The target group of stakeholders consisted of professionals who are directly

or indirectly involved in a child's death and parents who have lost a child under the age of 2. Because the results of this study were going to be used for a pilot implementation, we recruited professionals as representatives of healthcare organizations located in the pilot region (two eastern provinces of the Netherlands). We recruited the professionals through their managers or head of the departments of the health and child care organizations where the professionals work. Parents were recruited through the boards of the Parents' Association of Cot Death Children (in Dutch: *Vereniging Ouders van Wiegedoodkinderen*) [156] and of the Parents' Association of a Deceased Child (in Dutch: *Vereniging van Ouders van een Overleden Kind*) as representatives of these associations [157]. Professionals and parents were invited to participate in the focus groups by means of an invitation letter, which was sent by regular mail. The invitation letter contained information about the objective of the study and a short description of the method used. Twenty-one professionals and four parents signed up by email.

Data collection

Data were gathered through four face-to-face focus group discussions in May and September 2010. Of the 21 professionals who signed up, sixteen are professionally involved in the care for the child and his family at the very moment when a child dies and five in the period afterwards. These professionals were divided in three focus groups, as shown in Table 1. The fourth focus group consisted of three parents of a deceased child. The fourth parent who signed up was unable to join the focus group discussion (see Table 1).

TABLE 1. Number and background of participants in each focus group

	Focus group 1	Focus group 2	Focus group 3	Focus group 4
Participating professionals/parents	N	N	N	N
Pediatrician	3	4		
General Practitioner	1	1		
Forensic physician	1	1		
Preventive Child Health care professional (physician/nurse)	1	2		
Social worker		2		
Physician of the Child Protection Service			1	
Police officer			1	
Mental health care physician			2	
Manager of organization that provides support to children and adults and their families with disabilities (MEE)			1	
Parents				3

Each focus group was moderated by the second (MLH) or third (MB) author. The first author (SG) took notes and audiotaped each session with consent of the participants. An agenda and a semi-structured interview schedule were used to guide the focus group discussions. In total six questions were asked in each focus group about the participants’ opinions of the (dis)advantages of CDR 1) in general, 2) for the parents, 3) for professionals who provide information or 4) for participants in the CDR team, 5) for organisations, and 6) when CDR is implemented at a national level. The audiotaped focus group discussions were transcribed by the first author (SG) and the data were anonymized. The four transcribed records were used for analysis.

Data analysis

The transcribed records were analyzed using Atlas ti. [160]. A codebook was created based on the determinants of the MIDI [38]. A determinant was judged to be a facilitator if a participant described it in a way which indicated that it would lead to or enhance the achievement of the objectives of CDR or its implementation (i.e. positive labelling of a determinant). When a determinant was described by a participant in a way which indicated that it would hinder or reduce the achievement of the objectives of CDR or its implementation, it was judged as impeding (i.e. negative labelling of a determinant). Relevant text fragments corresponding to the determinants of the MIDI were selected by a second coder (master student). Next,

the first author (SG) coded all online focus groups and the second coder coded the same focus groups independent from the first author to minimize bias introduced into the results by researchers' selection. Subsequently, the text fragments that were provided with codes by the two coders were compared with each other. All differences in coding were discussed between the coders. Ultimately, consensus was reached about the definitive set of codes and the text fragments that corresponded to these codes. The codes with corresponding text fragments were arranged in order of the determinants of the MIDI. A subdivision was made into the facilitating and impeding determinants of the CDR method and of effective implementation, and stakeholders' recommendations.

Results

Thirteen of the 29 determinants presented by Fleuren et al.[38] were identified by the stakeholders as facilitating or impeding. Six of these determinants were mentioned in all four focus groups. Most of determinants were identified in the category "innovation" and "user". We did not find facilitating or impeding determinants that were not mentioned in the MIDI. The determinants identified in the focus groups are presented in Table 2.

In the presentation of the results we first focus on the benefits and drawbacks of CDR as a method and subsequently on the facilitators and barriers to effective implementation. The determinants are summarized and illustrated with relevant quotes. All quotes from professionals and parents regarding the facilitating and impeding determinants are presented in Appendix 6.2.

Benefits of CDR

Benefits of CDR were identified in personal benefits and outcome expectations (determinants associated with the user). With regard to *personal benefits* three benefits were mentioned directed at professionals. First of all participants perceived CDR as an instrument to check whether or not the professional responded to the death according to established guidelines and/or protocols. A second benefit is indicated in the following quote:

“Positive is the fact that you are immediately aware of reporting every child death to the Child Death Review team, and that you have to report every death, which is not an automatic procedure.” (focus group: professionals)

Third, professionals might also benefit from the findings of the CDR team. Reviews can enable improvement of the quality of (health) care and the education of professionals. With regard to parents two benefits were mentioned by participants. First, it was noticed that CDR might provide parents a clear explanation for their child’s death, which can be considered as a second opinion. Second, well conducted death reviews might influence the mourning process of parents positively. Support of the family was perceived as important. With respect to *outcome expectations*, participants first of all expected that through conducting reviews, substandard factors in (health) care could be identified which could lead to recommendations from different perspectives in order to improve (terminal) care. Second, they experienced an added value in aggregating data to identify certain patterns in child deaths from which recommendations might be translated into regional or national policy to prevent future deaths. Third, it was expected that reviewing a child’s death might result in a better classification of the death, for example in cases of unrecognized child abuse.

TABLE 2. Number of times participants in the focus groups mentioned MIDI¹ determinants as facilitating or impeding in the implementation of CDR

Determinants	Facilitating	Impeding
Determinants associated with the characteristics of the innovation		
Procedural clarity	1	2
Completeness	6	18
Complexity	-	1
Compatibility	1	-
Relevance for client	12	5
Determinants associated with the characteristics of the adopting person (user)		
Personal benefits/drawbacks	14	25
Outcome expectations	29	9
Client cooperation	18	23
Descriptive norm	1	1
Knowledge	-	3
Determinants associated with the characteristics of the organisation		
Formal ratification by management	1	1
Time available	-	7
Determinants associated with the socio-political context		
Legislation and regulations	8	9

¹ Fleuren MA, Paulussen TG, Van Dommelen P, Van Buuren S. Towards a measurement instrument for determinants of innovations. *International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua*. 2014;26(5):501-10

The relevance for the client (i.e. professionals and parents), a determinant associated with the innovation, was identified as another benefit of CDR. Participants considered the understanding of the circumstances leading to death as *relevant* for professionals and parents. It was mentioned that professionals might learn from each other. They also might use the conclusions of the CDR team for their own practice in order to improve the quality of care. With regard to parents, analyzing a child's death was perceived as showing respect to the child.

The following quote indicates a second relevance for parents:

“A strength of the method is the fact that a review is not only conducted in cases of special circumstances, but in every child death. CDR is offered to every parent of a deceased child. So, it is not assumed that suspicious circumstances had been present leading to death.” (focus group: professionals)

In the focus groups it was also mentioned that CDR might be an added value in the identification of specific groups of child deaths.

There were no determinants associated with the organisation and socio-political context identified as benefits of CDR.

Drawbacks of CDR

The emotional burden for professionals and parents was perceived as a drawback associated with *personal benefits* (determinant associated with the user) and the *relevance* for the parents (determinant associated with the innovation). Next to this, some of the participants indicated that it is time consuming to provide information, to anonymize data and to coordinate everything in order to review a child's death. In relation to *outcome expectations* (determinant associated with the user) and *relevance* for the parents (determinant associated with the innovation) participants discussed whether CDR has an added value in individual cases and deaths due to natural causes. Next to this, it was expected that parents do not want to sign the consent form shortly after the death of their child or when consent is asked by an unknown person. Chemistry in contact was mentioned as important. Another reason not be willing to sign the consent form is illustrated in the following quote:

“I think that if parental consent for autopsy is asked in a blunt manner or by a wrong person at the wrong time and as a parent you have said ‘no’, then this will determine the further course of the investigation.” (focus group: parents)

There were no determinants associated with the organisation and socio-political context identified as drawback of CDR.

Facilitators to effective implementation

Procedural clarity, completeness and compatibility (determinants associated with the innovation) were identified in the focus groups as facilitating to effective implementation. With respect to the *procedural clarity* it was considered as important to know which professional meets the parents in order to obtain their consent. In relation to *completeness* of the CDR method, three facilitating factors were identified. First, the multidisciplinary approach was mentioned as facilitating as illustrated in the following quote:

“If all disciplines provide information, the chance will increase to come to the proper reconstruction about what exactly happened. When you hear that from one perspective, it is always coloured and contains miscommunication and occupational deformation.” (focus group: parents)

Second, the fact that feedback of the findings is provided to professionals was considered as a facilitating factor. Third, the presence of a behavioural scientist as one of the core members of the CDR team was perceived as positive as illustrated in the following quote:

“With regard to the evaluation of the aftercare I think the presence of a behavioural scientist as one of the core members of the CDR team is positive.” (focus group: professionals)

In relation to *compatibility*, similarities with the audits of perinatal deaths, that are common practice in the Netherlands, were identified as facilitating.

The cooperation of the client and descriptive norms that are determinants associated with the user were other facilitators identified in relation to effective implementation. Regarding the *cooperation of the client*, participants expected parents to cooperate more easily when they are fully informed about the objective and procedure of CDR shortly after the death of their child and are asked to provide consent in written form a few weeks after their child's death. It was mentioned that signing a consent form emphasizes the respect towards the parents who have lost their child. Next to the informed consent a second facilitating factor in the cooperation of parents is illustrated in the following quote:

“As a parent you have lost a child that is very special, but at the same time you can do something positive. By cooperating in CDR parents could contribute to the prevention of future deaths.” (focus group: parents)

In order to obtain cooperation of professionals the use of anonymized data to analyse the causes of child deaths was mentioned as a benefit. In relation to descriptive norms some participants expected that only a few of their colleagues would participate in CDR, because participation is assumed to be an emotional burden and time consuming.

There were no facilitators identified in relation to the determinants associated with the organisation.

With regard to the determinants associated with the socio-political context the following quote illustrates what was identified as facilitating to implementation:

“If parents gave their consent, confidentiality is not a problem anymore.” (focus group: professionals)

Barriers to effective implementation

Procedural clarity, completeness and complexity (determinants associated with the innovation) were identified as barriers to effective implementation. In relation to the *procedural clarity* it was mentioned that professionals might decide not to notify a child’s death to be reviewed when clear agreements about feedback to professionals are lacking. Next to this, the stratification of the CDR process was perceived as unclear. To gather all information from the (medical) files of the deceased child necessary to analyze the death properly was considered as troublesome and therefore as a barrier related to completeness of the CDR method. First of all, as noticed in the following quote:

“Not everyone has an extensive (medical) file, but one can have a lot of experience with the parents or deceased child that is not noted in the (medical) file.” (focus group: professionals)

Second, as indicated in one focus group data in electronic files can be changed, which was perceived as worrisome. Third, it was mentioned that information systems used in organizations within and between regions differ from each other which might hinder the exchange of information. In response to this, participants discussed the fact that professionals might decide not to provide information, despite the presence of parental consent. This would certainly concern cases in which the Public Prosecutor is investigating the death. Another barrier related to *completeness* of the CDR method is illustrated in the following quote:

“What surprises me a bit is that professionals involved are not present during the CDR meeting. I think that’s remarkable, because that will make the communication more equally clear and obvious. Written information could be misinterpreted.” (focus group: professionals)

Regarding the *complexity* it was mentioned that it requires a lot of energy for professionals to find out in detail the circumstances leading to death.

The cooperation of the client, descriptive norm and knowledge that are determinants associated with the user were identified as other barriers to effective implementation. The legal consequences for professionals and organizations was perceived as a barrier for *cooperation*. Despite the fact that the CDR team will analyse a death with all due care without blaming someone, parents might sue professionals if they know that substandard factors in care have contributed to their child’s death. Not only professionals but also parents might be anxious to be considered partly responsible for the death. Therefore, they might decide not to participate in CDR especially when a child’s death is expected to result in negative publicity in the media. Another barrier identified is indicated in the following quote:

“If you are involved in such a case, especially if you’re directly involved, it will cost you emotionally and practically very much time. Then the paperwork is not that what everyone is waiting for.” (focus group: professionals)

The fact that professionals might perceive participation to CDR as time consuming was considered as another barrier. Finally, parents might decide not to participate when they perceive that they will not get full disclosure of the findings of the CDR team. Participants wondered whether CDR team members have sufficient *knowledge*

to analyse medical procedures. In relation to the *descriptive norm* it was mentioned that it might be difficult to obtain the cooperation of all paediatricians.

With regard to the barriers associated with the organisation it was indicated that professionals who are requested to provide information to the CDR team have busy work schedules and not enough time. Another barrier identified is illustrated in the following quote:

“When actions should be set out within certain professional groups that are employed, you have to do with a management that must support these actions and has to give time to be able to implement them in practice.” (focus group: professionals/parents)

Of the determinants associated with the socio-political context barriers were found in the professional confidentiality, the involvement of the Public Prosecutor and the Dutch rules and regulations as indicated in the following two quotes:

“In the interest of the investigation which is still ongoing, a forensic physician just can't give information merely because he/she can only report to the Public Prosecutor.” (focus group: professionals)

“It should be figured out how CDR fits well into the Dutch system of health care and justice that is a totally different culture in relation to other countries where CDR is implemented.” (focus group: professionals)

Recommendations of stakeholders

Both professionals and parents who participated in the focus group discussions provided recommendations. These are arranged according to the four groups of determinants and summarized in Table 3. Most recommendations are directed at determinants associated with the innovation, i.e. procedural clarity and completeness, and associated with the user, i.e. personal benefits and client cooperation. With regard to the innovation it was recommended that a format should be used to guide the conversation with parents in order to obtain their consent and to help professionals in providing information that is needed to review a child's death. Second, the general practitioner, preventive child health care professional or paediatrician should be approached for information as a standard procedure. Third,

in case the death of a child is investigated by the Public Prosecutor agreements should be made for reviewing the death. Fourth, CDR could join other review processes that are conducted in the Netherlands. Finally, feedback of the findings should be given to professionals and parents. In relation to the determinants associated with the user it was recommended that the CDR team should be independent and chaired by a person who has an overall view and is objective. Second, the time investment of the CDR team members should be clear. Third, in order to obtain the cooperation of parents they should be fully informed about the objective of CDR and should be asked for consent a couple of weeks after the death of their child. Finally, data should be anonymized at an early stage. With regard to the organisation and socio-political context time should be facilitated by managers and CDR should be adjusted to the Dutch law and regulations respectively.

TABLE 3. Recommendations provided by the professionals and parents who participated in the focus groups categorized in the four groups of determinants

Determinant	Recommendations
Innovation	Professionals should document everything in the (medical) file of the child (parents).
	A format should be used to guide the conversation with parents in order to obtain consent (parents/professionals). This format describes 1. how to conduct this conversation, 2. when this conversation takes place, 3. who is requesting parental consent and 4. who is providing feedback (professionals).
	Feedback of the findings of the CDR team should be given to professionals as well as to the parents with the help of a mediator (parents). Agreements should be made about who is providing feedback to the professionals and parents (for example the attending physician) and how this is provided to them. Feedback to parents should be provided only in case of individual recommendations (professionals). If shortcomings in care are identified, professionals should offer parents their apologies. This was considered important for their grieving process (parents).
	When parents are asked to give their consent, they should be informed who is providing them feedback of the findings (professionals).
	Professionals, such as the general practitioner, preventive child health care professional or pediatrician, should be approached for information as a standard procedure. The information system of the child can be accessed to see who else is involved in the care of the child/family (professionals).
	A guideline/format should be used to help professionals in providing the information needed to review the death. It should be clear how much time the process of information gathering takes (professionals).
	Professionals should provide complete and correct information independent from each other to the CDR team (parents).
	The benefits of CDR should be emphasized in order to ensure that professionals provide all information to the CDR team (parents).
	In case a death is investigated by the Public Prosecutor agreements should be made with the Public Prosecutor/Ministry of Security and Justice for reviewing the death by the CDR team (professionals).
	In case of an unexplained death of a child CDR should join the NODO-procedure. Data from the NODO-procedure can be used for CDR to analyse the death in order to make recommendations directed to prevention (professionals).
User	The CDR team should be an independent team in order to prevent bias (i.e. personal interest) (professionals).
	The composition of the CDR team depends on the kind of child death that is being reviewed. The chair should be a 'heavy' figure who has an overall view and is objective. He/she has the knowledge and has no interest in a particular organisation. Someone from the Health Care Inspectorate could also be considered as a chair, but this could cause some resistance for professionals to cooperate (professionals).
	The time investment per CDR team member should be clear (professionals).
	The CDR team is obliged to get at least one preventive activity out of the recommendations made (professionals).
	In order to obtain the cooperation of parents to review their child's death parents should be informed that autopsy data could be used in the CDR (parents).
	In order to obtain the cooperation of parents they should fully be informed about CDR by the general practitioner or pediatrician (parents).

	Parental consent should be asked a couple of weeks after the death of the child by the pediatrician, general practitioner, preventive child health care professional or just the person who is involved around the time of death. Parents could also be asked whether they like to be requested by the attending physician or somebody else to give their consent (professionals/parents).
	In order to obtain the cooperation of parents and professionals data should be anonymized at an early stage to conduct a review (parents/professionals). To reduce traceability to persons deceased children from another region should be reviewed (professionals).
	Parents should have the possibility to check whether the information is correct or not before it is provided to the CDR team. The general practitioner, pediatrician or a confidant could support parents in this (parents).
	More publicity to the general public is needed, so that parents know that after the death of their child a review is conducted (parents).
Organisation	It should be clear what the implementation of CDR means for organisations (i.e. time investment, costs) (professionals).
	The management of organisations should be involved to facilitate time for professionals to cooperate in CDR (professionals).
	Consultation with care insurers is needed for financial coverage of CDR (parents).
	Collaboration of professionals with the CDR team should be facilitated by organisations (parents).
Socio-political context	It should be clear which competencies the CDR team have (professionals).
	The CDR process should be adjusted to the Dutch laws and regulations (professionals).

Discussion

In this study we examined the stakeholders' opinions on the implementation of CDR in the Netherlands.

The identified facilitating and impeding factors are directed at two stages of the process of change, i.e. implementation and continuation. Most determinants were directed at the innovation and user. The relative paucity of determinants associated with the organisation might be caused by the composition of the focus groups that contained mainly participants who have an executive role in the care for the child and family or who are an experience expert as parent of a deceased child. The focus group participants considered the improvement of the quality of (health) care as a benefit of CDR. In the focus groups of professionals more benefits were expected in reviewing groups of certain child deaths. To achieve improvement of (health) care, feedback of the findings of the CDR team to professionals and regional or national authorities, was indicated in the focus groups as necessary. Similar to what has been concluded in the USA and Australia, dissemination of CDR findings to professionals,

legislators, agencies and public is one of the important factors to develop a successful CDR program [31, 171]. Reviewing a child's death was considered in the focus group involving parents as a second opinion that was identified as another benefit of CDR, while in the focus group of professionals the emotional burden was perceived as a drawback of CDR.

The focus group participants perceived the multidisciplinary approach as one of the facilitators to effective implementation. As has been concluded in the evaluation of the CDR process in Australia, the multidisciplinary composition of the CDR team, that is independent of the government, is necessary in order to be effective [171]. Next to this, engagement of motivated professionals and good working relationships are essential for the CDR process to be successful, as highlighted in a study in England [35, 172].

Other facilitators to effective implementation were identified in the cooperation of parents and professionals. Parents were expected to cooperate more easily when they are completely informed about the procedure shortly after the death of their child, oral and written, and are asked for consent a couple of weeks after the death of their child. Signing a consent form was considered to be facilitating in order to obtain the information from professionals. To get the cooperation of professionals the need was stressed to minimize the effort for them and to anonymize data as soon as possible. Using a format for data collection or joining the procedure in case of a sudden and unexpected death was recommended as being helpful in reducing the effort. As found in a study in England, already having structures in place, like a protocol for sudden infant deaths or tools for data collection, could help establish a CDR process [35].

The lack of complete information to review the child's death was considered to be one of the barriers to effective implementation. Some participants noticed that medical files might not contain all relevant information and expected that professionals might decide not to provide information despite parental consent. Other barriers were the legal consequences for professionals and organisations, time implications, insufficient ratification by the management and professional confidentiality that were perceived in the focus groups involving professionals as well as parents. These barriers were also found in England [35]. Legislation could tackle issues of confidentiality. A legal basis for conducting reviews not only

provides the opportunity to share sensitive information and protect confidentiality [31], but it enables also that all aspects of the review process are standardized [30] and protects the independence of the CDR team [171].

The focus group participants recommended to use a consent form and to review a child's death with anonymized data that should reduce issues of confidentiality. They also recommended that the management of organisations should be involved to facilitate time required to cooperate in CDR. If necessary, they recommended to consult medical insurance companies to inform them that CDR is provided as extra care in order to ensure financial coverage. Financial resources are important for a successful implementation of the CDR process [31, 35, 172]. Furthermore, they recommended that the CDR process should be adjusted to the Dutch laws and regulations and agreements should be made with the Public Prosecutor/ Ministry of Security and Justice in case a child's death is investigated by this authority. These recommendations could be used as input for the implementation strategy.

Strengths and limitation of the study

One major strength of this study is that we could collect data from a very diverse group of professionals of several stakeholder organisations. Another strength was the use of face-to-face focus groups in which the ideas, motives, interests and thoughts of the professionals and parents about the implementation of CDR could be explored thoroughly in a confidential atmosphere [173-175]. The small number of participants in the focus group with parents of a deceased child is a limitation, because we might not have all the opinions and experiences regarding the facilitating and impeding determinants.

Finally, the MIDI proved to be a useful instrument for analysis of the discussions. This framework helped us in structuring the determinants of implementation, thereby increasing the possibility to generalize and make recommendations applicable to other parts of the Netherlands and other countries.

Conclusion and recommendations

If CDR would be implemented in the Netherlands, which is subject to debate, the determinants identified as facilitating to implementation of CDR and the

recommendations provided for the barriers can be used as input for the strategy for implementation. According to the results of the focus groups the focus within this strategy should be particularly on the determinants associated with the user (emphasizing the personal benefits for professionals and parents, the use of a consent form and a format to gather information, and analysing anonymized data), organization (informing managers about CDR) and social-political context (adapting CDR to the Dutch regulations and to the procedures of the Public Prosecutor). In a pilot study it needs to be determined to what extent the chosen implementation strategy is effective and whether the results of reviewing child deaths contribute substantially to achieving the four objectives of CDR. If the pilot shows that CDR is indeed very time consuming and of limited added value in cases in which the cause of death is clear, one might consider to start with reviewing only specific child deaths, such as sleep-related infant deaths or theme-related deaths according to the International Classification of Diseases (ICD). In cases of explained deaths in children a CDR might be conducted only to examine whether family support was provided sufficiently.

APPENDIX 6.1. *Overview of MIDI determinants¹*

Determinants	Description of the determinants
<i>Determinants associated with the innovation</i>	
1. Procedural clarity	Extent to which the innovation is described in clear steps or procedures
2. Correctness	Degree to which the innovation is based on factually correct knowledge
3. Completeness	Degree to which the activities described in the innovation are complete
4. Complexity	Degree to which implementation of the innovation is complex
5. Compatibility	Degree to which the innovation is compatible with the values and working method in place
6. Observability	Visibility of the outcomes for the user
7. Relevance for client	Degree to which the user believes the innovation is relevant for his/her client
<i>Determinants associated with the adopting person (user)</i>	
8. Personal benefits/drawbacks	Degree to which using the innovation has (dis)advantage for the users themselves
9. Outcome expectations	Perceived probability and importance of achieving the client objectives as intended by the innovation
10. Personal obligation	Degree to which the innovation fits in with the tasks for which the user feels responsible when doing his/her work
11. Client satisfaction	Degree to which the user expects clients to be satisfied with the innovation
12. Client cooperation	Degree to which the user expects clients to cooperate with the innovation
13. Social support	Support experienced or expected by the user from important social referents relating to the use of the innovation
14. Descriptive norm	Colleagues' observed behaviour; degree to which colleagues use the innovation
15. Subjective norm	The influence of important others on the use of the innovation
16. Self-efficacy	Degree to which the user believes he or she is able to implement the activities involved in the innovation
17. Knowledge	Degree to which the user has the knowledge needed to use the innovation
18. Awareness of content of innovation	Degree to which the user has learnt about the content of the innovation
<i>Determinants associated with the organisation</i>	
19. Formal ratification by management	Formal ratification of the innovation by management, e.g. by including the use of the innovation in policy documents
20. Replacement when staff leave	Replacement of staff leaving the organisation
21. Staff capacity	Adequate staffing in the department or in the organisation where the innovation is being used
22. Financial resources	Availability of financial resources needed to use the innovation

Determinants	Description of the determinants
23. Time available	Amount of time available to use the innovation
24. Material resources and facilities	Presence of materials and other resources or facilities necessary for the use of the innovation as intended (such as equipment, materials or space)
25. Coordinator	The presence of one or more persons responsible for coordinating the implementation of the innovation in the organisation
26. Unsettled organisation	Degree to which there are other changes in progress (organisational or otherwise) that represent obstacles to the process of implementing the innovation
27. Information accessible about innovation use	Accessibility of information about the use of the innovation
28. Performance feedback	Feedback to the user about progress with the innovation process
<i>Determinants associated with the socio-political context</i>	
29. Legislation and regulations	Degree to which the innovation fits in with existing legislation and regulations established by the competent authorities

¹ Fleuren MA, Paulussen TG, Van Dommelen P, Van Buuren S. Towards a measurement instrument for determinants of innovations. International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua. 2014;26(5):501-10

APPENDIX 6.2. Quotes from professionals and parents regarding the facilitators and impeding determinants

Professionals	
Determinant	Facilitators
Procedural clarity	<i>It's pleasant for the doctor concerned to know that he/she is the one who will have a conversation with the parents. Then that's clear and that person can keep an eye on the situation.</i>
Completeness	<i>I think it's a big advantage that there are so many disciplines around the table, because you hear from different people different things.</i>
	<i>I think the complexity should not be a reason not to review a child's death in order to get more clarity. Although it can be very complex in many cases, there might be cases in which a multidisciplinary team discovers circumstances surrounding death or other factors, such as communication problems, from which recommendations could be made directed at a national level.</i>
	<i>When I am asked to provide the information we have about the child, I would like to see the information we have is actually provided by us and not by the Child Protection Service.</i>
	<i>With regard to the evaluation of the aftercare I think the presence of a behavioural scientist as one of the core members of the CDR team is positive.</i>
Compatibility	<i>What I've read about it, is that the perinatal audit and CDR in England are actually pretty much the same only just a different target group.</i>
Relevance for client	<i>A strength of the method is the fact that a review is not only conducted in cases of special circumstances, but in every child death. CDR is offered to every parent of a deceased child. So, it is not assumed that suspicious circumstances had been present leading to death.</i>
	<i>It must be taken into consideration how stressful it is for the family and also for (health) care professionals. But I think you can limit the burden. If you organize it well then I think it should be acceptable and then I do see the benefits.</i>
	<i>I think a very extensive investigation has an added value in addition to the NODO procedure. If you gather information from other disciplines more data come to light than just only a home visit and a postmortem examination performed by the pathologist after the death of a child.</i>
	<i>For the improvement of the analysis of individual cases I do not think you need a CDR, only for larger groups of child deaths.</i>
	<i>I think you should want to know why children die in the Netherlands.</i>
	<i>Unless the communication does not work well within the group (i.e. of professionals), the group will never reveal their problems. In that case it is good to look at the case from the outside with a helicopter view.</i>
	<i>I think it shows some respect to the child whose death is being investigated seriously.</i>
	<i>Depending on the situation support of parents is important. We are focused, of course, in the first place on the safety of the other child.</i>
	<i>Quite often the police doesn't hear from the hospital what has happened. The police must therefore get the information herself. By providing feedback you know what took place, what went well or wrong, children in problem situations or other children present in the family</i>

Personal benefits/ drawbacks	<i>It may be a good tool to check if you've done well.</i>
	<i>Anonymize information as soon as possible, because of the confidentiality of data obtained.</i>
	<i>Positive is the fact that you are immediately aware of reporting every child death to the CDR team, and that you have to report every death, which is not an automatic procedure</i>
	<i>Eventually, in the process of dealing with the death of their child it could be helpful for parents to know where their child has died from. Even if nothing has been found, there has been made some effort in considering factors that might have contributed to the death.</i>
	<i>In many situations I have found it very pleasant that feedback is given.</i>
Outcome expectations	<i>When a child's death is discussed within the CDR team, a conclusion could be that in spite of all the possibilities out there and despite the fact that there are a lot of agencies involved, it is not possible to obtain a closed system to prevent the death. Then you want this kind of cases to be aggregated to a higher level, so you can prevent similar cases.</i>
	<i>How are those professionals trained? This could be questioned when a CDR team discusses a deceased child. That's an improvement.</i>
	<i>You can learn from deceased children for future cases, I think.</i>
	<i>There are of course many examples where terminal care could be improved. I think it is possible and important to do that.</i>
	<i>I think that you can recognize patterns if groups of child deaths are combined from which lessons can be learned.</i>
	<i>I see potential improvements in health care by implementing CDR.</i>
	<i>Not to point to the past, but to get advice for prevention in the future.</i>
	<i>I really think that children, especially the small ones, die of abuse that we have never recognized. You can mistreat a child without seeing it.</i>
	<i>But I see it much more in a broader context in which in the Netherlands there will be more attention for prevention.</i>
	<i>Child Death Reviews seem to me to be a very good preventive tool for the future not only to professionals but also to the parents if more is known about causes of death. It's just a taboo to talk about the causes of death of children.</i>
	<i>A great strength of CDR is that you may be able to recognize patterns by bundling cases. I think that's very important.</i>
	<i>I still think that CDR has an added value. Not to shake one's finger at the organization, but in order to detect patterns and to make recommendations.</i>
	<i>Trends could be discovered that can be translated into national policy.</i>
	<i>Substandard factors in care within certain hospitals could be noticed.</i>
	<i>Recommendations from different angles. I think that's important.</i>
<i>And to check whether there is after-care.</i>	
<i>If something happened with a child and doctors will evaluate it's death with recommendations directed at a regional level, then I have a positive attitude towards CDR.</i>	
Client cooperation	<i>When parental consent is not asked shortly after the death of their child you (as professional) have time to think about how to formulate it. You also have more time to gather your information and give the information to parents. I think the chance of success (i.e. participation of parents) is much greater.</i>
	<i>Well, parents also want to know what has happened to their child who died.</i>
	<i>We assume that parents are well informed about the purpose of CDR.</i>
Descriptive norm	<i>I think some pediatricians are highly motivated.</i>

Formal ratification by management	<i>Perhaps managers could play a role for example in the pledge of secrecy.</i>
Legislation and regulations	<i>If parental consent is present, confidentiality is not a problem.</i>
	<i>The objective of a CDR team is not to evaluate the individual case completely whether procedures went well, but more to aggregate to a higher level.</i>
	<i>If parents gave their consent, confidentiality is not a problem anymore.</i>
	<i>If data are anonymized then it can be used for research.</i>
	<i>If parents gave their consent, information could be provided to the CDR team.</i>
	<i>If the objective of CDR is to investigate the causes of death and what conditions are needed to prevent child deaths in the future than it is alright to use anonymous data.</i>
Impeding determinants	
Procedural clarity	<i>For me the stratification in that process is still a bit unclear.</i>
	<i>I agree with providing feedback, otherwise open ends remain present with the consequence that professionals actually do not notify a child's death anymore.</i>
Completeness	<i>But in order to be able to aggregate the conclusions of a CDR team to a higher level, I wonder whether a CDR team, regardless of the expertise of its members, gets its own wisdom to make some recommendations to other hospitals.</i>
	<i>It seems difficult to get data from paper (medical) files when no interviews with the people involved are held.</i>
	<i>What surprises me a bit is that professionals involved are not present during the CDR meeting. I think that's remarkable, because that will make the communication more equally clear and obvious. Written information could be misinterpreted.</i>
	<i>You should also consider that some people are not going to give the information. What is the quality of a CDR if you have only half of the information? Does it make sense to discuss it?</i>
	<i>The data collection is not so simple. Where do you draw the boundaries of what you can not automatically check? Especially when you think that there might be an important psychological factor that has contributed to the death of the child. You need to collect a lot of data if you want to avoid to be biased.</i>
	<i>Not everyone has an extensive (medical) file, but one can have a lot of experience with the parents or deceased child that is not noted in the (medical) file.</i>
	<i>If parents give their consent, it doesn't mean that doctors provide information.</i>
	<i>If you do not ask parental consent to request that information, it is still questionable whether you will receive the information from the doctor or other instances where the child is known.</i>
	<i>But the strictly forensic group: the parent who beats his child to death, is under investigation of the Public Prosecutor and you really do not get the information until the criminal case has been closed. But I'm sure you're not going to get that information, because a Public Prosecutor just has a duty of confidentiality.</i>
	<i>Each region is organized very differently. In our region the reference index will soon be used. VIS 2 (registration system) tells me basically nothing. That makes it difficult, because everything is organized so differently everywhere.</i>
Complexity	<i>The complexity is found in the detailed description of the situation. It requires an accurate report from obstetricians and pediatricians in order to figure out what exactly has happened.</i>

<p>Relevance for the client</p>	<p><i>But what is the added value in case a child is dying from leukemia in which the disease course is clear? You may assume that all procedures have been properly completed. Can you then still learn from that case?</i></p>
	<p><i>I personally think the aim is very good, but not for the individual improvement. In that case a simple and faster way could be used.</i></p>
	<p><i>But can you then give feedback to the parents? That is more difficult.</i></p>
	<p><i>For me cooperation depends on the idea of how burdensome it is for that family who has just lost a young child.</i></p>
	<p><i>And you also want to prevent some medical difference between the CDR team and board of medical examiners. Suppose the CDR team has come up with wrong conclusions afterwards. That seems to me a tragedy for those parents who experience a trauma already because of the death of their child.</i></p>
<p>Personal benefits/drawbacks</p>	<p><i>If data are not protected in the right way, it will give the blockage in providing information.</i></p>
	<p><i>Protection for themselves (i.e. professionals) and for the organizations.</i></p>
	<p><i>The difficulty is that there is a committee that examines what, if any, could have been improved in a case. In essence it means for those parents that there has been a mistake somewhere. Regardless of the utmost care with which such a committee is trying to define conclusions and recommendations, it may have the wrong effect in individual cases. Then people feel threatened.</i></p>
	<p><i>It applies not only to doctors but to all those who provide information. What is equally important is the area of tension. The point is not who is right, but there will be professionals who are afraid to make their data available because they might even doubt themselves.</i></p>
	<p><i>At that point the doors are closed and you say nothing. Parents could also have the same experience, because they are considered guilty until proven otherwise. There is always a double meaning. I do not know if people realize this well enough.</i></p>
	<p><i>I totally agree with you. Not that I am not willing to cooperate. Indeed, it will be discussed although it is not the objective of CDR.</i></p>
	<p><i>As a doctor you need to provide your information to an independent committee that analyses the case. You do not know how independent those people are. That simply plays a role.</i></p>
	<p><i>I still find it difficult to obtain the information from the CDR team while I did not participate in the discussion. In giving feedback of the findings to parents I may get questions about which I do not know the motivation that well.</i></p>
	<p><i>If you are involved in such a case, especially if you're directly involved, it will cost you emotionally and practically very much time. Then the paperwork is not that what everyone is waiting for.</i></p>
	<p><i>It is emotionally stressful and it takes an incredible amount of time.</i></p>
	<p><i>It is also difficult to decide what you want to know. On the one hand you have to be very broad and, on the other hand, it must be considered that the person from whom you request the information has got minimal extra work.</i></p>
	<p><i>Anonymity of the practitioner and the patient.</i></p>
	<p><i>Anyway, if it's something special, then of course everyone knows what it is about.</i></p>
	<p><i>It is quite a lot of work if you want to review all deceased children.</i></p>
	<p><i>But there is also a lot of coordination in the retrieval of that data. That's a lot of work.</i></p>
<p><i>I think that professionals might feel assaulted if there is something new, because as a professional you think: "I have that conversation with the parents and I do it very well."</i></p>	

Outcome expectations	<i>I find it difficult to look for the tangible advantages of CDR.</i>
	<i>And you will not learn from every case, I think, except the small improvements at the individual level of course.</i>
	<i>Before you know you obviously have an incredible amount of different focus points where you could do something with it, but what can not all be accomplished.</i>
	<i>It seems to me terribly difficult for a committee with all kinds of different disciplines to have an opinion at a given time. So I'm wondering what you can achieve with the natural causes of death.</i>
	<i>You actually need enough cases with question marks to establish the value of CDR.</i>
	<i>On the other hand I wonder whether CDR is the right method. Could it be done on a smaller scale? There are consultations that are probably not optimal.</i>
	<i>Parents obviously want to know the cause of their child's death. So I do not understand the aspect of confidentiality. If the Health Care Inspectorate is not present during the case discussion, then professionals can freely talk about the deceased child.</i>
	Client cooperation
<i>Negative publicity in the media makes people defensive.</i>	
<i>Even something like this. If you even want to interview parents and they have a very negative experience with professionals.</i>	
<i>Suppose parents know more about the cause of their child's death, they might decide not to participate.</i>	
<i>If parental consent is asked at the moment their child has died, I think the threshold for participation for some people becomes higher.</i>	
<i>And if you discuss it with your team, then there is always something that could have been done better and that keeps you busy. This limits you in giving space to others who are evaluating the case.</i>	
<i>If you ask me to obtain parental consent on day 3 after CPR failed, at that moment I am still thinking: "What have I done wrong that this healthy child has died?" Then I am a little less approachable for asking parental consent than after 6 weeks thinking that it had to happen in this way.</i>	
<i>If it creates more work than the threshold to participate is much higher.</i>	
<i>Parents may refuse to cooperate or doctors can think: "I do not support CDR. I'm not going to put more pressure on those parents." This also plays a role.</i>	
<i>It could also be that dad wants to participate, but mom does not or vice versa. This is also seen in suspicious cases of child abuse.</i>	
<i>There was a recent piece in the newspaper about parents who lost a twin at 16 weeks. I was then accidentally involved from the beginning to the end. The information was not valid on many points.</i>	
<i>It is also important to make clear agreements about who is then informed. I think that is a precondition. It is not effective when the CDR team members go apart after such a meeting and no agreements are made about follow up.</i>	
<i>What I always find a pitfall if proper arrangements are made with people is that parents seem to cooperate. They give you the impression that they cooperate, but in fact they don't.</i>	
Descriptive norm	<i>I think when you talk about the burden for pediatricians support from all paediatricians in the region is necessary. I think that is not so easy.</i>

Knowledge	<i>The entire medical procedure that has preceded death will be examined. I think that's not so easy.</i>
	<i>It is a very extensive procedure to evaluate medical practice, which of course happens sometimes especially when parents think that mistakes were made. A regional or national disciplinary committee reaches a decision with many remarks after a lot of hours of work. With many caveats often. It will be difficult to review child deaths in the Netherlands and to draw lessons from it.</i>
Time available	<i>I think that time plays definitely a role.</i>
	<i>It is emotionally stressful and it takes an incredible amount of time.</i>
	<i>It is difficult to make a paper file anonymous. That is quite a job.</i>
	<i>Those who must provide the information, are all people who are very busy.</i>
Legislation and regulations	<i>Confidentiality</i>
	<i>Anonymity of the practitioner and the patient.</i>
	<i>In the interest of the investigation which is still ongoing, a forensic physician just can't give information merely because he/she can only report to the Public Prosecutor.</i>
	<i>Parents can not be forced to participate.</i>
	<i>It should be figured out how CDR fits well into the Dutch system of health care and justice that is a totally different culture in relation to other countries where CDR is implemented.</i>
	<i>The CDR procedure as used in England and USA can not be implemented in the Netherlands. It should be translated into a Dutch version.</i>
	<i>Information could not be requested without the signature of the parents.</i>
Parents	Facilitators
Completeness	<i>If all disciplines provide information, the chance will increase to come to the proper reconstruction about what exactly happened. When you hear that from one perspective, it is always coloured and contains miscommunication and occupational deformation.</i>
	<i>What I find very pleasant is that all care providers must provide information to the CDR team.</i>
	<i>The chances are that nothing is being ignored because of the independent input.</i>
	<i>They (i.e. professionals) can learn from each other.</i>
Relevance for the client	<i>That they might say: "We are professionally considering that as very pleasant, because that is something we have noticed very few."</i>
	<i>The quality of care provided in a hospital, can thus be improved. It is a process in which we continually try to improve quality.</i>

Personal benefits/ drawbacks	<i>A major advantage of this procedure for parents is that signing a consent form stresses the respect towards parents who have just lost a child. I think that it is very important for a parent that he/she will be acknowledged and knows that the death of his/her child will be examined thoroughly. Maybe there are some recommendations to prevent a similar death.</i>
	<i>The information is provided to the CDR team after which the child's death is examined again. If something went wrong, the parent can ask the doctor to explain better what has happened. I think that in itself is a very pleasant idea.</i>
	<i>For parents it can be important to independently verify what has happened with their child. It is not only for the future and for other children, but also for parents who are offered an independent second opinion.</i>
	<i>Parents who have lost a child, think differently about the value of a child. I notice it myself. I keep more of the living children for myself, but I also think for the children to show them something of their youth. This can also be an advantage for parents that their child's death is properly analyzed.</i>
	<i>I think it (CDR) gives more involvement.</i>
	<i>I think that professional associations also receive information from which they can benefit.</i>
	<i>That is a common experience that can be very comforting for parents because the name of the child may be mentioned.</i>
Outcome expectations	<i>Exactly, I also hope that this might be the interpretation in our society, in which we actually keep the deceased almost quiet.</i>
	<i>And as a professional you do not want to condemn. You try to develop guidelines to improve communication and training of professionals who just started.</i>
	<i>CDR has the advantage to provide parents prevention in their future health. It is known that the relationship between parents comes under pressure when they have lost their child, because men and women grief differently. If CDR is properly arranged, it will provide long-term prevention in terms of health and retaining work.</i>
	<i>You can view this in two ways. A CDR is only for the future and for improvement, but not for the individual case. So it's anonymous and parents are not informed. It is not about making mistakes and liability. Or data are not anonymized and retrievable for the parents. This is of course a big difference.</i>
	<i>I do not know how you should solve this legally, but CDR seems to me for the future, the science and improvement and not for the claim culture in the individual case.</i>
	<i>I hope they also conclude that when things are not optimally proceeded that it can be improved.</i>
	<i>I think that a CDR team has more authority to provide good advice to the government that does not depend on an individual hospital or local situation.</i>
	<i>Trends can be identified.</i>
	<i>More co-operation between professionals.</i>
	<i>I think CDR has also an advantage in making recommendations for the future that put more weight on the scale when a pattern is identified by the CDR team. As a parent you do not get all the information by yourself.</i>
	<i>Maybe CDR might result in training for assistants in this subject or being informed about it.</i>
<i>Perhaps CDR might even provide input for peer review within professional groups.</i>	

Client cooperation	<i>It is nice that you can still consult someone like the general practitioner. Parental consent is requested later.</i>
	<i>I thought that the decision for that signature follows immediately after the death, but parental consent is given later. Then you're more likely that parents want to participate.</i>
	<i>I suppose it's all been communicated to parents and that they sign a consent form.</i>
	<i>It is also important that parents clearly are informed about the procedure to which they give their consent.</i>
	<i>As a parent you have lost a child that is very special, but at the same time you can do something positive. By cooperating in CDR parents could contribute to the prevention of future deaths</i>
	<i>That may be an argument to win someone over.</i>
	<i>I think this can be illuminated from two sides. Maybe you do not want it at first, but later you do want to participate in CDR.</i>
	<i>You need the parents to get the information, so you also owe them something (i.e. feedback of the findings).</i>
	<i>Starting with respect and appreciation. Positive reinforcement towards professionals is very important.</i>
	<i>It seems to me useful to mention positive points of CDR in an annual report.</i>
	<i>You could also think of people who have the gift of writing good articles. They could describe a CDR case in a professional journal.</i>
<i>If CDR is well-known people might approach it positively.</i>	
Legislation and regulations	<i>I suppose it's all been communicated to parents and that they sign a consent form.</i>
	<i>It is also important that parents clearly are informed about the procedure to which they give their consent.</i>
Impeding determinants	
Completeness	<i>The conversation with the pediatrician that takes place 6-8 weeks after the death needs to be reported which is not the case.</i>
	<i>There is no conversation with the parents before the information written down on paper is provided to the CDR team.</i>
	<i>The input of information has to be recorded. But if the information is not written down, how do you deal with that?</i>
	<i>I am thinking about the first responders who have to write the reports and provide these to the CDR team. The fact that a general practitioner (GP) may think that he/she should actually make a home visit after the first phone call, which he/she did not. The GP does not include that information in his/her report.</i>
	<i>As a professional you have a conversation with another professional or you get information on paper that can result in miscommunication.</i>
	<i>There is a disadvantage of documenting electronic data.</i>
Complexity	<i>But maybe they (i.e. professionals) initially think "more work and more bureaucracy."</i>

Personal benefits/ drawbacks	<i>In my opinion you give away your child for the second time. It's taken from you and you want to have and keep everything. Then the question is asked to further analyze your child's death and you give away your child again.</i>
	<i>Parents are very willing to eventually respect those mistakes. They are much less willing when they feel there is not full disclosure.</i>
	<i>People are all producing cows, so they think of more work. One thinks that he is doing well, so why do I have to provide that information? The other thinks he might not do so well and they're going to check him.</i>
	<i>They (i.e. professionals) will think: "let me do my job".</i>
	<i>There will be parents who figured out that there is a communication problem.</i>
	<i>Parents need to know that a team is talking about their child and they are waiting for the conclusion. As a parent you can be suspicious about that because a parent might think that professionals protect themselves.</i>
Outcome expectations	<i>It should not get the title of "we're going to find the ones who are guilty." This will lead to a legal context which is not the objective of CDR.</i>
Client cooperation	<i>Otherwise, I expect that you are going to get a lot of problems in obtaining the signature on the consent form. That seems to me a very difficult job. I guess I had not signed the consent form.</i>
	<i>I think that if parental consent for autopsy is asked in a blunt manner or by a wrong person at the wrong time and as a parent you have said 'no', then this will determine the further course of the investigation.</i>
	<i>That is almost a taboo for a parent to indicate that there is no permission for autopsy.</i>
	<i>You might even think that the forensic doctors could also be questioned who is going to ask parental consent.</i>
	<i>You have to take the media with you, otherwise they can manipulate the information.</i>
	<i>I thought right away that parental consent should not be asked by a person, who you do not know. You easily think that he/she has a personal interest and you do not want that person asking for consent.</i>
	<i>Sometimes it is the chemistry with the person who is asking parental consent which can be very important.</i>
Formal ratification by management	<i>When actions should be set out within certain professional groups that are employed, you have to do with a management that must support these actions and has to give time to be able to implement them in practice</i>
Time available	<i>Professionals could say: "I have no time for writing a report."</i>
	<i>Management might provide not enough time to provide information.</i>

CHAPTER 7

Implementation of Child Death Review in the Netherlands: results of a pilot study

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Abstract

BACKGROUND Child mortality in the Netherlands declined gradually in the past decades. In total 1130 children and youth aged 0 to 19 years died in 2014 (i.e. 29.4 per 100,000 live births). A better understanding of the background and the circumstances surrounding the death of children as well as the manner and cause of death may lead to preventive measures. Child Death Review (CDR) is a method to systematically analyze child deaths by a multidisciplinary team to identify avoidable factors that may have contributed to the death and to give directions for prevention. CDR could be an addition to further reduce avoidable child deaths in the Netherlands. The purpose of this study is to explore the strengths, weaknesses, opportunities and threats (SWOT) of the pilot-implementation of CDR in a Dutch region. The results are translated in recommendations for future implementation of the CDR method in the Netherlands.

METHODS Children who lived in the pilot region and died aged 29 days after birth until 2 years were, after parental consent, included for reviewing by a regional CDR team. Eighteen logs and seven transcribed records of CDR meetings concerning 6 deceased children were analyzed using Atlas ti. The SWOT framework was used to identify important themes.

RESULTS The most important strengths identified were the expertise of and cooperation within the CDR team and the available materials. An important weakness was the poor cooperation of some professional groups. The fact that parents and professionals endorse the objective of CDR was an important opportunity. The lack of statutory basis was a threat.

CONCLUSIONS Many obstacles need to be taken away before large-scale implementation of CDR in the Netherlands becomes possible. The most important precondition for implementation is the acceptance among professionals and the statutory basis of the CDR method.

Background

Child mortality in the Netherlands has declined gradually in the past decades [7, 48]. In 2014, 1130 children in the age of 0 to 19 years died (mortality rate 29.4 per 100,000 live births) [7]. In 8 out of 10 cases, the death was classified as due to a natural cause. Most children die in their first year, primarily due to conditions in the perinatal period and congenital abnormalities [7]. A better understanding of the background and the circumstances surrounding the death of a child as well as the manner and cause of death may lead to targeted preventive measures. In the Netherlands systematic analysis of child deaths only occurs in cases of Sudden and Unexpected Deaths in Infants (SUDI) by the National Cot Death Study Group [176] and in perinatal deaths by perinatal health care providers who participate in an obstetric collaboration [20]. Also, unexplained deaths in minors have been systematically examined in a Dutch pilot between October 2012 and January 2014. This so-called NODO-procedure (in Dutch Nader Onderzoek DoodsOorzaak) was regulated by law, and requested further investigation of the child's death in order to clarify the primary cause of death [24, 25]. After its initial national pilot period, the Ministry of Health, Welfare and Sport concluded that further examination into the cause of death requested by the parents should be organized regionally in a less extensive procedure. In order to achieve this, organizations involved in child deaths have developed a multidisciplinary guideline that describes the procedure in case of unexplained death in minors [26].

A systematic analysis is not available for all child deaths in the Netherlands. In addition to the analysis of SUDI cases, perinatal deaths and unexplained death in minors, a standardized Child Death Review (CDR) could contribute to a further decline of avoidable child deaths in the Netherlands.

CDR is a method in which a multidisciplinary team systematically analyzes child deaths in order to identify avoidable factors that may have contributed to the death and that may give directions for prevention [31]. CDR has its origin in the United States of America (USA) where the first team started in the Los Angeles County in 1978. At first, the aim of CDR was to review suspicious child deaths in which abuse or neglect could have been a factor leading to the death. Gradually, CDR teams evolved in other states of America and some of them expanded their scope to reviewing all child deaths [30, 32, 35, 126]. Nowadays nearly half of the US states review child

deaths from all causes [16]. In the late 1990's, CDR was introduced in Canada and Australia [34] followed by New Zealand and the United Kingdom (UK) [30, 127, 177]. The implementation of CDR differs between these countries; not solely in the collection of data but also in legal foundation, focus, funding, family involvement and the location of the actual review [29, 30].

However different their implementation may be, studies have shown that CDR has the potential to identify avoidable factors in child deaths. For example, Child Fatality Review Teams in Arizona and Philadelphia (USA) concluded that 38% and 37% respectively of all deaths of children older than one month up to the age of 18 (and 21 respectively) years were considered preventable [33, 168]. In the UK it was concluded that 29% of child deaths might be preventable [5]. In 20% of the completed reviews in England in 2010 to 2011 modifiable factors in child deaths were identified [30]. These modifiable factors could be translated into effective intervention processes that might lead to a reduction in certain child deaths, like the safe sleep campaigns has resulted in a decrease in cases of Sudden Infant Death Syndrome (SIDS) [16, 123, 178, 179] and the government traffic safety interventions that have reduced transport-related accidental deaths in children [48, 123].

To implement CDR in the Netherlands, support of organizations involved in child and family (health) care is required. Therefore, a bottom-up approach should be used to mobilize these organizations. This will ensure that CDR is effectively implemented, because in this way professionals involved are more motivated to adopt the method in their own practice [169].

In 2010, the authors of this paper conducted a feasibility study to examine which important parameters are needed to successfully implement the CDR. Three focus group sessions were held with professionals who are involved in a child's death and one focus group with parents of a deceased child [180]. Based on the results of these focus groups we developed a strategy for implementation of CDR including a protocol that described the CDR procedure. Afterwards, a pilot implementation was started in the Eastern part of the Netherlands in January 2011 to determine to what extent the chosen implementation strategy was effective. This paper answers the following research question: which strengths, weaknesses, opportunities and threats in the pilot implementation of CDR can be identified and which recommendations can be made for future development of the CDR method in the Netherlands?

Methods

Study design

We used a qualitative, descriptive design to evaluate the pilot implementation of CDR in the Eastern part of the Netherlands. The SWOT framework, previously used as a tool for strategic management in the private sector [181], was used to identify Strengths and Weaknesses of an organization (i.e. internal environment) and Opportunities and Threats in the external environment (i.e. contextual factors as political, economic, social, technological, environmental and legal factors). The SWOT framework that is based on three pillars: stakeholder expectations, resources in the organization (i.e. people, means, finance and capabilities) and contextual factors, is suitable as a model for strategic analysis in the health care sector [181, 182]. In determining a strategy for further implementation, strengths and opportunities should be maximized and weaknesses and threats minimized [183].

The study was reviewed and approved by the institutional Ethical Committee (Ethics Committee of the faculty of Behavioral, Management and Social Sciences, reference number 16001). According to the criteria of Dutch Medical Research Involving Human Subjects Act, this study did not need to be submitted for ethical approval by a Medical Ethical Committee. This article does not contain any studies with animals performed by any of the authors. Informed consent was obtained from all individual participants included in the study.

The Child Death Review protocol

The CDR procedure, described in a protocol [184], consisted of twelve steps that are outlined below. The CDR coordinator, who is also the researcher of this study (first author SG), fulfilled a secretarial role in this procedure.

Inclusion of cases

The death of a child living in the pilot region was notified by healthcare professionals who contacted the CDR coordinator by telephone or e-mail. In this contact they consulted the CDR coordinator about the best way to approach parents for reviewing their child's death (first step).

Next, the CDR coordinator asked a professional who has a confidential relationship with the parents to inform them about the CDR procedure in order to get informed consent for reviewing their child's death (second step). To this end, specific written information material was made available to the parents. This professional notified the CDR coordinator (third step) as to whether the parents agreed to be approached by the CDR coordinator. When parents gave their permission, the CDR coordinator contacted the parents. In this contact parents were asked to give their consent for reviewing their child's death by a CDR team (fourth step). The CDR team consisted of a chair, who is a forensic pediatrician, a general practitioner, a pediatrician, a preventive child health care physician, a forensic physician, a social worker and a psychotherapist. Then parents signed a consent form. After receiving this form, it was archived by the CDR coordinator (fifth step).

Intake

The CDR coordinator contacted all professionals who were involved before or around the time of death (sixth step). These professionals were asked to complete an intake form. This intake form was the same as used in the UK (i.e. agency report form; see Appendix 7.1) [35]. In a standard way, the general practitioner, the preventive child health care professional and the pediatrician, if involved, were approached. After receipt of all intake forms, the CDR coordinator wrote a chronological report with the assistance of the chair of the CDR team (seventh step). Then, the CDR coordinator anonymized all data (eighth step). Next the coordinator scheduled a CDR meeting (ninth step). To prepare for that meeting, the intake form and chronological report were sent to the CDR team members and chair.

CDR meeting

Before in the CDR meeting the review process started (tenth step) all CDR team members and the chair completed a confidentiality agreement. The CDR coordinator filled in the analysis proforma form. This form is used in the UK to analyze a child's death [35] and was translated and adapted to the Dutch legislation and regulations (see Appendix 7.2). During the CDR meeting, factors intrinsic to the child, the family and environment, the parenting capacity and in relation to the service provision that may have contributed to the death, were identified. For all identified factors, the CDR team determined levels of influence. After the cause of death had been categorized,

issues were identified and the CDR team formulated recommendations. The review ended with a follow-up plan for the family and possible actions (eleventh step). Finally, all data from reviewed cases were digitally archived in a secure environment (twelfth step) [185].

Data collection

The target group of the CDR pilot project were all children living in a part of two (eastern) provinces of the Netherlands and who died aged between 29 days and 2 years in the period between January 2011 and December 2012. We chose this age category as child mortality in the Netherlands is the highest under the age of 2. Child deaths until 28 days after birth are reviewed in the Dutch perinatal audits [20], so these deceased children were not included in the CDR pilot project. Eighteen deceased children were reported. Signaling was done by eight pediatricians, five preventive child health care physicians, four forensic physicians and one Public Prosecutor. Of each of the eighteen deceased children, the CDR coordinator made a log. This log contains the name of the professional who notified the death and the date of reporting, names of other professionals involved, background information of the deceased child (age, gender, date of death, cause and place of death), and actions by the CDR coordinator to get parental consent. The process of obtaining parental consent is recorded by the CDR coordinator. Each log ended at the stage when parental consent became available or could not be obtained. In six out of eighteen deceased children, the parents gave their consent for reviewing the death of their child. Hence these six cases were included in the study. They were reviewed in seven CDR meetings. The review of each deceased child was scheduled in a one-hour meeting. Because the CDR team had to get used to the CDR method, the review of the first deceased child took two meetings. Each CDR meeting was audiotaped with consent of all CDR team members. The first author (SG) transcribed the recordings verbally.

In the reviews of the cases, factors have been identified that may have contributed to an increased vulnerability, ill health or even death. The CDR team has also identified factors that provide a complete and sufficient explanation for the death in the domains child's needs, family and environment and service provision (see Table 1). Eighteen logs and seven transcribed records of the CDR meetings concerning six deceased children were used for analysis after the CDR coordinator had anonymized the data.

TABLE 1. Number of cases in which factors, arranged per domain, were identified that may have contributed to vulnerability, ill-health or death or that provide a complete or sufficient explanation for the death, based on the review of the 6 cases

Domains	Number of cases in which the factor was identified
Child's needs	
<i>Acute/sudden onset illness</i>	4
<i>Chronic long term illness</i>	
Epilepsy	1
Other chronic illness	4
<i>Disability of impairment</i>	
Motor impairment	2
Other disability or impairment	3
Family and environment	
<i>Condition</i>	
Emotional/behavioural/mental health condition in a parent or caregiver	1
Smoking by the parent/caregiver in household or during pregnancy	1
Parenting capacity	0
Service provision	2

Data analysis

The logs and transcripts were analyzed according to the SWOT-framework using the software program Atlas.ti. [160] We defined 'strength' as any resources in the CDR team that inspired the team to be effective. Any resources in the CDR team that hindered progress of the CDR team were considered to be a 'weakness'. 'Opportunity' was defined as any contextual factor that promoted the execution of tasks by the individual professionals in the CDR team or the CDR team as organizational unit. Conversely, 'threat' was defined as any contextual factor that could act as a barrier to the execution of tasks by the professionals in the CDR team or the CDR team as organizational unit.

The first author (SG) analyzed the documents first and coded relevant text fragments according to a coding scheme. In this coding scheme the CDR team was seen as the organization (i.e. internal environment) operating within the broader organizational system in the Netherlands (i.e. external environment). Every resource or contextual factor that could be interpreted as respectively a strength or weakness or

opportunity or threat was provided by a code. Stakeholders who play an important role for the optimal functioning of the organization were listed in the coding scheme and were provided with a code as well. Only text fragments in relation to the external environment were combined with codes of the stakeholders. In case the role of the stakeholder was mentioned in the text fragment, the associated code was added to the code of the contextual factor concerned. Next, the fourth author (MB) independently coded the relevant text fragments in the same way. Both authors compared the codes and the corresponding text fragments. Differences were discussed until consensus was reached.

Results

Strengths

Strengths could be identified in people, means and finance that inspired the development of the CDR team as shown in Table 2. The CDR coordinator provided additional information about the aim and procedure of CDR to professionals and parents. The forensic and pediatric expertise of the chair proved to be very valuable in the preparation of the CDR meetings as well as during the reviews, in which she approached each case from a broad view. Furthermore, it turned out that the CDR team members perceived the multidisciplinary approach as valuable; they complemented each other in a positive way. Due to the composition of the team they also called each other's attention to stick to the facts and not interpret when analyzing a child's death. They also were committed and cooperated as a team in order to improve the CDR procedure.

The written materials and the special website, called SERRAFIM (Systematic Evaluation with Risk analysis and Review of Adverse Factors in Infant and child Mortality) [186], were supportive in informing parents and professionals about the CDR procedure and obtaining parental consent. During the meetings the materials available to review a child's death seemed to be helpful to set the parameters in which the CDR team functions and to structure the information and review process.

TABLE 2. Overview of the strengths, weaknesses, opportunities and threats identified in the child death review pilot study

Strengths	Weaknesses
People	People
<ul style="list-style-type: none"> • CDR coordinator <ul style="list-style-type: none"> – contributed to the inclusion of cases • Chair <ul style="list-style-type: none"> – forensic and pediatric expertise – supported in writing the chronological report • Team <ul style="list-style-type: none"> – multidisciplinary approach – made proposals and recommendations directed at the intake and analysis of cases – reached consensus to refine the CDR procedure 	<ul style="list-style-type: none"> • CDR coordinator <ul style="list-style-type: none"> – could not complete the process to get parental consent in 2 cases in time – failed once to send the documents for the CDR meeting in time – has insufficient expertise to select relevant information from the medical record of the deceased child • Chair and CDR team members <ul style="list-style-type: none"> – voluntariness of participation • CDR team <ul style="list-style-type: none"> – limited experience
Means	Means
<ul style="list-style-type: none"> • Materials to inform parents and professionals (leaflet for parents, consent form, SERRAFIM website) • Materials to review a case (DVD ‘Why Jason died’, CDR protocol, confidentiality agreement, document with rules for an efficient meeting, intake and analysis form, recording equipment) 	<ul style="list-style-type: none"> • Lack of essential information from professionals and parents • Illogical ranking of items on the intake and analysis forms • Lack of a clear description how to define the primary and secondary cause of death and the way a death should be classified
Finance	Finance
<ul style="list-style-type: none"> • Fee for chair and CDR team members • Reimbursement of travel expenses 	<ul style="list-style-type: none"> • Insufficient financial resources for the CDR coordinator
Opportunities	Threats
Political factors	Political factors
<ul style="list-style-type: none"> • Added value to the legally prescribed NODO-procedure • National attention of the topic ‘child death’ • Providing a source of information for professionals, parents and others 	<ul style="list-style-type: none"> • The influence of the NODO-procedure on the inclusion of cases
Social factors	Social factors
<ul style="list-style-type: none"> • The objectives of the CDR promoted participation 	<ul style="list-style-type: none"> • Personal reasons of parents and professionals for not participating
Environmental factors	Environmental factors
<ul style="list-style-type: none"> • Collaboration with the National Cot Death Study Group • Reduction of the effort for parents in providing information • Highlighting positive experiences • Presenting at conferences or meetings and publishing in national magazines • Making use of experiences with conducting reviews nationally and in the UK 	<ul style="list-style-type: none"> • Influence of the Dutch Healthcare Authority on the participation of health care professionals in the CDR team
Legal factors	Legal factors
<ul style="list-style-type: none"> • Cooperation of the Public Prosecutor • Signed consent form to obtain information 	<ul style="list-style-type: none"> • Lack of statutory basis

With regard to the financial resources, strengths were identified in the fact that the CDR team members and chair were rewarded for their effort and travel expenses were reimbursed.

Weaknesses

Weaknesses could be identified in people, means, finance and capabilities that hindered the progress of the CDR team as presented in Table 2. In the process of obtaining parental consent, the intake and the preparation of the CDR meeting the CDR coordinator was not always able to act according to the determined procedure. Another weakness was identified in the fact that the chair and CDR team members participated alongside their own practice or had other obligations, which affected the continuity in the team. Due to personal reasons the chair needed to be replaced by a team member with limited experience. Other engagements hindered the preparation of some cases by the chair and the attendance of some of the team members. Furthermore, the CDR team needed time to gain enough experience with the CDR method to be able to review the cases efficiently. The view on service provision differed between the members with their different backgrounds. This limited the number of cases that could be discussed in one meeting.

Due to lack of essential information from professionals involved and from the parents in one case, not every death of a child could be analyzed properly. First of all, professionals did not always provide the information needed to understand the mechanism of death. Second, in some cases of infant death it appeared that also the gynecologist and midwife had to be approached by the CDR coordinator for information. However, as perinatal deaths were excluded in our project, approaching the gynecologist and midwife was not a standard procedure in our protocol. Therefore, essential information about the period during pregnancy and labor and after birth could not always be obtained. Third, information about the primary and secondary cause of death written down on the medical death certificate was always lacking and could not be provided to the CDR coordinator. It is not a custom to keep a copy of this certificate in the deceased child's medical file. Furthermore, it is not possible to request the individual medical death certificates from Statistics Netherlands. Next to the lack of essential information weaknesses were also found in the intake and analysis forms with regard to certain items that were not clear in terms of ranking or description.

The lack of sufficient financial resources hindered the CDR coordinator to invest sufficient time and thereby to fulfill her function optimally. The lack of time prohibited the CDR coordinator in keeping the inventory of child deaths in the pilot region up to date; this proved to be rather labor-intensive as professionals did not contact the CDR coordinator themselves to notify the death of a child.

Opportunities

Contextual factors that promoted the execution of tasks by the CDR team could be found in political, social, environmental and legal factors as shown in Table 2. As a result of the experiences in the pilot study, one of the CDR team members indicated that CDR might be an addition to the NODO-procedure in cases of an unexpected child death. Furthermore, CDR might have another status when there is more attention to it nationally and when its aim is expanding in terms of providing a source of information for professionals, parents and others who are interested.

It turned out that parents who gave their consent and professionals who are involved in a child's death endorsed the objective of CDR that promoted them to participate. In most cases, the pediatrician next to the preventive child health care professional contributed in approaching parents to inform them about CDR. After parental consent the professionals who are involved, such as the pediatrician, general practitioner, preventive child health care professional, forensic physician and attorney, have contributed in providing information to the CDR coordinator.

In the pilot study the collaboration with the National Cot Death Study Group turned out to be valuable with regard to offering support to parents. This Study Group also offered to provide information after parental consent in two cases of sudden infant death that were notified by professionals. Increasing the participation of parents and professionals and the awareness of CDR were other opportunities identified. Next to this, exchanging experiences with conducting reviews was also recognized as an opportunity. It turned out that the same learning curve was present during the implementation of the perinatal audits in the Netherlands to get familiar with the method. With regard to legal factors the participation of the Public Prosecutor and the pediatricians in the provision of information only in the presence of a signed consent form was also seen as an opportunity.

Threats

Contextual factors acting as a barrier to the execution of tasks by the CDR team could be identified in political, social, environmental and legal factors as presented in Table 2. The NODO-procedure was identified as a threat for the implementation of CDR in three ways. First, it proved that professionals became confused to which procedure they needed to act when a child had died. Second, the poor implementation of the NODO-procedure contributed to a negative attitude of pediatricians to participate in CDR. Third, in case a child's death was included in the NODO-procedure and parents gave their consent for CDR it was likely to be difficult to obtain information gathered in the NODO-procedure. This information should be gathered again in order to review the death.

The way a verdict of the Dutch Healthcare Authority could influence the participation of a CDR team member was also identified as a threat. Furthermore, the lack of statutory basis limited the benefits of CDR.

The fact that parents and some professionals, such as a pediatrician and preventive child health care physician or nurse, did not want to participate in CDR limited the number of cases to be reviewed. In five out of twelve cases that could not be reviewed, parents gave a reason for not participating. Some parents indicated that they did not want to talk about their deceased child or wanted to be left alone. Others, going through a difficult time, did not have the energy to focus on other things besides themselves. One parent did not want to further let examine the death of her child.

In one of the remaining seven cases the attending physician indicated that the cause of death was clear and the case would therefore not be suitable for CDR. In another case the preventive child health care professional perceived that CDR would not have an added value compared to the review conducted by the Dutch Cot Death Committee. In the same case communication problems between parents and the professional was reported as a possible reason for the professional not to participate in CDR. Another reason was the extra burden for parents when information gathered during the NODO-procedure would not be available for CDR, as indicated by a professional in another case.

Discussion

In this study we examined the strengths, weaknesses, opportunities and threats in the implementation of CDR in a pilot region in the Eastern part of the Netherlands. We used the SWOT framework to analyze the logs and transcribed records of the CDR meetings. The findings provided recommendations for future implementation of CDR not only in the Netherlands, but also in other countries that consider establishing CDR teams.

Strengths are identified in the contribution of the CDR coordinator, the expertise of the second chair and team members, the available materials and the multidisciplinary approach. Similarly to what has been concluded in other studies, sufficient experience and a multidisciplinary team that conducts reviews in an atmosphere of trust is needed to be effective [30, 172]. It is also known that committed team members are necessary to operate effectively as concluded in a study where teams just started to evolve in England [172]. Next to this, sufficient resources as funding of administrative staff and professionals' time are required to function optimally [172]. It turned out that the available financial resources were sufficient for the chair and CDR team members, which is another strength.

Three identified weaknesses were: 1. the insufficient time and financial resources for the CDR coordinator to fulfill her function optimally, 2. other engagements of the chair and team members which affected the continuity within the team and, and 3. the fact that the CDR team could not always analyze a child's death properly because essential information, e.g. primary and secondary causes of death, from professionals was lacking. Although the available materials were supportive for the CDR team to be able to review a child's death, during the pilot some of the forms were adjusted to improve their use.

The benefits of CDR that promoted parents and professionals to participate and might be a valuable addition to the analysis of unexplained death in minors in the so-called NODO-procedure, were identified as an opportunity. Other opportunities were identified in reducing the effort for parents and highlighting the positive experiences to increase the participation of parents and professionals.

Confusion among professionals caused by the NODO-procedure that had just been introduced, the lack of statutory basis and personal reasons parents and professionals could have for rejecting participating in CDR, proved to be important threats for the notification of child deaths to the CDR coordinator. Together with the time constraints the CDR coordinator was facing, eighteen of the estimated total of 38 child deaths were captured in the pilot region during the study period. The insufficient participation of professionals could also be explained by the fact that they might have some degree of anxiety to provide information.

Strengths and limitations of this study

One major strength of this study is the collaboration with (inter)national experts in the field of reviewing child deaths, which improved the quality of the review process. During the pilot study experiences were exchanged and uncertainties with regard to the CDR method were discussed in order to review a child's death in the same way as in the UK. This provided the opportunity to compare the implementation of the procedure between the pilot region in the Netherlands and the UK.

The SWOT framework proved to be a suitable tool for analysis of the implementation of CDR, because this framework provided us specific points for future implementation. As we considered political, environmental and legal factors not only on a local but also on a national level in this study, the results might be used in other parts of the Netherlands and in other countries that consider to implement CDR. However, the framework should be used in a larger and representative group of deceased children, to be able to conclude whether this CDR protocol is the most suitable protocol to conduct CDR's.

The fact that the chair and CDR team members were highly motivated to make recommendations in order to improve the CDR method and to make proposals in order to put CDR on a national agenda was another strength.

The researcher (SG) fulfilled the secretarial function of CDR coordinator, but did not participate in the assessment of the cases. To prevent the risk of bias, the researcher and a second coder (MB) analyzed the logs and transcribed records. The fact that the logs with data on characteristics of the deceased child and with actions set out by the CDR coordinator to get parental consent were filled out without the use of a

predetermined structure was another limitation. If we had collected these data in a more structural way, the logs could have provided us with more specific information about the deceased children and the reasons why professionals and parents did not participate in the study. Finally, the relatively small number of the logs and transcribed records has implications for the conclusions of this study, which need to be drawn carefully. As long as there is no legal obligation to review child deaths, there is the risk of selection bias. Furthermore, CDR is not generally accepted among professionals involved in child deaths. If there had been a higher level of acceptance, we could have included more cases and this study probably would have provided us more detailed and valuable information.

Conclusions

This study must be seen as a first introduction and exploration of application of the methodology of CDR in the Netherlands. The multidisciplinary approach and the endorsement of the CDR objectives by parents and professionals turned out to be the most important strengths and opportunities in the implementation of CDR. The insufficient time and finances, the existence of other Child Death Review processes and the lack of statutory basis are identified as important weaknesses and threats. These obstacles need to be taken away before large-scale implementation of CDR becomes possible. The most important precondition for implementation is the acceptance among professionals and the statutory basis of the CDR method. Acceptance among professionals can be enlarged by the incorporation in professional standards, preferably supported by the management of healthcare organizations. Next to this, it should be considered how to better integrate Child Death Review processes that have partly different and partly overlapping objectives and target groups. More research is needed to find out which Child Death Review process is feasible to use for certain child deaths.

APPENDIX 7.1. Form B - Agency Report Form^{†††}

This form to be returned to CDOP Manager at: [redacted] Email:

Address: [redacted] Fax: [redacted]

The information on these forms and the security for transferring it should be clarified and agreed with your local Caldicott guardian.

Please complete this form based on the information you have and return it quickly to the CDOP manager. If in doubt about what information to provide, please discuss with your manager.

Completing the form: The form is sent out to all agencies involved with a child and family. As such you are not expected to complete all of the form. **You are asked to complete only those sections and questions on which you hold information.** Some information is collected in tick box or yes/no format to allow collation and comparison of data, but in each section there is space for more narrative/qualitative information which will help the CDOP to more fully understand the nature of each child’s death. If you do not have information for any particular item, please either circle or tick NK (Not Known) or NA (Not Applicable) or leave the item blank. It is preferable to circle or tick not known as this indicates to the CDOP that you have considered the question but have no information.

The form consists of six sections, A to F, along with supplementary forms B2 – B12 to be completed where appropriate according to the type of death. **Please note: If the death concerns the death of a neonate please complete form B2 first.**

Purpose: Form B is designed to gather information about each child’s death. Its primary purpose is to enable the local CDOP to review all children’s deaths in their area in order to understand patterns and factors contributing to children’s deaths and ultimately to take steps to prevent future child deaths.

Confidentiality: The information requested on this form will be used for the purposes of child death review as outlined in chapter 7 of Working Together. All bereaved parents are informed of these processes. The nature of the information collected means it is likely that some of the information is personal/sensitive data and therefore CDOPs should be mindful of their obligations under the Data Protection Act (DPA) 1998 when processing that information. All cases will be anonymised prior to discussion by the CDOP. All information gathered will be stored securely and only anonymised data will be collated at a regional or national level.

This page may be removed for the purposes of anonymisation prior to discussion at the CDOP

A: Identifying and Reporting Details

Full name of child	[redacted]	Date of birth	[redacted] / [redacted] / [redacted]
NHS No.	[redacted]	Date of death	[redacted] / [redacted] / [redacted]
Gender	Male Female	[redacted]	
Address (including postcode if known)	[redacted]		

^{†††} Government HMs. Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children. 2013 Reference: DFE-00030-2013.

Agency Report Provided by

Agency	█	Name	█
Address	█		
Postcode	█		
Tel No	█	Email	█

B: Summary of Case and Circumstances leading to the death

This section provides information on the nature and manner of the child's death. Please complete any information which you hold on the case.

The 'Details of the Death' section is to be completed by the treating doctor involved with the child at the time of death – other professionals can complete this section if they have the information.

Details of the Death	
What is your understanding of the cause of death? (complete registered cause of death, if known, below)	<input type="text"/>
What was the mode of death?	<input type="checkbox"/> Planned palliative care <input type="checkbox"/> Withholding, withdrawal or limitation of life-sustaining treatment <input type="checkbox"/> Brainstem death <input type="checkbox"/> Failed Cardiopulmonary resuscitation <input type="checkbox"/> Witnessed event <input type="checkbox"/> Found dead <input type="checkbox"/> Not known
Expected Unexpected	<input type="checkbox"/> <input type="checkbox"/>
Has a medical certificate of the cause of death been issued?	Yes / No / Not Known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Was this death referred to the coroner?	Yes / No / Not Applicable / Not Known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Was a post-mortem examination carried out?	Yes / No / Not Applicable / Not Known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Date of PM if known <input type="text"/> / <input type="text"/> / <input type="text"/> Place of PM if known <input type="text"/>
Has an inquest been held?	Yes / No / Not Applicable / Not Yet/ Not Known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Date of Inquest if known <input type="text"/> / <input type="text"/> / <input type="text"/>

Registered cause of death if known (for children over 28 days)	la <input type="text"/> lb <input type="text"/> lc <input type="text"/> ll <input type="text"/>
Registered cause of death if known (for neonatal deaths)	(a) main diseases or conditions in infant <input type="text"/> (b) other diseases or conditions in infant <input type="text"/> (c) main maternal diseases or conditions affecting infant <input type="text"/> (d) other maternal diseases or conditions affecting infant <input type="text"/> (e) other relevant conditions <input type="text"/>

All - please complete

Where was the child at the time of the event or condition which led to the death?	<input type="checkbox"/> Acute Hospital	<input type="checkbox"/> Emergency Department <input type="checkbox"/> Paediatric Ward <input type="checkbox"/> Neonatal Unit <input type="checkbox"/> Paediatric Intensive Care Unit <input type="checkbox"/> Adult Intensive Care Unit <input type="checkbox"/> Other
	<input type="checkbox"/> Home of normal residence	
	<input type="checkbox"/> Other private residence	
	<input type="checkbox"/> Foster Home	
	<input type="checkbox"/> Residential Care	
	<input type="checkbox"/> Public place	

<input type="checkbox"/>	School
<input type="checkbox"/>	Hospice
<input type="checkbox"/>	Mental health inpatient unit
<input type="checkbox"/>	Abroad
<input type="checkbox"/>	Other (specify) <input type="text"/>
<input type="checkbox"/>	Not known

Where was the child when the death was confirmed?	<input type="checkbox"/>	Acute Hospital	<input type="checkbox"/>	Emergency Department
			<input type="checkbox"/>	Paediatric Ward
			<input type="checkbox"/>	Neonatal Unit
			<input type="checkbox"/>	Paediatric Intensive Care Unit
			<input type="checkbox"/>	Adult Intensive Care Unit
			<input type="checkbox"/>	Other
		<input type="checkbox"/>	Home of normal residence	
	<input type="checkbox"/>	Other private residence		
	<input type="checkbox"/>	Foster Home		
	<input type="checkbox"/>	Residential Care		
	<input type="checkbox"/>	Public place		
	<input type="checkbox"/>	School		
	<input type="checkbox"/>	Hospice		
	<input type="checkbox"/>	Mental health inpatient unit		
	<input type="checkbox"/>	Abroad		
	<input type="checkbox"/>	Other (specify) <input type="text"/>		
	<input type="checkbox"/>	Not known		

Were any of the following events known to have occurred?		
<input type="checkbox"/>	Neonatal Death	Complete B2 - Please complete form B2 before continuing to complete the rest of this form, as you may not be required to provide any further information through Form B.
<input type="checkbox"/>	Death of a child with a life limiting condition (to be completed by the lead clinician or designated member of the palliative care team)	Complete B3

<input type="checkbox"/>	Sudden unexpected death in infancy (to be completed by the SUDI paediatrician or designated deputy, and will almost always be completed at or immediately after the local case review meeting. In those rare instances in which there is no local case review meeting the SUDI paediatrician or designated deputy should complete this form at the conclusion of the investigation)	Complete B4
<input type="checkbox"/>	Road traffic accident/collision	Complete B5
<input type="checkbox"/>	Drowning	Complete B6
<input type="checkbox"/>	Fire/burns	Complete B7
<input type="checkbox"/>	Poisoning	Complete B8
<input type="checkbox"/>	Other non-intentional injury/accidents/trauma	Complete B9
<input type="checkbox"/>	Substance misuse	Complete B10
<input type="checkbox"/>	Apparent homicide	Complete B11
<input type="checkbox"/>	Apparent suicide	Complete B12

Circumstances of Death:

Please provide a narrative account of the circumstances leading to the death. This should include a chronology of significant events (e.g. contact with service; changes in family circumstances) in the background history, and details of any important issues identified.

Consider: Events leading to the death; Early family history; Pregnancy and birth; Infancy; Pre-school; School years; Adolescence

C: The Child

This section provides information about the child and any known conditions or factors intrinsic to the child that may have contributed to the death. Please complete any information which you hold on the case.

Birth weight (gm or oz / lb)	<input type="text"/> gms <input type="text"/> lbs <input type="text"/> oz	Gestational age at birth (completed weeks)	<input type="text"/>
Last known weight (gm or oz / lb) Date	<input type="text"/> gms <input type="text"/> lbs <input type="text"/> oz <input type="text"/> / <input type="text"/> / <input type="text"/>	Last known height (ft/in or cm) Date	<input type="text"/> cm <input type="text"/> ft <input type="text"/> in <input type="text"/> / <input type="text"/> / <input type="text"/>
Any known medical conditions at the time of death? If yes, please provide details below		Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Was the child fully immunised? <input type="text"/>		Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Date of last immunisation <input type="text"/> / <input type="text"/> / <input type="text"/>	
Any known developmental impairment or disability at the time of death? If yes, please provide details below <input type="text"/>		Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Any medication at the time of death? If yes, please provide details below <input type="text"/>		Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Education/Occupation	<input type="checkbox"/>	Not yet in education	<input type="text"/>
	<input type="checkbox"/>	Nursery	<input type="text"/>
	<input type="checkbox"/>	School	<input type="text"/>
	<input type="checkbox"/>	College	<input type="text"/>
	<input type="checkbox"/>	Not in education	<input type="text"/>
	<input type="checkbox"/>	Left education	<input type="checkbox"/> Employed
			<input type="checkbox"/> Unemployed
If employed, please provide occupation		<input type="text"/>	
Ethnic group	<input type="checkbox"/> White	<input type="checkbox"/> English/Welsh/Scottish/Northern Irish/ British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy or Irish Traveller <input type="checkbox"/> Any other White background (please specify) <input type="text"/>	
	<input type="checkbox"/> Mixed/ multiple ethnic groups	<input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other mixed/multiple ethnic background (please specify) <input type="text"/>	

	<input type="checkbox"/> Asian or Asian British	<input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background (please specify) <input type="text"/>	
	<input type="checkbox"/> Black/African/Caribbean/Black British	<input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black/African/Caribbean background (please specify) <input type="text"/>	
	<input type="checkbox"/> Other ethnic group	<input type="checkbox"/> Arab <input type="checkbox"/> Any other ethnic group (please specify) <input type="text"/>	
	<input type="checkbox"/> Not known/ not stated		
Religion (please state)	<input type="text"/>		

Factors in the child:
 Please provide a narrative description of any relevant factors within the child that have not already been covered. Include any known health needs; factors influencing health; growth parameters development/educational issues; behavioural issues; social relationships; identity and independence; any identified factors in the child that may have contributed to the death. Include strengths, as well as difficulties.

D: Family and Environment

This section provides details of the child's family and close environment. Please complete with any information known to you.

Please circle or tick your responses

	Age/DoB	Gender	Relationship to child and/or family	Occupation	Living in primary household?***
Mother	<input type="text"/>	F	Mother	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Father	<input type="text"/>	M	Father	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Other significant others (e.g. Mother's partner; significant carer. Please number and complete any information known; further adults can be added below)					
1 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
2 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Siblings (Please number and complete any information known; further siblings can be added below, please include step and half siblings)					
1 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
2 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
6 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
7 <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Was the child/family an asylum seeker	Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
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Further family information

(In relation to the primary household or other household where the child spends a significant amount of time)

Please circle or tick your responses

*** If the child is living in more than one household, for example where the parents have separated, the primary household is where the child spends most of his/her time; please provide any relevant details in the narrative section.

	Mother	Father	Other adult 1	Other adult 2
Smoker	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Any Known:				
Disability, including learning disability?	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Physical health issues?	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Mental health issues?	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Substance misuse?	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Alcohol misuse?	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Known to police	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Y / N / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Are mother and father related to each other (excluding marriage)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Please provide details. <input type="text"/>
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Any known domestic violence in the household? (please provide details below)
Yes / No / Not known <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

<p>Factors in the family and environment:</p> <p>Please provide a description of any relevant factors known to you that have not been covered elsewhere.</p> <p>Consider: family structure and functioning; wider family relationships; housing; employment and income; social integration and support; community resources. Include strengths and difficulties</p>

E: Parenting Capacity

The purpose of this section is to understand factors in relation to the care of the child that may have been of relevance in any way to the child's death, and also factors that may have contributed to support and nurture of the child. Please complete any information known to you.

Where was the child living at the time of their death or the event leading to their death?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Parental home Other relatives Foster carers Private fostering Residential unit Long stay hospital Hospice Other
Who was directly looking after the child at the time of their death or the event that led to their death? (please tick all that apply)	<input type="checkbox"/> <input type="checkbox"/>	Mother Father
	<input type="checkbox"/>	Other adults (please list and give adults relationships to the child) <input type="text"/>
	<input type="checkbox"/>	Child/young person (please list and give age and relationships to the child) <input type="text"/>
	<input type="checkbox"/> <input type="checkbox"/>	Health care staff Others (please list below) <input type="text"/>

Was the child subject to a child protection plan?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	At the time of death Previously Not at all
Category of most recent child protection plan:	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Physical abuse Neglect Emotional abuse Sexual abuse Not known
Was the child subject to any statutory orders?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	At the time of death Previously Not at all
Category of most recent statutory order:	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Police Powers of Protection Emergency Protection Order Interim Care Order Care Order Supervision Order Residence Order Section 20 (Children Act 1989) Antisocial behaviour order Other court order, please specify: <input type="text"/>
Had the child been assessed as a child in need under section 17 of the Children Act 1989?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	At the time of death Previously Not at all

Were any siblings subject to a child protection plan?	At the time of death Previously Not at all
Were any siblings subject to any statutory orders?	At the time of death Previously Not at all

Factors in the parenting capacity:

Provide a narrative description of the parenting capacity with any relevant factors known to you and not already covered elsewhere.

Consider issues around provision of basic care; health care (including antenatal care where relevant); safety; emotional warmth; stimulation; guidance and boundaries; stability. Include strengths as well as difficulties.



F: Service Provision

The purpose of this section is to obtain a profile of the services being offered to the child and family; the effectiveness of those services in supporting the child and family; and to identify any unmet needs or gaps in services. Please complete any information you are able to on your agency.

Details of agency involvement

Please indicate whether any of the services listed were involved with the child, or in neonatal deaths, with the mother. Where any service was involved, please provide details in the narrative section below.

Please circle or tick your responses

Agency / professional	Involved at time of death or in relation to the final illness ⁵⁵⁵	Involved previously
Primary Health Care	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Secondary / Tertiary Hospital Services	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Secondary / Tertiary Community Health Services	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Hospice Services	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Child & Adolescent Mental Health	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Police	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Local Authority Children's Services	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Education	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Connexions	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Probation	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■
Other (please specify) ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■	Y / N / NK / NA ■ ■ ■ ■

⁵⁵⁵ Include all those providing services at the time of death or in relation to the final illness, even if not present at the time of the death; e.g. child on school roll; planned out patient follow up; active social work case; palliative care.

If no professionals involved at the time of death, what was the last known contact of a professional from your agency?	Professional <input type="text"/> Date of last known contact <input type="text"/> / <input type="text"/> / <input type="text"/> Nature of contact <input type="text"/> <input type="checkbox"/> No known contact from this agency <input type="checkbox"/> Not known
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Were there any identified unmet needs / gaps in services? (if yes, please provide details below)	Y / N / NK / NA <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Were there any identified difficulties in family engagement with services? (if yes, please provide details below)	Y / N / NK / NA <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Factors in relation to service provision

Please complete any information known to you in relation to service provision that has not been covered elsewhere.

Consider any identified services both required and provided; the nature and timing of any services provided; any gaps between child's or family member's needs and service provision; any issues in relation to service provision or uptake, positive/negative in relation to bereavement care.

Was there a formal Critical Incident investigation – if yes, please state which specific agency	Y / N / NK / NA <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
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Any other internal agency investigation (please specify)

Is this child death the subject of a serious case review	Y / N / NK / NA <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
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Issues for discussion

Include any action or learning you consider should be taken forward as a result of the child's death; issues that require broader multi-agency discussion

APPENDIX 7.2. Analysis Proforma ****

This proforma is used by the Child Death Overview Panel (CDOP) to:

- *evaluate information about the child’s death;*
- *identify lessons to be learnt; and*
- *to inform an understanding of all child deaths at a national level.*

Where prior to the CDOP meeting, a local case discussion is held, the local team may complete a draft Form C to be forwarded to the CDOP to inform their deliberations.

Agencies represented at the meeting:	
Primary Health Care	Yes No
Paediatrics	Yes No
Hospital Services	Yes No
Mental Health Services	Yes No
Ambulance Services	Yes No
Police	Yes No
Children’s Social Care Services	Yes No
Schools	Yes No
Other (Specify)	

List of documents available for discussion

Cause of death as presently understood

Case Summary
A few paragraphs at most: a summary of the background and a factual description of events leading up to death. This should be as short as possible.

**** Government HMs. Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children. 2013 Reference: DFE-00030-2013.

The CDOP should analyse any relevant environmental, extrinsic, medical or personal factors that may have contributed to the child's death under the following headings.

For each of the four domains below, determine different levels of influence (0-3) for any identified factors:

0 – Information not available

1 – No factors identified or factors identified but are unlikely to have contributed to the death

2 – Factors identified that may have contributed to vulnerability, ill-health or death

3 – Factors identified that provide a complete and sufficient explanation for the death

This information should inform the learning of lessons at a local level.

Domain - Child's needs		
Factors intrinsic to the child Include any known health needs; factors influencing health; development/ educational issues; behavioural issues; social relationships; identity and independence; abuse of drugs or alcohol; note strengths and difficulties		
Please enter relevant information		
Please tick the following boxes if these factors were present or may have contributed to the death		Relevance (0-3)
Condition:		
Acute / Sudden onset illness Specify:	Yes / No / NK	
Chronic long term illness		
Asthma	Yes / No / NK	
Epilepsy	Yes / No / NK	
Diabetes	Yes / No / NK	
Other chronic illness Specify:	Yes / No / NK	
Disability or impairment		
Learning disabilities Specify:	Yes / No / NK	
Motor impairment Specify:	Yes / No / NK	
Sensory impairment Specify:	Yes / No / NK	
Other disability or impairment Specify:	Yes / No / NK	
Emotional / behavioural / mental health condition in the child Specify:	Yes / No / NK	
Allergies Specify:	Yes / No / NK	
Alcohol/substance misuse by the child Specify:	Yes / No / NK	

Domain - family and environment		
Factors in the family and environment Include family structure and functioning; including parental abuse of drugs or alcohol; wider family relationships; housing; employment and income; social integration and support; community resources; note strengths and difficulties		
Please enter relevant information		
Please tick the following boxes if these factors were present or may have contributed to the death		Relevance (0-3)
Condition:		
Emotional/behavioural/mental health condition in a parent or carer Specify:	Yes / No / NK	
Alcohol/substance misuse by a parent/carer Specify:	Yes / No / NK	
Smoking by the parent/carer in household Specify:	Yes / No / NK	
Smoking by the mother during pregnancy Specify:	Yes / No / NK	
Housing Specify:	Yes / No / NK	
Domestic violence Specify:	Yes / No / NK	
Co-sleeping Specify:	Yes / No / NK	
Bullying Specify:	Yes / No / NK	
Gang/knife crime Specify:	Yes / No / NK	
Pets/animal assault Specify:	Yes / No / NK	
Consanguinity Specify:	Yes / No / NK	

Domain - parenting capacity		
Factors in the parenting capacity Include issues around provision of basic care; health care (including antenatal care where relevant); safety; emotional warmth; stimulation; guidance and boundaries; stability; note strengths and difficulties		
Please enter relevant information		
Please tick the following boxes if these factors were present or may have contributed to the death		Relevance (0-3)
Condition:		
Poor parenting/supervision Specify:	Yes / No / NK	
Child abuse/neglect Specify:	Yes / No / NK	

Domain - service provision		
Factors in relation to service provision Include any identified services (either required or provided); any gaps between child's or family member's needs and service provision; any issues in relation to service provision or uptake		
Please enter relevant information		
Please tick the following boxes if these factors were present or may have contributed to the death		Relevance (0-3)
Condition:		
Access to health care Specify:	Yes / No / NK	
Prior medical intervention Specify:	Yes / No / NK	
Prior surgical intervention Specify:	Yes / No / NK	

The CDOP should categorise the likely/cause of death using the following schema.

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

Category	Name & description of category	Tick box below
1	Deliberately inflicted injury, abuse or neglect This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.	
2	Suicide or deliberate self-inflicted harm This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	
3	Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect. (category 1).	
4	Malignancy Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	
5	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	
6	Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.	
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	
8	Perinatal/neonatal event Death ultimately related to perinatal events, eg sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).	

9	<p>Infection Any primary infection (ie, not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.</p>	
10	<p>Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).</p>	

The panel should categorise the 'preventability' of the death – tick one box.

Preventable child deaths are defined in paragraphs 7.23 and 7.24 of *Working Together to Safeguard Children*

Modifiable factors identified	The panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths	
No Modifiable factors identified	The panel have not identified any potentially modifiable factors in relation to this death	
	Inadequate information upon which to make a judgement. <i>NB this category should be used very rarely indeed.</i>	

Issues identified in the review
List the issues identified by the review group. This list may include the absence of certain key persons from the discussion or the lack of key documents.

Learning Points
List the learning points that emerge. These may well overlap with the issues and with recommendations.

Recommendations
List any recommendations, even if already picked up as learning points or 'issues'
Specific agency
LSCB
Regional
National

Follow up plans for the family, where relevant

Possible Actions		
Should this death be referred to another agency or Authority (e.g. Police, Coroner, Health and Safety Executive, Serious Case Review panel) for further investigation or enquiry? If so, please state		
<input type="checkbox"/>	Yes	<input type="checkbox"/> No
<input type="checkbox"/>	Already done	
If yes please specify;		

CHAPTER 8

How to prevent future
child deaths and optimize
family support in the
Netherlands?

Introduction

As nations have agreed to continue their efforts to end avoidable child deaths [3], they need to know which preventive measures could be taken in order to achieve this goal. Understanding of the nature and patterns of child death and of the factors that have contributed to death is essential in order to direct preventive strategies [187, 188]. By identifying avoidable factors that have contributed to death recommendations for possible interventions can be made [5, 30, 31]. In addition to this, appropriate family support is essential in order to improve relatives' coping with bereavement [5, 14].

In the Netherlands concerted efforts have been made with regard to the identification of causes of child deaths and circumstantial factors that have contributed to certain child deaths in the past decades. Improvements in the questions on and processing of the medical and death certificates of the cause of death by Statistics Netherlands, that are in line with the recommendations of the World Health Organization (WHO) since 1950 [12], have resulted in a better quality of cause-specific deaths statistics. Analysis of child deaths occurs in cases of Sudden and Unexpected Deaths in Infants (SUDI) by the National Cot Death Study Group [22], in perinatal deaths by obstetric care professionals [20] and in transport-related child deaths by the Institute for Road Safety Research [23]. In case of unexplained death in minors the NODOK-procedure (in Dutch Nader Onderzoek naar de DoodsOorzaak van Kinderen) has been implemented August 1st 2016 [27]. Although a decline is observed in child deaths in the Netherlands [7], there are still avoidable child deaths.

The aim of this thesis was to investigate how to prevent future child deaths and optimize family support in the Netherlands. In order to achieve this aim trends and patterns of child deaths in the Netherlands were described first. Then, the way Dutch professionals respond to a child's death, including the support they provide to parents of deceased children, was explored. As studies have shown that Child Death Review (CDR) has the potential to identify avoidable factors that contributed to death [5, 30, 33, 168] in order to prevent future child deaths [5, 31], and pays attention to the needs of bereaved parents [5], CDR might contribute to preventing future child deaths and improving relatives' coping with bereavement in the Netherlands. Therefore, an implementation study on the systematic analysis of child deaths according to the CDR method was conducted.

This chapter first describes the main findings of the study followed by a general discussion. Next, strengths and weaknesses related to the study are discussed. After a general conclusion recommendations for further research and policy recommendations are provided.

Main findings

Part A. Epidemiology

For targeted preventive measures it is necessary to understand the nature and patterns of child mortality and common categories of child deaths in the Netherlands. To give directions for future prevention in the Netherlands, an overview of child mortality from natural causes from 1950-2014 was given in **chapter 2** and of child mortality from external causes from 1969-2011 in **chapter 3**. In both chapters data was used from the electronic database of Statistics Netherlands.

In **chapter 2** the following research questions were answered: a. Which trends can be observed in child mortality due to natural causes in children aged 0 up to and including 19 in the Netherlands in the past decades? and b. What has contributed to these trends? The analyzed data showed that most deceased children died before they reached their first birthday, mainly due to certain conditions originating in the perinatal period and congenital malformations and chromosomal abnormalities. These categories of child deaths together with death due to neoplasms were the highest incidence groups of natural child deaths in 2014. Although in 1950 children frequently died from infectious diseases and diseases of the respiratory and digestive system, these categories of natural causes of child deaths were rare in 2014. The incidence of Sudden Infant Death Syndrome (SIDS) increased from 1973 until 1987, after which a decrease was observed until 6.4/100,000 children aged 0 year in 2014. The increased standard of living and the improvements in sanitation, hygiene, housing and access to health care, contributed to a decrease in several causes of child deaths. In addition to this, improvements in diagnostics, medical treatment and surgery, and the introduction of preventive measures, such as mass vaccination [55] and informing parents about the risk factors of certain diseases or conditions, like SIDS, contributed to the decline in child deaths from natural causes in the Netherlands since 1950.

Chapter 3 described changes in the pattern of external causes of child mortality in the Netherlands in groups classified by age and sex in deceased Dutch children aged 0-19 years from 1969 to 2011. In this chapter possible explanations for the low Dutch child mortality rates from external causes were also given. Mortality due to external causes declined in the Netherlands, particularly due to decreases in road traffic accidents and other external causes of accidental injury in all age groups. The efforts of the Dutch Government, the Consumer Safety Institute, and the Institute for Road Safety Research, contributed to a decline in unintentional injuries. Death due to intentional self-harm increased significantly, and assault and events of undetermined intent remained constant. In other high-income countries the same trends in external causes were observed [91, 92, 95].

Part B. Responding to child deaths

In the Netherlands professionals from several organizations are involved when a child dies and respond to the child's death according to protocols, guidelines or other working agreements. **Chapter 4** described the results of a study that is conducted in order to determine to what extent the existing procedures of organizations involved in the child (health) care in the Netherlands cover the four objectives of CDR in responding to a child's death. Protocols, guidelines or other working agreements and interview reports that describe the responsibilities and activities in case of a child's death of participating organizations with an operative range in the Eastern part of the Netherlands and some directed at a national level, were analyzed. From the document analysis it was concluded that the procedures of Dutch organizations - when combined - covered the largest part of the CDR objectives. However, the procedures focused on a particular part of child mortality only, namely perinatal deaths, SUDI and fatal child abuse cases. Therefore, a comprehensive overview of avoidable factors that give directions for prevention of child deaths is lacking. In addition to this, it was concluded that support of the family should be more systematically included in the procedures of organizations. Of what is known, the Preventive Child Health care uses a guideline for care after the death of a child and offers a systematic program of care when the family receives another child, namely Care of Next Infants (CONI) [189].

Chapter 5 described a study in which four asynchronous online focus groups with parents of a deceased child under the age of two were conducted and a questionnaire

was used to answer the following research questions: a. What bereavement care did parents in the Netherlands receive after the death of their child? and b. Did this care meet their needs? In this study 64 parents living throughout the country were recruited through the chairs of three parents' associations. Fifty-seven of them completed a questionnaire on background characteristics. Most parents reported about the emotional support they received after the death of their child, particularly from family, primary care professionals and their social network. Instrumental and informational support was mainly provided by secondary care professionals, i.e. paediatrician, gynaecologist, other medical specialist, nurse, personnel of the Accident and Emergency department. Although increasing attention has been paid to supporting families after the death of a child, still one-fifth to slightly more than half of the parents in this study lacked some sort of support or experienced support that was not in line with their needs or wishes. It should be taken into account that the children of the parents in this study died between 1970 and 2012 and that there is nowadays a greater understanding of the loss and pain parents experience after the death of their child, than years ago. Parents in this study emphasised that they would like to be approached with empathy and be acknowledged in their bereavement. Next to this, support initiated by professionals should always include listening to parents and asking them at key moments after their child's death whether they need (extra) support and what kind of support they would like to receive.

Part C. Implementation of Child Death Review

In the Netherlands an overview of avoidable factors that give directions for prevention is available for certain categories of child deaths, like SUDI, perinatal deaths and transport-related child deaths. It might be desirable to extent the scope of systematic analysis to other categories of child deaths in order to prevent future deaths. We therefore explored whether it is possible to analyze child deaths systematically in the Netherlands according to the CDR method.

In order to design a strategy for a pilot implementation the identification of determinants for successful implementation of an innovation in healthcare is considered essential, as concluded by other researchers [37, 169, 190]. In **chapter 6** a study was described in which four focus groups were conducted with important stakeholders: three with professionals who are involved in children's deaths and one with parents who have lost a child under the age of two. Focus groups were

chosen as the research method, because the interaction within a focus group enables to explore the views and experiences of people thoroughly [174, 175]. The following research questions were answered: a. What are the stakeholders' opinions regarding the facilitating and impeding factors in the implementation of CDR in the Netherlands; and b. Which recommendations do stakeholders give for the implementation of CDR in the Netherlands? To identify the facilitating and impeding factors associated with the innovation, user, organization and social-political context the Measurement Instrument for Determinants of Innovations (MIDI), developed by Fleuren et al., was used [37, 38]. The MIDI proved to be a useful instrument for structuring the determinants of implementation. Determinants associated with the 'client/patient' were defined under the user as mentioned in the MIDI [38]. According to the results of the focus groups, the focus within a strategy for implementation of CDR in the Netherlands should be particularly on the determinants associated with the user (emphasizing the personal benefits for professionals and parents, the use of a consent form and a format to gather information, and analysing anonymised data), organization (informing managers about CDR) and social-political context (adapting CDR to the Dutch regulations and legislation and to the procedures of the Public Prosecutor).

In chapter 6 determinants on which a strategy for implementation of CDR should focus, were identified. Next, a study on a pilot implementation was conducted in order to determine to what extent the chosen implementation strategy was effective. Before the pilot study of CDR started in two Eastern provinces in the Netherlands in January 2011, a strategy was determined based on the results of chapter 6, that included the development of necessary forms and a CDR protocol [184]. In this protocol the CDR procedure was described and adapted to the Dutch regulations and legislation. Furthermore, the managers of organizations involved in child (health) care located in the pilot region were informed about CDR and the pilot study. Eighteen deceased children were reported in the pilot study. In six out of eighteen deceased children, parents gave their consent for reviewing the death of their child. Hence these six cases were included in the study.

To determine to what extent the chosen implementation strategy was effective, the following questions were answered in the pilot study: a. Which strengths, weaknesses, opportunities and threats (SWOT) in the pilot implementation of CDR can be identified? and b. Which recommendations can be made for future development of the CDR method in the Netherlands? The results of this study were described in

chapter 7. The SWOT-framework proved to be a suitable tool for identifying political, environmental and legal factors not only on a local but also on a national level. The implementation study provided useful suggestions for implementation of CDR in the Netherlands, but at the same time also arguments against introduction of this method. The multidisciplinary approach and the endorsement of the CDR objectives by parents and professionals turned out to be the most important strengths and opportunities in the implementation of CDR. The insufficient time and finances, the lack of coordination between other Child Death Review processes and the lack of statutory basis were identified as important weaknesses and threats. Sufficient resources for CDR panels to function effectively and the overlap of other review processes were important items that emerged after analyzing the implementation of review processes in England [172]. The barriers found in the pilot study need to be taken away before large scale implementation of CDR can take place.

General discussion

To prevent future child deaths in the Netherlands it would be desirable to analyze the causes and circumstances surrounding death systematically in all child deaths, to aggregate these data on a regional or national level and to translate the recommendations in preventive interventions. The primary causes of death completed on the medical and death certificates on the cause of death that are received and processed by Statistics Netherlands, form the basis for targeted prevention. In addition to the primary causes of death it is also important to know the secondary causes and other factors that have contributed to death to understand the death of a child completely.

Future child deaths can be prevented when stakeholders take responsibility for examining the death of children in a comprehensive way in order to improve the survival of children. Furthermore, family support needs to be part of the standard procedures of organizations involved in the (health) care for children and their families and be consistent with the needs and the wishes of the parents. It appears that parents value ongoing support after the death of their child.

Dutch health care professionals and health policy makers are facing the challenge to organize a system of analyzing and collecting mortality data for child deaths and

to optimize bereavement care. Of the 992 children aged 0-19 years that died in the Netherlands in 2015, 295 die in the first week and 125 die from the second until the fourth week after birth [7]. As those child deaths are analyzed in the perinatal audits, SUDI cases are reviewed by the National Cot Death Study Group, unexplained death in minors are included in the NODOK-procedure and the transport-related deaths by the Institute for Road Safety Research, these review processes should be taken into account in designing a structure for analyzing child deaths.

Because analyzing all child deaths appears to be labor-intensive [191] and expensive, one might consider to maintain a kind of stratification with a difference in intensity in analyzing child deaths, starting with for example the categories of child deaths in which the greatest potential for prevention is to be expected or where parents benefit the most. These categories might be deaths due to congenital anomalies, that impacts other children in the family or parents in their decision to have a next child, and sudden and unexpected deaths in children, like SUDI, suicide or unintentional injuries. In order to achieve this, professionals and politicians need to create and coordinate a policy which states the categories of child deaths that will be analyzed, who is responsible for analyzing these categories, the purpose and frequency of analyzing child deaths and the method of collecting data for epidemiological research. The aggregated data then result in an overview of identified factors that have contributed to death and recommendations that can be translated in preventive interventions.

In the design and implementation of strategies to prevent future child deaths it is important to monitor child deaths and associated risk factors and to have knowledge of efficacy, cost, and acceptability of any preventive intervention [188, 192]. For example, in the USA strategies to reduce preterm birth and complications, including mortality, are developed. It is stated that these strategies can only be implemented and evaluated effectively, when preterm births, associated risk factors and outcomes are monitored [192]. An example of effective implementation of an intervention is seen in New Zealand, where an addition of the Safe Sleep program has been implemented in 2009 to address the stalled rate of change in SUDI mortality for Maori infants. This program consists of five intervention strands to promote safe infant sleep, including the supply of a portable Infant Safe Sleep Device, that is called the Wahakure and Pepi-pod, on a cost-recovery basis [193]. It turns out that the post-perinatal mortality has decreased, particularly in Maori

and in regions with the best supply of the Infant Safe Sleep Device [193]. As in this thesis the cost-effectiveness has not been investigated, another challenge for Dutch health care professionals and health policy makers will be the translation of the results of the reviews in the implementation of interventions in which cost-effectiveness is taken into account.

Strengths and weaknesses of the study

This study provides a starting point for Dutch health care policy makers and professionals to direct their efforts to prevent future child deaths and improve bereavement care. One of the strengths of this study is that it not only shows on which causes of child deaths Dutch politics and health care professionals could focus, like congenital abnormalities, cancer and suicide, but it considers also another point of view in responding to child deaths in terms of systematic analysis and interagency working in order to identify avoidable factors and optimize family support.

A second strength of the study is the involvement of parents of a deceased child as important stakeholders and the study of parents' experiences with support after the death of their child. These studies provide health care professionals insights in what parents consider important in the procedure after their child's death, including bereavement care.

However, there are two methodological limitations. First of all, in the presentation of the patterns of child death in the Netherlands the results are based on the primary causes of child deaths recorded by Statistics Netherlands as the official registrar in the Netherlands. The quality of these data largely determines the validity of the trends described. As the causes of death were coded manually up until 2012 by the medical coders of Statistics Netherlands intercoder differences might be present resulting in misclassification which could hinder the interpretation of trends in time. It is found that misclassification is low for major causes of deaths, such as cancers, but is high for chronic diseases [10]. Misclassification can be reduced by using software for coding and selecting the cause of death [10]. Since 2013 causes of death are partly coded manually by Statistics Netherlands [44]. It should be noted that the absence of the secondary causes of deaths in the Dutch causes of death statistics creates a gap in understanding the death of a child completely. Information

on the secondary causes of death might identify additional risk factors that can be translated in suggestions for prevention.

Second, in order to examine the response of Dutch health care professionals to a child's death, data were only collected on procedures i.e. written in protocols, guidelines or other working agreements. This does not give information on whether and to what extent the organizations actually act in case of a child's death. Professionals within these organizations may provide other care than described in those documents. In addition to this, the extent to which organizations have a multidisciplinary case discussion within their own organization after a child has died, is not explored either. It might be possible that organizations focus on a broader spectrum of child deaths in terms of identifying avoidable factors that give direction to prevention than is concluded in this study.

Despite the fact that this study has limitations in terms of the quality and amount of data, this study provides health care professionals and health policy makers insight not only into the causes of death prevention could focus but also into how future child deaths can be prevented and family support can be optimized in the Netherlands.

General conclusion

Even though child mortality in the Netherlands has declined in the past decades, there are still child deaths that are avoidable. In the Netherlands analysis of child deaths occurs in perinatal deaths, cases of SUDI and transport-related deaths. Unexplained deaths in minors are reviewed in the NODOK-procedure which is implemented since August 2016. As these systematic analyses have resulted in the identification of factors that have contributed to death, conducting reviews might be extended to other categories of child deaths in order to prevent future child deaths in the Netherlands. Child Death Review (CDR) is a method in which each child death is systematically analysed by a multidisciplinary team in order to identify avoidable factors in four domains (i.e. factors intrinsic to the child, factors in the family and environment, parenting capacity, and service provision) and give direction for prevention. In this study it is explored whether CDR could contribute to prevent future child deaths in the Netherlands. Despite the benefits related to the CDR method, the disadvantages found argue against the implementation of CDR

in all child deaths in the Netherlands. In order to set up a system to prevent future child deaths the existing review structures need to be taken into account and should remain unaffected. Regarding family support and data collection the National Cot Death Study Group supports parents and collects detailed epidemiological information, which has proved to be effective since SIDS reduced from almost 200 cases a year to 10-15 cases a year. Perined also collects data on perinatal deaths on a regional and national level in order to implement preventive interventions in perinatal care.

A reduction of avoidable child deaths is achievable when systematic analysis of child deaths has become a standard procedure in which a stratification with a difference in intensity is applied regarding categories of child deaths. Future research is necessary in order to examine which child death review process is feasible to use for certain child deaths and how to involve parents in the review process.

Recommendations

The results described in this thesis provide recommendations for further research and policy recommendations, which are mentioned below.

Recommendations for further research

As analysis of child deaths occurs already in perinatal deaths, SUDI cases and transport-related deaths and as unexplained deaths in minors started to be reviewed in the NODOK-procedure since August 2016, further research into a comprehensive policy directed on all child deaths in the Netherlands is recommended. This policy should preferably include a stratification with a difference in intensity in analyzing categories of child deaths and indicate which Child Death Review process can be used for certain child deaths. In order to review certain child deaths according to the CDR method it is recommended to examine whether the CDR protocol and forms developed in the pilot study are sufficiently useful in practice.

It is known that only in England families, although not attending the CDR meetings, are informed and involved in the CDR process [30, 172]. In the Netherlands the extent to which parents are involved in the review process depends on the category of

child deaths. In SUDI cases home visits always precede the review process, because detailed information about for example sleeping position, place of sleeping, how the baby is found and use of bedding is gathered during the interview with the parents by the pediatrician. They give consent to gather medical information from the forensic physician, general practitioner and pediatrician, if involved. Sometimes specific support is offered or asked for, such as social worker or psychologist or specialist who can offer Eye Movement Desensitization and Reprocessing. An interview with the parents is also included in the NODOK-procedure and the Child Suicide Review, which is implemented in a Dutch pilot region [194]. Further research into the involvement of parents and other family members of the deceased child in the review processes in the Netherlands is therefore recommended.

Policy recommendations

In order to prevent future child deaths in the Netherlands, first of all it is recommended that professionals and the government create a coordinated policy, that states the categories of child deaths that will be analyzed according to a stratification process. This policy should also include who is responsible for analyzing which categories of child deaths, the purpose and frequency of analyzing these deaths, and the method of data collection.

Second, professional associations should incorporate the multidisciplinary way of analyzing child deaths systematically in professional standards, preferably supported by the management of healthcare organizations. Third, as legislation can be an important tool in establishing, supporting and standardizing child death review processes [30, 31], it is recommended to embed child death review processes in Dutch legislation. Finally, it is important to have protocols in which the procedure of systematic analysis, the composition of a multidisciplinary team and the prerequisites for analyzing a child's death are described. For conducting a review it is necessary to have a multidisciplinary team with a core membership in which team members are committed to come together and are trained for reviewing child deaths. Next to this, a confidential atmosphere is necessary, which can be created by the use of an independent chair and by signing a confidential agreement.

The suggestions provided in this study can support health care professionals and health policy makers in their effort to prevent future child deaths and improve family

support in the Netherlands. Every child's death appeals society to investigate his/her death thoroughly in order to understand why this child has died at that moment and to help parents in coping with the loss.

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SUMMARY

Samenvatting

Summary

Background and aim of the thesis

Worldwide 6.1 million live-born children under the age of five died from natural and external causes in 2014. According to the Convention on the Rights of the Child appropriate measures should be taken by State Parties to ensure the survival and development of the child to a maximum extent and to diminish infant and child mortality. As countries have tried to reduce the global under-five child mortality rate with two-thirds between 1990 and 2015, which is defined as the Millennium Development Goal 4 by the World Health Organization, only 62 of the 195 countries have achieved this degree of reduction. As a consequence world leaders have renewed their goals in which every nation is expected to make every effort to further reduce preventable child deaths.

In the Netherlands child mortality has declined in the past centuries due to improvements in social circumstances, sanitation, housing, hygiene and health care, and lower birth rates. Although 1130 Dutch children aged 0 up to and including 19 years (mortality rate 29.4 per 100,000 children) died in 2014, there are still child deaths that are avoidable. Understanding the nature and patterns of child mortality and the factors that have contributed to death is essential to direct preventive strategies.

The aim of this thesis is to investigate how to prevent future child deaths and optimize family support in the Netherlands. In order to answer these questions the patterns of child mortality in the Netherlands are described in part A, 'Epidemiology'. Then, the way Dutch professionals respond to a child's death, including the support they provide to parents of deceased children, is explored in part B, 'Responding to child deaths'. As Child Death Review (CDR) has the potential to identify avoidable factors that contributed to death and pays attention to the needs of bereaved parents, CDR might contribute to prevent future child deaths and to improve relatives' coping with bereavement in the Netherlands. Therefore, the possibility of analyzing child deaths systematically in the Netherlands according to the CDR method is examined in part C, 'Implementation of Child Death Review'.

The results of this study might support health care professionals and health policy makers in their efforts to prevent future child deaths and optimize family support in the Netherlands.

Part A. Epidemiology

Chapter 2 describes the pattern of natural causes of child deaths in the Netherlands from 1950 to 2014. Mortality data due to natural causes from all deceased Dutch children aged 0-19 for the period 1950-2014 were analyzed using the electronic database of Statistics Netherlands. Age standardization was applied using the European standard population of 2013 to control for different age distributions among populations over time. Infectious diseases and diseases of the respiratory and digestive system occurred regularly in the causes of death statistics of 1950, but are rare natural causes of child deaths in 2014. The incidence of Sudden Infant Death Syndrome (SIDS) has increased from 1973 until 1987, after which a decrease is observed until a very low incidence in 2014. Certain conditions originating in the perinatal period, congenital malformations, chromosomal abnormalities and neoplasms are the highest incidence groups of natural child deaths in 2014.

In chapter 3 changes in the pattern of external causes of child mortality in the Netherlands are described in groups classified by age and sex in deceased Dutch children aged 0-19 from 1969 to 2011 using the electronic database of Statistics Netherlands. Mortality due to external causes has declined in the Netherlands, particularly due to decreases in road traffic accidents and other external causes of accidental injury in all age groups. The efforts of the Dutch Government, the Consumer Safety Institute, and the Institute for Road Safety Research, have contributed to a decline in unintentional injuries. Death due to intentional self-harm increased significantly, and assault and events of undetermined intent remained constant.

Part B. Responding to child deaths

Chapter 4 describes the results of a study that is conducted in order to determine to what extent the existing procedures of organizations involved in the (health) care for children located in the Eastern part of the Netherlands and on a national level cover the four CDR objectives in responding to a child's death. Protocols,

guidelines or other working agreements and interview reports that describe the responsibilities and activities in case of a child's death of participating organizations were analyzed. It is concluded that the procedures of Dutch organizations - when combined - cover the largest part of the CDR objectives. However, the procedures focus on a particular part of child mortality only, namely perinatal deaths, Sudden and Unexpected Death in Infants (SUDI) and fatal child abuse cases. A complete overview of avoidable factors that give directions for prevention of child deaths is therefore lacking. In addition to this it is concluded that support of the family should be more systematically included in the procedures of organizations.

In chapter 5 the results of a study on parents' experiences with support after the death of their child are described. Four asynchronous online focus groups with parents of a deceased child under the age of two and a questionnaire were used to explore what bereavement care parents in the Netherlands received after the death of their child and whether this care met their needs. Most parents reported about the emotional support they received after the death of their child, particularly from family, primary care professionals and their social network. Instrumental and informational support was mainly provided by secondary care professionals. Although there is more focus on bereavement care, still one-fifth to slightly more than half of the parents in this study lacked some sort of support or experienced support that was not in line with their needs or wishes. Parents emphasise that they would like to be approached with empathy and be acknowledged in their bereavement. Next to this, parents appreciate follow-up appointments with professionals, in which continuing support is offered to the family.

Part C. Implementation of Child Death Review

Chapter 6 describes the results of a study that examined the opinions of stakeholders about the implementation of CDR in the Netherlands. Four face-to-face focus groups were held with professionals and parents of a deceased child under the age of two years. The facilitating and impeding factors were identified using the Measurement Instrument for Determinants of Innovations (MIDI). The MIDI proved to be a useful instrument for structuring the determinants of implementation. According to the results of the focus groups the focus within a strategy for implementation of CDR in the Netherlands should be particularly on the determinants associated with the user (emphasizing the personal benefits for professionals and parents, the use of a

consent form and a format to gather information, and analysing anonymized data), organization (informing managers about CDR) and social-political context (adapting CDR to the Dutch regulations and legislation and to the procedures of the Public Prosecutor).

In chapter 7 the strengths, weaknesses, opportunities and threats (SWOT) that were identified in a pilot study on the implementation of CDR are described. The SWOT-frame work proved to be a suitable tool for identifying political, environmental and legal factors not only on a local but also on a national level. The implementation study provided useful suggestions for implementation of CDR in the Netherlands, but at the same time also arguments against introduction of this method. The multidisciplinary approach and the endorsement of the CDR objectives by parents and professionals turned out to be the most important strengths and opportunities in the implementation of CDR. The insufficient time and finances, the existence of other Child Death Review processes and the lack of statutory basis are identified as important weaknesses and threats. The barriers found in this implementation study need to be taken away before large scale implementation of CDR can take place.

Prevention of future child deaths and optimizing family support in the Netherlands

In chapter 8 the main conclusions are discussed. To prevent future child deaths in the Netherlands it would be desirable to analyze the causes and circumstances surrounding death systematically in all child deaths, to aggregate these data on a regional or national level and to translate the recommendations in preventive interventions. Future child deaths can be prevented when stakeholders take responsibility for examining the death of children in a comprehensive way in order to improve the survival of children. This occurs already in SUDI cases (National Cot Death Study Group), perinatal deaths (Perined) and transport-related child deaths (Institute for Road Safety Research). Unexplained deaths in minors are reviewed in the NODOK-procedure since August 2016.

Furthermore, family support needs to be part of the procedures of organizations involved in the (health) care for children and their families and be consistent with the needs and the wishes of the parents.

Of the 992 children aged 0-19 years that died in the Netherlands in 2015, 295 die in the first week and 125 die from the second until the fourth week after birth. As those child deaths are analyzed in the perinatal audits, SUDI cases are reviewed by the National Cot Death Study Group and unexplained death in minors are included in the NODOK-procedure, these review processes should be taken into account in designing a structure for analyzing child deaths.

Although analyzing all child deaths appears to be labor-intensive and expensive, one might consider to maintain a kind of stratification in analyzing child deaths, starting with for example the categories of child deaths in which the greatest potential for prevention is to be expected or where parents benefit the most.

Further research is necessary in order to examine which child death review process is feasible to use for certain child deaths. As in the Netherlands parents are involved only in SUDI cases and unexplained death in minors during the process of information gathering, further research into the involvement of parents in the review process of other categories of child deaths is recommended.

Samenvatting

Achtergrond en doel van dit proefschrift

Wereldwijd stierven er in 2014 6,1 miljoen kinderen onder de leeftijd van 5 jaar aan natuurlijke of niet-natuurlijke oorzaken. Volgens het Internationaal Verdrag inzake de Rechten van het Kind dienen overheden passende maatregelen te treffen om de overlevings- en ontwikkelingskansen van kinderen te vergroten en de zuigelingen- en kindersterfte te verminderen. Tussen 1990 en 2015 hebben landen getracht de wereldwijde kindersterfte onder de leeftijd van 5 jaar met twee derde te reduceren, ook wel Millennium Ontwikkelingsdoel 4 genoemd. Slechts 62 van de 195 landen hebben deze doelstelling gehaald. Naar aanleiding hiervan hebben wereldleiders de doelen opnieuw gedefinieerd, waarbij elk land alles in het werk stelt om vermijdbare kindersterfte verder te reduceren.

In Nederland is de kindersterfte in de afgelopen eeuwen afgenomen door betere sociale omstandigheden, sanitaire voorzieningen, huisvesting, hygiëne en gezondheidszorg, en door daling van de geboortecijfers. Hoewel in 2014 1130 kinderen in de leeftijd van 0 tot en met 19 jaar zijn overleden (sterftecijfer 29,4 per 100.000 kinderen), zijn er nog overlijdensgevallen onder kinderen die vermijdbaar zijn. Om effectieve preventieve maatregelen te ontwikkelen is begrip van de aard van en trends in sterfte bij kinderen en van de factoren die hebben bijgedragen aan het overlijden, essentieel.

Het doel van dit proefschrift is om te onderzoeken hoe in Nederland toekomstige sterfgevallen onder kinderen voorkomen kunnen worden en hoe de ondersteuning van het gezin kan worden geoptimaliseerd. Om deze vragen te kunnen beantwoorden worden de trends in kindersterfte in Nederland beschreven in onderdeel A, 'Epidemiologie'. Daarna wordt de manier waarop professionals handelen naar aanleiding van het overlijden van een kind, inclusief de ondersteuning die zij aan deze ouders bieden, onderzocht in onderdeel B, 'Handelen bij overlijden van kinderen'. Met behulp van Child Death Review (CDR) is het mogelijk om vermijdbare factoren, die hebben bijgedragen aan het overlijden, te identificeren, en wordt aandacht geschonken aan ouders die in rouw zijn. CDR zou hierdoor kunnen bijdragen aan het voorkomen van toekomstige sterfgevallen onder kinderen en de rouwbegeleiding bij familieleden kunnen verbeteren. Om deze reden wordt

in onderdeel C, 'Implementatie van Child Death Review', de mogelijkheid van het systematisch analyseren van overlijdensgevallen onder kinderen volgens de CDR methode nader onderzocht.

De resultaten van deze studie kunnen professionals en beleidsmakers in de gezondheidszorg ondersteunen in hun inspanningen om toekomstige sterfgevallen onder kinderen te voorkomen en begeleiding aan het gezin te optimaliseren.

Onderdeel A. Epidemiologie

Hoofdstuk 2 geeft een beschrijving van het patroon van natuurlijke doodsoorzaken bij kinderen in Nederland van 1950 tot en met 2014. Gegevens over de sterfte door natuurlijke oorzaken van alle overleden kinderen in Nederland in de leeftijd van 0 - 19 jaar voor de periode 1950 - 2014, verkregen uit de elektronische databank van het Centraal Bureau voor de Statistiek (CBS), werden geanalyseerd. De sterftcijfers werden gestandaardiseerd naar leeftijd, waarbij gebruik werd gemaakt van de Europese standaardpopulatie van 2013, om verschillen in leeftijdsverdelingen in populaties in de tijd te corrigeren. Infectieuze en parasitaire ziekten en ziekten van de ademhalingsorganen en spijsverteringsorganen kwamen in de doodsoorzakenstatistiek van 1950 regelmatig voor, maar zijn zeldzame doodsoorzaken in 2014. De incidentie van wiegendood is tussen 1973 en 1987 toegenomen, waarna een afname tot een zeer lage incidentie in 2014 is waargenomen. Aandoeningen van de perinatale periode, aangeboren afwijkingen en nieuwvormingen vormen de hoogste incidentie groepen van natuurlijke doodsoorzaken bij kinderen in 2014.

In hoofdstuk 3 worden de veranderingen in het patroon van niet-natuurlijke doodsoorzaken bij overleden kinderen in de leeftijd van 0-19 jaar in Nederland van 1969 tot en met 2011 in groepen geclassificeerd naar leeftijd en geslacht, beschreven, waarbij gebruik is gemaakt van de elektronische databank van het CBS. De sterfte als gevolg van niet-natuurlijke oorzaken is in Nederland afgenomen, voornamelijk door een afname van verkeersongevallen en overige uitwendige oorzaken van accidenteel letsel in alle leeftijdsgroepen. De inspanningen van de Nederlandse overheid, VeiligheidNL en Stichting Wetenschappelijk Onderzoek Verkeersveiligheid hebben bijgedragen aan een afname van ongevallen, waarbij geen sprake is van opzet. Overlijden door opzettelijke zelfbeschadiging steeg significant, en moord en doodslag en gebeurtenissen waarbij opzet onbekend is, bleven constant.

Onderdeel B. Handelen bij overlijden van kinderen

Hoofdstuk 4 beschrijft een studie die uitgevoerd is om te bepalen in welke mate de bestaande procedures van organisaties, betrokken bij de (gezondheid)zorg voor kinderen en gelokaliseerd in het oosten van Nederland en op nationaal niveau, in geval van overlijden van een kind de vier CDR doelen dekken. Protocollen, richtlijnen, overige werkafspraken en interview verslagen, die de verantwoordelijkheden en activiteiten in geval van een overlijden van een kind van participerende organisaties beschrijven, werden geanalyseerd. Geconcludeerd wordt dat indien de procedures van Nederlandse organisaties gecombineerd worden, het grootste deel van de CDR doelen wordt gedekt. Echter, de procedures richten zich op een deel van de kindersterfte, namelijk perinatale sterfte, plotseling en onverwacht overlijden bij zuigelingen en fatale kindermishandeling. Een volledig overzicht van vermijdbare factoren die richting geven aan preventie van kindersterfte wordt dan ook gemist. In aanvulling hierop wordt geconcludeerd dat begeleiding van het gezin systematischer opgenomen kan worden in de procedures van organisaties.

In hoofdstuk 5 worden de resultaten van een studie naar de ervaringen van ouders over de ondersteuning na het overlijden van hun kind beschreven. Vier asynchrone online focus groepen met ouders van een overleden kind onder de leeftijd van twee jaar en een vragenlijst werden gebruikt om te onderzoeken welke ondersteuning in de rouwverwerking ouders na het overlijden van hun kind hebben ontvangen en of deze ondersteuning voldeed aan hun behoeften. De meeste ouders benoemden de emotionele ondersteuning die ze hebben ontvangen na het overlijden van hun kind, vooral van familie, professionals in de eerstelijns gezondheidszorg en hun sociale netwerk. Instrumentele en informatieve ondersteuning werd voornamelijk geboden door professionals in de tweedelijns gezondheidszorg. Hoewel er meer aandacht is voor rouwbegeleiding, gaf een vijfde tot iets meer dan de helft van de ouders in deze studie aan een bepaalde vorm van ondersteuning te missen of ondersteuning te hebben ervaren die niet overeenkomstig was met hun behoeftes of wensen. Ouders benadrukken dat zij graag benaderd willen worden met empathie en erkend willen worden in hun rouw. Daarnaast stellen ouders vervolgfafspraken met professionals op prijs, waarin ondersteuning voor het gezin continu wordt aangeboden.

Onderdeel C. Implementatie van Child Death Review

Hoofdstuk 6 beschrijft een studie waarin de meningen van stakeholders over de implementatie van CDR in Nederland werden onderzocht. Er vonden vier face-to-face focusgroepen met professionals en ouders van een overleden kind onder de leeftijd van twee jaar plaats. De bevorderende en belemmerende factoren werden geïdentificeerd met behulp van het MeetInstrument Determinanten voor Innovaties (MIDI). De MIDI bleek een bruikbaar instrument voor het structureren van determinanten van de implementatie. Volgens de resultaten van de focusgroepen zou de implementatiestrategie van CDR zich voornamelijk moeten richten op de determinanten geassocieerd met de gebruiker (het benadrukken van de persoonlijke voordelen voor professionals en ouders, het gebruik van een toestemmingsformulier en een format voor het verzamelen van informatie, en analyseren van geanonimiseerde data), organisatie (managers informeren over CDR) en sociaal-politieke context (CDR aanpassen aan de Nederlandse wet- en regelgeving en de procedures van de Officier van Justitie).

In hoofdstuk 7 worden de sterktes, zwaktes, kansen en bedreigingen (SWOT) die geïdentificeerd zijn in een pilot studie over de implementatie van CDR, beschreven. Het SWOT-raamwerk bleek geschikt te zijn voor het identificeren van politieke, omgevings- en wettelijke factoren op zowel lokaal als landelijk niveau. De implementatiestudie leverde bruikbare suggesties voor implementatie van CDR in Nederland op, maar bracht tegelijkertijd ook argumenten tegen introductie van deze methode. De multidisciplinaire benadering en het onderschrijven van de CDR doelen door ouders en professionals bleken de meest belangrijkste sterktes en kansen in de implementatie van CDR te zijn. Onvoldoende tijd en financiële middelen, de aanwezigheid van andere Child Death Review processen en het gebrek aan wettelijke verankering zijn als belangrijkste zwaktes en bedreigingen geïdentificeerd. De barrières die in deze implementatiestudie gevonden zijn, moeten eerst worden weggenomen voordat grootschalige implementatie van CDR kan plaatsvinden.

Preventie van toekomstige sterfgevallen onder kinderen en het optimaliseren van gezinsondersteuning in Nederland

In hoofdstuk 8 worden de voornaamste bevindingen besproken. Om toekomstige sterfgevallen onder kinderen in Nederland te kunnen voorkomen zou het wenselijk

zijn om bij elk overlijden van een kind de oorzaken en omstandigheden rondom het overlijden systematisch te analyseren, om deze data vervolgens te aggregeren naar een regionaal of landelijk niveau en om de aanbevelingen om te zetten in preventieve interventies. Toekomstige sterfgevallen onder kinderen kunnen worden voorkomen wanneer stakeholders verantwoordelijkheid nemen voor de uitvoering van een diepgaand onderzoek naar het overlijden van kinderen met als doel de overlevingskansen van kinderen te vergroten. Dit gebeurt al in gevallen van plotseling en onverwacht overlijden bij zuigelingen (Landelijke Werkgroep Wiegendood), perinatale sterfte (Perined) en sterfte door vervoersongevallen (Stichting Wetenschappelijk Onderzoek Verkeersveiligheid). Het onverwacht overlijden van een minderjarige wordt sinds augustus 2016 nader onderzocht in de NODOK-procedure. Verder dient ondersteuning van het gezin onderdeel van de procedures van organisaties te zijn, betrokken in de (gezondheids)zorg voor kinderen, en in overeenstemming te zijn met de behoeftes en wensen van ouders.

Van de 992 kinderen in de leeftijd van 0-19 jaar die in Nederland in 2015 zijn overleden, stierven er 295 in de eerste week en 125 vanaf de tweede tot en met de vierde week na de geboorte. Deze sterfgevallen worden in de perinatale audits geanalyseerd. Bij het ontwikkelen van een structuur voor het analyseren van sterfgevallen onder kinderen moet rekening gehouden worden met andere reviewprocessen als de perinatale audits, Landelijke Werkgroep Wiegendood en de NODOK-procedure. Hoewel het analyseren van alle sterfgevallen onder kinderen arbeidsintensief en duur lijkt te zijn, zou men kunnen overwegen om een vorm van stratificatie bij de analyse van overlijdensgevallen te hanteren, waarin bijvoorbeeld gestart kan worden met categorieën overlijdensgevallen waarbij het grootste potentieel in preventie wordt verwacht of ouders het meest gebaat zijn.

Verder onderzoek naar welk reviewproces bruikbaar is voor bepaalde groepen sterfgevallen onder kinderen is noodzakelijk. Aangezien ouders alleen in geval van plotseling en onverwacht overlijden van zuigelingen en minderjarigen tijdens het proces van informatieverzameling worden betrokken, wordt nader onderzoek naar het betrekken van ouders in het reviewproces van andere categorieën sterfgevallen onder kinderen aangeraden.

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Sandra

CURRICULUM VITAE

Curriculum Vitae



Sandra Gijzen was born on October 25, 1974 in Hengelo (Ov.), the Netherlands. She attended the Gymnasium of the Grundel Lyceum in Hengelo (Ov.) and obtained her secondary school diploma in 1993. She started studying Medicine at the University of Groningen in that same year. In 1997 she has conducted a scientific internship at the pediatric oncology department of the Kalafong Hospital in Pretoria, South Africa, for three months. After her graduation in 2000 she started to work as an emergency physician for one year at the Medical Spectrum Twente hospital in Enschede. From

2001 to present she is working as a Child Health Care physician at the Municipal Health Service (in Dutch: GGD) Twente. She obtained her degree in the field of Child Health care at TNO Child Health in 2009. Her focus is on children with intellectual disabilities, developmental issues and behavior problems, and child abuse. She is one of the intra-agency consultants Child abuse and neglect at the Child Health Care department of the GGD Twente. Next to her work as a Preventive Child Health Care physician she has practiced forensic medicine at the Municipal Health Service Twente during the period 2002 until 2006. Because of her interest in research she started as a PhD candidate at The Institute for Innovation and Governance Studies of the University of Twente in Enschede since 2010, next to her work as a Child Health Care physician. Her PhD project is called "A feasibility study on the implementation of Child Death Review in the Netherlands", which is part of a cross-border Euregio project Germany-the Netherlands. In this PhD project the University of Twente collaborated with the University of Münster and TNO Child Health.

Since 2012 she is also the secretary of the VVC (in Dutch: Vergader Voorbereidings Commissie) of the AJN (in Dutch: Artsen Jeugdgezondheidszorg Nederland). The VVC organizes scientific meetings 3 times a year for Child Health Care physicians. The topics of these meetings are current and relevant.

Since April 2016 she spends a part of her work as a member of the Team Youth and Family (in Dutch: Team Jeugd en Gezin) in Hengelo (Ov.), where she provides input from her professional background to the cases that are notified to the team.

**PUBLICATIONS,
PRESENTATIONS AND
CONTRIBUTIONS**

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