

A common problem in children with chd health essay

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1. Introduction

Within this chapter the following topics will be discussed: 1) general introduction, in which the problem definition is given and the objective of this research is presented, 2) contextual background, where relevant background for this research is presented, 3) actor analysis, revealing the involved stakeholders, and 4) conceptual model, where the focus and content of this research is given.

1.1 General introduction

One of the most common major birth defects are congenital heart diseases (CHD), which relate to problems with the heart and/or the major arteries (Baardman, Bakker, van Dis, Bots, & Vaartjes, 2011; Vaartjes, Bakker, & Bots, 2007). As stated by Roman & Parrish (2011), CHD are "characterized by anomalies in the structure of the heart and its related valves and vessels". In the Netherlands, the average prevalence of CHD is 74/10.000 births, indicating that 1.300-1.400 children with CHD are born annually (Baardman et al., 2011). A common problem in children with CHD is malnutrition (Roman & Parrish, 2011; Varan, Tokel, & Yilmaz, 1999; Woodward, 2007). Malnutrition is generally caused by inadequate intake, inefficient absorption, and/or increased energy requirement (Roman & Parrish, 2011; Varan et al., 1999). Due to this malnutrition, many infants require supplemental feeding in the form of enteral feeding, which is also known as tube feeding (Roman & Parrish, 2011). The tube feeding is necessary for survival and adequate growth, but is nonetheless seen as a disruptive technology for both the child and parents' everyday life (Heaton,

Noyes, Sloper & Shah, 2005). As stated by Forchielli & Bines (2008), "advances in tube design, methods of delivery, and formulas have made enteral nutrition therapy safer, cheaper, and easier to administer for a wide range of disorders in childhood". Due to advances in medical technology and medical research, survival rates have improved and better treatment options are available (Wang & Barnard, 2004). These advances contributed to a shift in caring for children with chronic diseases at a hospital to caring for these children at home. Over the past decades, delivering tube feeding at home has become an important addition in the management of the care for children and infants with chronic diseases (Forchielli & Bines, 2008). It is believed that home-based care for children with CHD can relieve malnutrition, and increase the wellbeing of the child (Puntis, 2011; Daveluy, Guimber, Mention, Lescut, Michaud, Turck, & Gottrand, 2005). Besides the benefits for the child, the delivery of tube feeding can also provide a respite for families and caregivers (Forchielli & Bines, 2008). Despite the possible benefits of tube feeding a child at home, there are also certain limitations. First, as described by Woodward (2007), there are still certain risks of aspiration if the tube is dislodged or incorrectly placed. Secondly, because the parents as non-professionals, are expected to perform certain medical procedures that were previously only conducted by medical professionals, the impact of caring for a child with CHD is significant. As stated by Wang & Barnard (2004), "parents may experience contradictory expectations because they are asked to become sophisticated healthcare experts and be responsible for their child's care at home, but at the same time are expected to defer to, and comply with advice from professionals". Thirdly, the impact

of caring for a tube feeding dependent child can have adverse health impacts on the parents or primary caregivers (Wang & Barnard, 2004). In order for the tube feeding to be safely and effectively provided at home, adequate support and training is necessary (Forchielli & Bines, 2008; Puntis, 2001). However, previously conducted research on behalf of the Dutch patient association CHD (PAH) has shown that this support is not optimal, and highlighted the need for optimising the support parents receive when tube feeding a child at home (Verwijzing AGP). An important aspect of the lacking support, as expressed by the parents, was the need for information. The current research will therefore directly relate to optimising this support in relation to the training and information that is given to the parents or caregivers at the time of discharge of their child from hospital to home.

Research objective

The objective of this report is to make recommendations to the PAH regarding how to optimally train non-professionals in performing medical procedures at home and to describe what is necessary to achieve the optimal training.

Research question

The research question regarding the research objective is as follows: "How can non-professionals be trained to be able to conduct medical procedures at home, and what is necessary to achieve this?"

1. 2 Contextual background

Relevant background information will be presented in this chapter with regard to the following topics: 1) CHD, where more in-depth information is

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provided and different treatment options are presented, 2) Tube feeding, where the method of tube feeding is described and long-term effects are presented, 3) Home-based care, where consequences of home-based care are given, and 4) Training and support, in which options for optimal training and support are given and a reflection on the method of training is presented.

CHD

The anomalies in the structure of the heart and valves are a result a malformations in the fetal period. CHD can be structured according to three groups, 1) congenital construction errors of the heart, 2) cardiomyopathy, and 3) arrhythmias (PAH, n. d.). The cause of the defect is often unknown, however maternal smoking, genetics, and chromosomal abnormalities are believed to be contributing factors to CHD (Roman & Parrish, 2011; Baardman et al., 2011). As described by Roman & Parrish (2011), the diagnosis of CHD can be given prenatal with use of echocardiography, or postnatal after heart murmur, cyanosis, or failure to thrive is presented. Currently, CHD are often diagnosed prenatally (Baardman et al., 2011). As stated by Roman & Parrish (2011), " although CHD are relatively rare, they are the most common birth defect responsible for mortality in the neonatal period". The survival of individuals with CHD depends on the type and severity of CHD (Nousi & Christou, 2010). Nonetheless, nowadays 85 percent of the children with a CHD reaches adulthood (PAH, n. d.). In some cases the CHD may resolve spontaneously, however most children require some form of medical or surgical treatment (Roman & Parrish, 2011; PAH, n. d.). The

treatment that is necessary for instance depends on the type and severity of the defect(s) and the clinical condition of the child (Roman & Parrish, 2011).

Tube feeding

In order to decrease the malnutrition in children with CHD, tube feeding is often provided. Tube feeding provides an effective option for children with increased energy needs that are difficult to achieve via the oral route (Forchielli & Bines, 2008). Tube feeding is defined as " the delivery of food via a tube directly into the gastrointestinal tract" (Forchielli & Bines, 2008). Tube feeding mimics the normal gastrointestinal response following the ingestion of a meal. However, the oral phase of obtaining a meal is not mimicked by tube feeding (Forchielli & Bines, 2008). While tube feeding is effective in reducing the malnutrition, research has shown that long-term oral feeding difficulties often arise (Mason, Harris, & Blissett, 2005). The transition from tube feeding to normal food can be difficult, which sometimes leads to children continuing tube feeding long-term although able to eat (Wright, Smith, & Morrison, 2010). Various factors contribute to this difficult transition. For instance, resistance to weaning onto oral feeding, undeveloped feeding skills, and a disrupted appetite are of influence (Mason et al., 2005; Wright et al., 2010). Support with regard to this transition is of great importance. However, research has shown that parents are experiencing a lack in support with regard to decreasing the tube feeding (Verwijzing AGP). This research indicated that a speech therapist can support parents in the transition from tube feeding to normal food (Verwijzing AGP).

Home-based care

As stated before, home-based care has become an important component of healthcare. As was observed by Wang & Barnard (2004), various factors have contributed to the development of home-based care, for instance the increasing hospital costs, the ability to transfer medical technology into the home, and the consumer preference. Daveluy (2005) believes that home-based tube feeding is a safe and effective support method, that it can relieve malnutrition, and leads to children being happier and more active. It was stated by Daveluy (2005) that " home-based enteral nutrition is a valuable alternative to hospital-based enteral nutrition. However, as observed by Wang & Barnard (2004), the development of the home care environment has resulted in blurring of the boundary between hospital and home. The authors believe that " the traditional meaning of home is altered by intrusion of medical machinery" (Wang & Barnard, 2004). Parents are carrying out complex clinical procedures, which were normally undertaken by professionals (Kirk & Glendinning, 2002).

Training and support

The training and support that parents and primary caregivers receive is very important. Previously conducted research, on behalf of the PAH, indicated that the support and training is not optimal (Verwijzing AGP). The study indicated that support from medical professional is not always sufficient, that there is a lack in sufficient information, and that communication problems often occur (Verwijzing AGP). Beliefs about the training and support parents should receive are stated in literature. Forchielli & Bines (2008) believe that attention should be given to appropriate patient selection, education, and

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the provision of technical support. The authors believe that the training of patients, caregivers, or their families is ideally performed by a multidisciplinary team (Forchielli & Bines, 2008). Forchielli & Bines (2008) also state that an essential component of successfully administering tube feeding at home is the availability of health professional to provide support. It was observed from previous research that this essential component is currently insufficient (Verwijzing AGP). Puntis (2001) states that " training and support is needed, but also believed that the hospital outreach services [...] should be further developed in order to bridge the gap between home and hospital". The author believes that such an activity should be coordinated by a multidisciplinary nutritional team (Puntis, 2001). Griffin (2002) mentions that " support of the family of the infant with CHD requires a thorough assessment of the family's knowledge of heart disease, previous experience with illness, and interpretation of the current situation". The author believes that parents should be supported by the provision of information and the inclusion of families in decision-making (Griffin, 2002). Griffin (2002) states that " families must also be active participants in discharge planning to ensure a successful transition from the hospital to home". Hier stuk over verschillende groepen mensen en hoe deze hun informatie opnemen

1. 3. Actor analysis

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1. 4 Conceptual model

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