Communication between family and professionals in health care and education when the family has a child with a chronic health condition

A Systematic Literature Review

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ABSTRACT

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Main title: Communication between family and professionals in health care and education when the family has a child with a chronic health condition
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Having a child with a chronic health condition places an extra burden of care on the everyday life of parents, who are directly responsible for the welfare of their child. Due to this, both caring and balancing between home, health care and education setting, are the responsibilities of the parent whose child needs to be away from their natural settings when undergoing treatment. Ideal hospital care can be facilitated by the effective communication between professionals within health care, education and family. This study is aimed at exploring how the communication is arranged for or spontaneously constituted between these professionals; In the case that the family has a 0-18 years old child with a chronic health condition which demands spending periods of time in health care setting absent from home, school or kindergarten. A systematic literature review based on 4 databases extracted 14 articles from 8 countries. Studies included were empirical-9 qualitative, 3 quantitative and 2 mixed-studies. Communication was researched in relation to the children with a variety of different chronic health condition. Participants of the included studies can be associated with the health care, education and families of the children. The results are presented in a way that addresses the communication between different parties of participants. The review shows the problems according to the communication due to the misinterpreted or lack of information and provides some good practices and suggestions; Such as using the key-workers as the organizers of co-operation and improving the communication to decrease the problem.

Keywords: systematic literature review, communication, chronic health condition of a child, health care professional, education professional, family

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Introduction

This systematic literature review is related to children with chronic health conditions and addresses the communication between the professionals in health care, education and family.

Children should be a priority to their primary caregivers, who should fulfil their needs and support them in every stage of their lives. After the diagnosis of illness or disease, the family needs ongoing consultations from professionals to adjust to the situation (Sand, Blom, Forsander & Lundin, 2017). For the ill child, professionals in health care provide comprehensive pediatric care, to optimize care, safety and development, but also provide critical information to parents, regarding prevention of complications.

School liaison is considered as supportive linkage between family, professionals in education and health care (Vanclooster, Benoot, Bilsen, Peremans & Jansen, 2018), but often the child returns to school and experiences detractions of the health plan because of the lack of communication between health care and education professionals (Selekman & Calamaro, 2014). When children and their families are tested by the illness and hospitalization, it results in stress and creates multiple challenges. Hence, through improving the hospitalization experience, the quality of care for children and their families is being upgraded (Christian, 2018).

Since the diagnosis of the illness, some parents may continue suffering regarding their child’s diagnosis and health care professionals should try to help them cope with it (Popp, Robinson, Britner & Blank, 2014). Concerning children with chronic health conditions, the pediatric care has a primary environment role. The child often spends a great amount of time there, which should be spent at home together with family or peers within the education setting instead.

Communication is a key factor in different areas when talking about human beings and the relations between them. In medical care, communication can have critical meaning for the patient (McCarthy, 2016), but also when communicating with the patient and among team members. Regardless of who we are communicating with, it is important to ensure that our communication is understandable, meets the learning needs of the target group in terms of clarity, and has usefulness, trustworthiness and rigor (Moore & Jull, 2018; Naughton, 2018). A child’s illness is influencing every aspect of the family life as the experience of illness integrates into their daily routine but due to the time constraints, families and their concerns are often
neglected by professionals in health care (Jacobs, 2002). Communication between the professionals in education, health care and family of the child with chronic health condition may not always be self-evident, although the child should be the target for the collaboration.

2 Background

2.1 Chronic health condition

The number of children living with a long-term disease has increased throughout the world in recent years (Judson, 2004). Chronic illness is any disorder that persists over a long period and affects physical, emotional, intellectual, vocational, social or spiritual functioning (Mosby's Medical Dictionary, 2009). Chronic health condition in childhood can be defined as a) occurring in children aged 0-18 years, b) the diagnosis is based on medical scientific knowledge, c) is not curable for the moment or is highly resistant to treatment (mental health), d) the presence of the disease has occurred three or more times during the last year and will probably come back again (Mokkink, van der Lee, Grootenhuis, Offringa, & Heymans, 2008). However, in the context of this literature review, the term chronic health condition is used to describe children who have spent lengthy periods of time in a health care setting for treatment purposes and therefore need to stay away from school, kindergarten or home.

2.2 Communication

Communication can be described as the result of any action (physical, written, or verbal) that conveys meanings between two individuals (Oxford Reference, 2018). Adjustment of information according to the family's needs and situation is proved to be important to the family's well-being (Hopia, Tomlinson, Paavilainen, & Åstedt-Kurki, 2005). Failures in communication may occur when the information is unclear, complex, too much information is given at once or when the messages are incomplete, unclear and incorrect (Rogers, 2015). In a case of children with a chronic health condition, it is important to maintain the human element of communication, such as face-to-face and phone contact with each other. Communication is also important when informing about the disease and health as well as between professionals in education, health care and family to help each other to keep in touch (St Leger & Campbell, 2008).
2.3 Environments of the child

For the child, the parts of his/her network are possible to be looked at as the basic environments, as they are the most immediate for the child’s development. The network is a group of individuals and communication channels between some or all of the pairs, indicating the routes along which information can flow or messages can be transmitted. The structure of the network often determined by the organizational structure of the group (Colman, 2015).

The bioecological model describes the development of the individuals based on the concepts of process, person, context and time (Tudge, Mokrova, Hatfield & Karnik, 2009). The bioecological theory explains which influences different environments, relations between closer and more remote environments, time process and personal factors of the child (Bronfenbrenner, 1980). According to Bronfenbrenner & Ceci (1994) this evolving theoretical system consist of four elements, such as proximal process (process happening in a longer period of time, which affects development), person characteristics (characteristics such as age, gender, skin colour, past experiences, financial resources and so on), context (microsystem-closest environment; mesosystem-relations between microsystems; exosystem-people and places, which child does not come into contact with, but still influence him/her; macrosystem- dominant beliefs and ideologies, politics) and time (when the incidents happen in person’s life and what is the historical context of this period of time). All these processes simultaneously influence the development of the human being (Bronfenbrenner & Ceci, 1994; Tudge et al., 2016). Environments are playing an important role (Tudge et al., 2009) and the bioecological model concentrates mostly to impact on environments and is not as much personality centered (Bronfenbrenner, 1980). In the context of this literature review, the concepts of microsystem and mesosystem are directly related to the topic. In connection to the child with a chronic health condition, the family and the settings of health care and education can be viewed as microsystems that are most close and natural for the child. Communication between family and professionals of health care and education as relationships exist in the mesosystems.

The health care setting is an inappropriate place for children to grow up in, as children may be exposed to sights, sounds and disturbances, that are not developmentally beneficial for them. As the surrounding children are also not typically functioning, they may not be able to play and interact with them. Parents can visit or be there, but the environment does not provide
enough privacy to compensate home environment and interactions with family members. Access to education, peers and friends are also limited (Hewitt-Taylor, 2008).

It is an extremely heavy emotional burden that parents have to carry when their child becomes ill and is admitted to health care setting. They need encouragement and support for their self-confidence when they are in this environment with their child (Hopia et al., 2005). The worry about the inclusion into kindergarten and school setting increases the burden of care (Vonneilich, Lüdecke, & Kofahl, 2016) even more. Situations occurring in education setting due to the chronic health condition, such as the sudden need for help due to the dropping blood sugar or the need for toilet in case of renal failure or ostomies, are stressful for children and their parents. Children constantly worry about the raised attention by peers and possible neglect and the parents worry about getting the help needed. The lack of communication is realized, as the education professionals expect the child and the family to share information about the illness before the re-entry process to school and the parents presume information exchange between professionals in health care and education (Kliebenstein & Broome, 2000). To facilitate the discharge from the health care setting, support focusing the child’s needs in the home and education setting are important and a range of health, emotional, technical and social aspects need to be taken into consideration (Hewitt-Taylor, 2008).

2.4 Rationale

A child’s chronic health condition has a severe stressful impact not only on the child but the entire family as well; It changes the rhythm of everyday life and adjustments have to be made. Not only inside the family life, but in an education setting as well as the child is expected to continue in kindergarten, or school when the disease and treatment allow. How the communication is arranged for or spontaneously constituted between the professionals in health care, education and family is so far investigated partly and as being part of some other study, however not systematically reviewed in one context

As the studies from different continents show various consistencies related to the topic of communication. This may also be applicable to professionals within health care and education, as further research and discussion are conducted, to avoid misinterpretation.
3 Aim and research question

This study attempted to systematically sum up and review literature about currently mapped situations, problems, good practices and suggestions; related to the communication between professionals within family, health care and education. Knowledge gathered by conducting a systematic literature review about this topic, may be supportive for the professionals assisting in the improvement of communication with children affected by a chronic health condition.

The aim of the study is to explore how communication between professionals in health care, education and family is arranged for or spontaneously constituted, when the family has a child with a chronic health condition. To attain the aim of the study, the following research questions were to be answered:

- How the communication is arranged for or spontaneously constituted between the professionals in health care and family, when the family has a child with chronic health condition?
- How the communication is arranged for or spontaneously constituted between the professionals in education and family, when the family has a child with chronic health condition?
- How the communication is arranged for or spontaneously constituted between the professionals in health care and education, when the family has a child with chronic health condition?
4 Method and data analysis

In this section, study design, selection criteria, search strategy, study selection, quality assessment, data-analysis, peer review and ethics are described.

4.1 Study design

In this study, a systematic literature review, was conducted. The systematic literature review provides a critical account of the literature to demonstrate why a new research study is required and if the body of research is systematically reviewed within a certain area it can explore areas where the research should have more focus on (Aveyard, 2010). Based on the inclusion/exclusion criteria and following the aim together with research questions, the literature review explored new insights of the topic, limited by available articles (Sadiq & Tahir, 2016).

4.2 Selection criteria

The articles of the conducted review had to be published within the last 20 years (1998-2018), peer reviewed, written in English, full text available for free. They focused solely on empirical research studies. Systematic reviews and descriptive articles were therefore not included.

The interest in this systematic literature review was the communication between units of the child’s network, in particular between professionals in health care, education and family. The concept of family was not limited by having both parents or having biological parents. However, studies focusing mainly on the research of the foster care were excluded. Children diagnosed with a chronic health condition, with the main issue of spending long or frequent periods away from education or home setting, were included. The age limit was set between the age of 0-18 years, which is also stated by the Convention on the Rights of the Child (Convention on the Rights of the Child, 1989). Studies addressing children, whose health problems were described as being cured with ongoing treatment or whose treatments had ended, and the child was cured, were not included. Studies with communication between the professionals of health care, education and family of the child were included, information given in detail in Appendixes G, H and I. Articles about communication within the unit (parent-to-parent support, communication inside a hospital) and papers focusing on forth parties (communication regulated by the local government) were excluded, because they did not address the topic. The content of the article had to relate to the communication issue or describe it but did not have to be the main topic of the research. To cover more aspects, the child’s age limit was left broad
and not limited to a specific school or kindergarten age. Table 1 describes an overview of the inclusion and exclusion criteria of the study.

Table 1

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td><strong>Professionals of education, health care and families of the children 0-18 years old</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Children with chronic health condition, which require spending considerable amount of time in health care setting</strong></td>
</tr>
<tr>
<td><strong>Content</strong></td>
<td><strong>Communication experiences between professionals of health care and education</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Communication experiences between professionals of health care and family</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Communication experiences between professionals of education and family</strong></td>
</tr>
<tr>
<td><strong>Design</strong></td>
<td><strong>Empirical studies</strong></td>
</tr>
<tr>
<td><strong>Publication type</strong></td>
<td><strong>Peer review article</strong></td>
</tr>
<tr>
<td><strong>Full text available for free</strong></td>
<td><strong>Languages: English</strong></td>
</tr>
</tbody>
</table>

### 4.3 Search strategy

For this systematic literature review, the database searches were conducted in March and April 2018. Databases CINAHL, ERIC, PsycINFO and ScienceDirect were used. These databases contain information from the sectors of health, education and psychology and include studies that focus on families, health care and education professionals but also communication.

The inclusion and exclusion criteria were the base to find appropriate search words within these databases. All the searches were performed by advanced search options. Thesaurus terms were used to conduct the search in ERIC, PsycINFO. Heading terms were used in CINAHL. In ScienceDirect search words used in other databases were used. Searches addressed communication, health care, education and family setting. To achieve final choice of the key
terms, all the databases were pre-searched several times. Table 2 shows the final key terms of the four databases.

Table 2

*Final key terms for the databases*

<table>
<thead>
<tr>
<th>Database</th>
<th>Key words and the strings of the search</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>parents OR mother OR father&lt;br&gt;AND communication NOT documentation&lt;br&gt;AND health care workers</td>
</tr>
<tr>
<td>ERIC</td>
<td>communication (thought transfer) OR cooperation&lt;br&gt;AND school personnel OR teachers&lt;br&gt;AND health personnel OR physicians&lt;br&gt;AND family (sociological unit) OR parents&lt;br&gt;AND children NOT adults&lt;br&gt;AND chronic disease OR chronic illness</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>hospitals OR medical personnel&lt;br&gt;AND schools OR school environment&lt;br&gt;AND collaboration OR communication</td>
</tr>
<tr>
<td>ScienceDirect</td>
<td>school staff OR school workers OR teachers&lt;br&gt;AND medical staff OR hospital workers&lt;br&gt;AND parent OR family&lt;br&gt;AND communication OR collaboration&lt;br&gt;AND chronic disease OR severe illness OR severe disease&lt;br&gt;NOT adult</td>
</tr>
</tbody>
</table>

### 4.4 Study selection

#### 4.4.1 Study selection protocol

Every database search was performed within one day, so that the changes made inside the database would not change the number of the result. The first choice was made by screening the headlines and abstracts and if suited, then the headline of the article was saved in a file. After finishing the search within one database, all the selected studies were screened reading the full-text. If then, the article still did not fit in the inclusion criteria, the headline was erased from the file not to extract further work and to get better overview of the amount of the studies. The articles that suited in the inclusion criteria, were filled in the protocol (Appendix A). The protocol contained different parts, such as number, headline, authors, publishing year,
publishing journal, summary, research questions, hypothesis, where the research was performed, how the recruitment was done, what type of study, participants of the study (amount, age), what problems the described children had, communication issues between education setting-family, education setting-health care setting and health care setting-family, but also the communication when all the parties were included together, conclusions by authors and problems brought out.

4.4.2 Study selection process

The flowchart of the searching process and article selection is shown in Figure 1. The searches were conducted in 11.03.2018 (CINAHL), 09.04.2018 (ERIC), 22.03.2018 (PsycINFO) and 27.03.2018 (ScienceDirect). All the searches were conducted from the beginning until the end separately in each database, which is possible to follow by the colours at the mentioned flowchart. The preliminary search gave a total of 1215 articles. Applying a filter of peer-review to databases ERIC and PsycINFO and a filter for selecting out the articles published before 1998 to ERIC, total of 729 remained. Out of which, 682 articles were excluded, because of the criteria of available for free and full text and the scan of headlines and abstracts. This led to full text screening of 47 articles. Of these 25 articles remained. 10 studies were not empirical and were removed. In addition, 1 article was excluded due to the insufficient quality, which led to the final number of 14 articles that are marked with “*” in reference list.

4.5 Quality assessment

To measure the quality of the articles and to be confident about including all the chosen articles in the systematic literature review, additional assessment was made after scanning the full-text. For assessment, modified CASP checklist (“CASP,” 2018) was used. Some of the used questions were taken straight from the example of qualitative research checklist, such as “did the study have a clearly focused issue”. Some were modified to fit the articles chosen, such as “was it clearly stated, that the study was a qualitative/quantitative/ mixed methodology”, because the number of articles also consisted of quantitative and mixed method studies also. Additional questions were added as the lastly, depending on the topic of the review, such as “does the study describe communication between all three parties of the child’s network”. Due to the changes, the modified version did not keep the same number of questions as the original consisted. Appendix B shows the form of the modified assessment tool questions for the articles. Appendix C shows how many points articles collected after the assessment procedure. All the questions (n=10) were able to be answered by choosing “YES”, “CAN’T TELL” or
“NO”, which gave the points accordingly 2, 1 or 0. This means, maximum score given to the article altogether could have been 20 and minimum 0. Only the articles with the score more than 75% of the maximum possible, were included by the author. The author of this review was also the one that set the scale, where score 18-20 was very high quality, 15-17 was high quality and less than 15 was low quality. The measurement showed, average score per article was 16,26 points, ranging from 13 up to 18. Out of all (n=15), one article (6,67%) was excluded after using assessment procedure, shown also on Figure 1, due to lower score (13, less than 75% of the maximum score). According to this criterion, there were 3 (21,43% of all the included articles, n=14) rated as very high quality and 11 (78,57% of all the included articles, n=14) rated as high-quality articles.

4.6 Peer review and ethics

Due to time restrictions, the author of the study performed the article searching process, scanned the headlines and abstracts and chose the articles, conducted the full-text scanning and inclusion-exclusion process alone.

To maintain the quality aspect of the review, a second reviewer, a colleague of the author, was asked to perform the full-text reading for every 3rd article in the extraction list. This was 5 articles (33,33%) out of first the 15. Out these 15 articles one showed a low quality and the first reviewer decided to exclude this one due to the assessment of the articles. The second reviewer received the articles by e-mail together with the topic of the systematic literature review, aim and research questions. The second reviewer, after scanning the full-text, agreed with the author about the inclusion and exclusion decision. The second reviewer pointed out that all the included articles addressed the research question and the aim of the paper and were therefore justified to be included. The excluded article had abandoned some of the planned research participants, the children with chronic health conditions, who were supposed to be interviewed according to the criterion of the study design. Named reason can be the source of trustworthiness towards the excluded study and its’ results.

The ethical principles of the Ethics Code that guide psychologists are beneficence, non-maleficence, fidelity, autonomy, justice, and self-care (Barnett, Behnke, Rosenthal & Koocher, 2007). The National Children’s Bureau (2003) urges the importance of keeping a record of informed consent and to clarify the limits of confidentiality. Furthermore, a research ethics committee specialized in child care should review and approve the research conducted with
11 children before it will be executed (Modi, Vohra & Preston, 2014). Articles included in this study are peer-reviewed and have approvals from the ethical committees.

![Flow chart of database searches](image)

**Figure 1.** Flow chart of database searches.

### 4.7 Data analysis

During the analysis process, all the included studies were reviewed according to the aim of the review and based on the set of the research questions, which were formed to targeting to fulfil the aim.
The extraction protocol (Appendix A) was scanned through several times to be sure all the data was found and noted from the texts. The articles were read through and scanned until all the aspects of the protocol were filled in. The protocol was used to extract and identify the content of the articles and information in connection to the research questions. The main data tracked from the articles addressed the communication between professionals in education, health care and family. Extraction protocol sifted information in the field in relation to current situation. Problematic areas are described under sub topic “Problems”. Also, the current good practices and suggestions, participants of the studies proposed to improve communication and cooperation are showed. As some of the studies proposed suggestions, that the other studies already described as the good practices, results addressed to this area are summed up in this literature review using sub topic “Good practices/suggestions” under each provided section.
5 Results

This section describes the characteristics of the study, but also the characteristics of the parties involved in this review by the research questions—professionals in education, health care and family. The characteristics of the children, that are the binding links between the different parts of their networks are also described.

5.1 Study characteristics

Characteristics of the included studies are shown in Appendix D. A short version of it is also shown in Table 3. The numbers showing further citation in the result section of this systematic literature review for the articles are brought out in mentioned table.

Table 3
Characters of included studies

<table>
<thead>
<tr>
<th>Number for further citation</th>
<th>Author of the study</th>
<th>Year</th>
<th>Country</th>
<th>Type</th>
<th>Quality assessment result</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger</td>
<td>2014</td>
<td>Australia</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta</td>
<td>2017</td>
<td>Australia</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad</td>
<td>2003</td>
<td>Israel</td>
<td>Mixed</td>
<td>High</td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King</td>
<td>2014</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>Very high</td>
</tr>
<tr>
<td>5</td>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp; Cohen</td>
<td>2015</td>
<td>Canada</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>6</td>
<td>Paget, Mallewa, Chinguo, Mahebere-Chirambo &amp; Gladstone</td>
<td>2016</td>
<td>Malawi</td>
<td>Qualitative</td>
<td>Very high</td>
</tr>
<tr>
<td>7</td>
<td>Mostert, Gunawan, van Dongen, van de Ven, Sitasresmi, Wolters, Veerman, Mantik &amp; Kaspers</td>
<td>2013</td>
<td>Indonesia</td>
<td>Quantitative</td>
<td>Very high</td>
</tr>
<tr>
<td>8</td>
<td>Poursanidou, Garner &amp; Watson</td>
<td>2008</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>9</td>
<td>Bradley-Klug, Sundman, Nadeau, Cunningham &amp; Ogg</td>
<td>2010</td>
<td>United States of America</td>
<td>Quantitative</td>
<td>High</td>
</tr>
<tr>
<td>10</td>
<td>Mayer., Parsons, Terrin, Tighiouart ja Jeruss</td>
<td>2005</td>
<td>United States of America/Japan</td>
<td>Quantitative</td>
<td>High</td>
</tr>
<tr>
<td>11</td>
<td>Kirk &amp; Glendinning</td>
<td>2002</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>12</td>
<td>Selekman</td>
<td>2016</td>
<td>United States of America</td>
<td>Mixed</td>
<td>High</td>
</tr>
<tr>
<td>13</td>
<td>Asprey &amp; Nash</td>
<td>2006</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>High</td>
</tr>
<tr>
<td>14</td>
<td>Sullivan, Fulmer &amp; Zigmond</td>
<td>2001</td>
<td>United States of America</td>
<td>Qualitative</td>
<td>High</td>
</tr>
</tbody>
</table>

The articles were chosen from 8 countries. More than one article came from United Kingdom (n=4), United States of America (n=4) and Australia (n=2). Israel, Canada, Malawi, Indonesia
and Japan are represented by 1 article. One study [10] was carried out in two different countries United States of America and Japan. The mean age of the articles was 8 years. Half of the articles [1, 2, 4, 5, 6, 7, 12] were published within the past 5 years (mean age 3 years) and the rest of the articles [3, 8, 9, 10, 11, 13, 14] were published within the past 8-17 years (mean age 13 years). Most of the articles (n=9; 64,28%) had a qualitative design, minority of the articles had quantitative (n=3; 21,43%) and mixed-method (n=2; 14,29%) design.

All (n=9) qualitative studies [1, 2, 4, 5, 6, 8, 11, 13, 14] used interviews to collect the data. Three studies [1, 4, 5] used focus groups. Out of quantitative studies (n=3) one [7] used self-administrated questionnaire and a semi-structured questionnaire. Two articles [9, 10] used surveys, which were sent by e-mail. Two studies [3, 12] used a mixed-design. One study [3] used a combination of interviews, which were analysed both quantitative and qualitative way. The other [12] used a combination of focus groups with electronic surveys that were conducted with a half a year gap between the two data collections. This was the only longitudinal study of this review.

5.2 Participant characteristics

This section describes the characteristics of the participants of the studies included in the systematic review. Not all parts of communication were covered in all the studies, as there was no limitation for the number of parties whom the communication should be between. Appendix E gives an overview of participants included in this review.

Professionals in health care were used as participants in ten studies [1, 2, 4, 5, 6, 7, 8, 9, 10, 11]. The number of participants included in those studies ranged between 9 and 706. Only three [2, 9, 10] out of ten studies specified the gender of the participants. The mean age and age range were covered accordingly in three [2, 9, 10] and two [2, 9] articles.

Professionals in education were used as participants in 3 articles [1, 8, 12]. The number of participants included in those studies ranged between 11 and 1294. In this study a survey, which included 1280 participants, was analysed. None of the studies specified the gender of the participants nor the mean age and age range.

Families as participants of the research were used in eight studies [3, 4, 5, 6, 8, 11, 13, 14]. The number of participants included in those studies ranged between 14 and 93. Out of these, one study [3] specified, they purposely used couples, two [5, 6] used one member per family and others did not specify, whether mother, father, both or the whole family participated.
Two studies [13, 14] also included children themselves as the informants in addition to the family. Four articles [3, 4, 5, 6] gave full information about the gender of the participants. Two articles [13, 14] gave information partly, describing the gender of the children participating, but did not give the same information about the other family members. Two articles [8, 11] did not inform about the gender of the participants at all. Mean age was brought out fully in two articles [3, 5] and partly in one [14] and age range fully in one [9] and partly in two [13, 14] studies.

The characteristics of the children are possible to be followed in Appendix F. Special needs of the children were mentioned differently. Some of the articles mentioned the conditions, such as very low birth weight [3], life-limiting [4, 13] and life-threatening [13] conditions, neuro-disability [6], cancer [7, 10] including acute lymphoblastic leukaemia [14], chronic renal failure [8], dependence of technology- tracheostomy tubes and intravenous aids [11] and gave additional explanation to the health situation, illness or disease. The genders of the children were specified only in three (21.49%) articles [5, 13, 14]. Mean age and age range both, were brought out clearly in six studies [14, 5, 6, 10, 11, 13]. Some of the studies used terms “infants” [3] and “under 18 years old” [1, 5], but also “school aged children” [9, 12] or just “children” [2, 4, 7, 8] to let the reader know about the relation to the children.

5.3 Findings of the articles

The overview of which studies covered which relations can be followed in Table 4. Only one study [1] covered all the studied relations, the rest described only one. Next, the findings about each sector follow separately, based on the protocol of full-text screening (Appendix A) that included these categories as the main touch points with research questions.

Table 4
Communication addressed in studies

<table>
<thead>
<tr>
<th>Number</th>
<th>Author of the study</th>
<th>Communication between health care professionals and family</th>
<th>Communication between education professionals and family</th>
<th>Communication between education and health care professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King, 2014</td>
<td>X</td>
<td></td>
<td></td>
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</tbody>
</table>
5.3.1 Communication between the professionals of health care and family, problems and good practices/ suggestions in the field

Findings suggest that in case a child has been in hospital care for a long time, health care workers have close relationships with families [1]. However, depending on the parents, some still preferred an indirect approach, whereas others may have preferred direct and detailed information about the child’s condition [3]. Commonly, parents expected professionals to share information about the child's situation, such as diagnosis, management, investigations, prognosis, how to care for the child at home but also to help with decision making [4, 7]. In some cases, parents saw acquiring information about their child’s condition as a privilege rather than a right and it was unusual to get requests for clarification [6]. Nevertheless, parents frequently desired to be involved in care planning and decision making but usually not about the final decisions [4].

Cooperation with parents transforms the nature of the parent-professional relationship as well as roles of professionals themselves, as it was often parents rather than the professionals...
who were the experts in the child’s care. Parents’ expertise came from the knowledge derived from the training programs they had undergone before their child’s discharge from hospital and in the experiential and intuitive knowledge derived from their subsequent experience of caring for their child [11].

5.3.1.1 Problems

Failure to provide information [3] and bureaucracy was a challenge as only certain professionals were authorized to share the information [2], making parents to wait even longer. Misunderstanding the meaning of information about medical situations given by health care professionals [2, 6] was often due to use of medical vocabulary, even though they know patients and parents would not understand [7]. Parents felt confused about information that was shared, as they experienced it to be insufficient or conflicting [11]. Only very few health care providers reported about always verifying if parents understand the information they provided [7].

Health care professionals often found it difficult to discuss the disease openly with parents and patients [7]. For example, most Japanese physicians did not explicitly tell the child their diagnosis [10]. Some clinicians suggested that information about severe condition and its treatment made parents more afraid or depressed about the future and concluded that families preferred not to know [7]. One study found out that if there were no predictions how long the child may live, the level of communication was decreased, and families were left with little assistance [4].

Some parents did not completely trust key-workers in health care to communicate with them about care co-ordination [5]. In one study health care workers tried to counsel parents about the future, that the child will grow older, but the health condition will stay the same. Parents often found it hard to believe the condition would not change with treatment and blamed health care setting for releasing the child too soon, as the child was still not well enough [6]. Wrong expectations towards health care professionals were also common, such as blaming nurses for the lack of professionalism and social workers offering emotional support rather than instrumental aid [3]. One study reflected on the difference of the communication by health care staff according to the status of the family. According to this, wealthier parents received more time, accuracy, thoroughness, and attention by prosperous socioeconomic families, whilst poor families received less explanation and cooperation from the medical team, and encountered more difficulty understanding the information [7].
One study [11] reported on problematic situations taking place as the result of the lack of communication. The parent had to take the role of co-ordinating communication, in addition to the aspects of everyday care which was a source of considerable stress [11]. The others reported that the burden of care was so great that they felt like too much of energy was needed for planning forward or ‘second guessing’ or just to orchestrate required discussions [4].

Health professionals reported feeling torn between the development of the family-focused role of providing counsel, which required time for communication that did not necessarily fit into schedules and budgets of the health care management [1]. Often health care professionals were expected to deliver good service against all odds, for instance to work longer than paid hours and being involved in tasks outside their competence [4].

5.3.1.2 Good practices/ suggestions

Good practice goes hand in hand with a working communication. Health care professionals were often the ones, who were communicating with both- the family and the medical team to build relations between them, keep in touch and share clear and honest information [7, 11]. Continuity [11], adequate time for counselling to assure the understanding of the information given was also highlighted [6]. In addition, an individualised approach and finding the suitable language to approach, was emphasised [3]. But also, to prepare the information beforehand to ease the burden for parents, to support them [4] and to make them feel like the clinicians were on their side [11]. This could be a task of a social worker, who acts as a middle-man in communication, interpreted information in a sensitive way, gave a context to a situation and explained medical situations [2]. Parents noted a variety of positive ways that key workers impacted the life of their child and family, including connecting them to new, altering existing and/or referral to additional services, co-ordinating outpatient visits, attaining funding and offering emotional support [4, 5, 11].

Many procedures done previously only in health care settings, are now performed at home. Nurses considered it their part to ensure by increasing communication with parents that clinical procedures were performed safely, and parents had confidence in making a right judgement in how to adjust the child’s medication or when to call out a doctor if the child seemed unwell. Parents found it reassuring to know that there was someone who was familiar with their child’s circumstances, who was easy to contact and personally approachable if they needed help, advice or information. Parents felt that this type of support promoted their confidence and helped them cope with taking caring of their child [11]. Another possible
method to better communication was found to be the use of care plans, so that parents did not have to repeat information within a clinic or emergency department setting, which helped them feel at ease about the providers having accurate, up-to-date information about the care of their child and assisted with the provision of timely and appropriate care [5].

5.3.2 Communication between professionals in education and family, problems and good practices/ suggestions in the field

In the context of education setting there are also many issues to talk about, because spending considerable time in treatments was hindering the child’s academic accomplishments [13]. In one hand teachers were not medical experts to be able to see health problems influencing the child and even then, it was hard to discuss the issue with parents [12], in the other hand parents needed more communication that support-persons were able to offer [13].

5.3.2.1 Problems

The communication between the education professionals and parents had many challenges and both claim that there was a lack of communication. Parents felt that they were giving information to their child’s school or college about their medical condition but expressed doubt as to whether this information had been read or understood [13]. For many parents, high standard of communication was not experienced. They expressed that the school or college did not keep in touch during periods of absence unless the communication was initiated by themselves [13]. Home-school diaries which could provide and efficient channel of communication, did not have any use [13].

The professionals in education experienced a lack of and a desire for information about the conditions their students had, especially what they should look for that indicated the child was in trouble and what they should do while they are waiting for help to arrive. It often took weeks or months until parents shared information that a child in their classroom had a chronic health condition that required their attention [12]. The teachers expressed frustration with parents, whose children were identified as needing services in the first grade, but parents disagreed because they did not want them to have special education. Parents waited until fourth grade, when it was clear to them that the child was struggling, to apply for the service they wanted their child to have, but the teachers had to make up 3 years by the time [12].
5.3.2.2 Good practices/ suggestions

However, when the communication between families and professionals in education was rated to be very good, education professionals felt well informed about the child’s health needs [13]. Some parents actively started to communicate with the teachers before the child would return to school, in order to give enough information about their condition, so the teacher could share it with the child's classmates [14]. Also, regular parents’ support meetings were arranged at school together with several education professionals in school [1]. In some cases, education professionals fostered support by providing students with a comfortable return to the classroom setting [14]. In the time of absence, some teachers replaced the missing child with a photography or a symbolic figure like a teddy bear and parents sent photos and e-mails from the child that were read out loud in class. It decreased the communication failure between the child and their peers but also between families [1].

5.3.3 Communication between professionals in health care and education, problems and good practices/ suggestions in the field

As there were different opinions whether the others beside the parents, such as education professionals, needed to know about the illness of the child or not [10], the relations between the professionals in health care and education might become difficult. In some cases, there were key workers in education settings, who managed the information between education and health care setting [1], but in other cases the health care staff turned to different education professionals to share information about the child’s health [9].

5.3.3.1 Problems

The findings suggested that a complex interplay of attitudinal, institutional and wider political and economic factors was likely to undermine the effectiveness of communication between health and education professionals [8]. Health care professionals reported that they communicated with the professionals in education a few times per year or less [9]. The barriers of communication expressed by the health care professionals were not having enough time in the day, finding education professionals inaccessible, not being able to obtain reimbursement for collaborating, not knowing with whom to collaborate, differing views on child development but also many education professionals and frequent changes of staff [9]. A second issue that stood out from the studies was a lack of knowledge and clarity on the part of health staff and teachers about each other’s roles and responsibilities in relation to children with a medical condition [8].
5.3.3.2 Good practices/ suggestions

During the time child was in hospital setting, health care professionals supported a young person with a visiting teacher. This involved a team approach beforehand to identify the student’s needs and to clarify their medical condition for teachers. So, they were aware of potential challenges and ways in which they could support the student including what information to give to other students [1]. Education professionals organised groups of children, usually good friends, to visit the health care setting or the student’s home. However, the visits needed to be arranged sensitively and prepared thoroughly [1]. A weekly session was arranged between the professionals in education and health care connecting what was happening to the young person in the health care setting and for the young person to keep up with what was happening at the education setting [1].

Some studies showed that the health care professionals ranked the collaboration with the education setting as very beneficial. In fact, some of the paediatricians indicated that they were currently collaborating with educational professionals. However, the most commonly reported frequency of collaboration with education professionals was only a few times per year [8, 9].
6 Discussion

This systematic review explores how communication between the professionals in health care, education and family is arranged for or spontaneously constituted, when the family had a child with a chronic health condition. To target this aim database searches resulted in a total of 14 suitable articles. In this section findings of the articles are discussed in relation to the background and other literature. Thereupon limitations are debated to reach out to the recommendations for future research.

6.1 Reflection on the findings

6.1.1 The communication between the professionals in health care and the family

In the case that the child has a chronic health condition that requires being in health care periods of time, communication becomes a critical link between the health care professionals and parents. In this review, several articles pointed out lack of communication and the reasons mentioned were limited time and knowledge, but also attitude issues concerning how much to share. High workloads, staff shortages and feeling unprepared to consult families about severe health conditions were also highlighted (Liben, Papadatou & Wolfe, 2007). Partnership-building between physicians and patients’ enhancing treatment strategies were easier when the patients were more engaged in the decision-making process and clinicians shared more information with them (Street, 2016). Other studies (Klick & Heuer, 2010) have showed the key steps for effective communication with families, i.e the communication should be used as a specific tool to help build relationships; resolve conflicts; deliver bad news; foster common understandings about challenges, hopes, and goals; and improve collaboration in decision-making and in determining care plans that are consistent with these hopes and goals. The task of communication in the care setting is to relieve the suffering of a conflict, confusion, and decision-making by creating a sense of teamwork and facilitating collaboration. Therefore, it can be said that the impact of communication cannot be overrated. In terms of success, there needs to be time for consultations and personnel training to be able to consult a child and the family. At the same time the attitudes must be changed in general to avoid silence and misunderstandings. Martin (2014) also agrees that the problems were created at the first stage when the information was not explained clearly, was omitted, or included many details without the support of helping the recipient remember the information. According to the results, once the needed information was in place, much could be done to motivate patients according to this
review—but only when there was a clear understanding of the patients’ life circumstances, concerns, ideals, and goals. Thus, effective communication was again, the key factor.

Several articles suggested for a key worker to represent a middle man who organizes communication, helps families to understand the process better and keep in touch with the medical team to share information back and forth. This is in line with Barbosa (2013), who recommends a discharge planner or a social worker who could be the organizer of the further communication. Thus, ensuring service availability and coverage, working in close contact with the medical team and having up-to-date information for the family of the child. This way, a key-worker would act similarly to a care manager, who is providing an individualized service to meet the needs of a particular person, rather than requiring the person to fit whatever was already available (Harris & White, 2018). In a clinical setting this would mean a collaboration between doctors, nurses and other specialists who will gather information about the child for a key-worker. He or she would then address it to the family and pass the parents’ questions to the medical team, for answering or arranging meetings to discuss the issues of the child.

6.1.2 The communication between the professionals in education and the family

Concerning the education setting, the results show that there are difficulties in the communication between the education professionals and the family. Teachers are accusing parents for not sharing enough information about the child with a medical condition, similarly to a study about school re-entry program (Worchel-Prevatt, et al., 1998). According to the study, the described family did not consider talking about their child’s illness at all to the education professionals. Sharing the information on time might trigger the co-operation and the professionals in education might try to adjust and educate themselves (Grier & Bradley-Klug, 2011; Hopkins & Hughes, 2016).

The results from the two cases in this literature review, showed that kindergarten workers started to gather information to help the child in a good way having met the parents who told the kindergarten workers about the child’s health condition. In the first case, the child had a brain tumour operated and in the second case, the breathing for the child was possible only by a breathing tube. The communication was hindered as parents in some cases of this review, accused teachers for not keeping in touch when the child should to be at home in health care setting due to health problems. Kaffenberger (2006) suggests that meetings should be arranged by the education counsellors as soon as there is information to be given about the child’s health condition in order to support the family and suggest available services in
education setting. The communication between the family and the education setting is only about the child and in case of the health condition, additional information needs to be shared. Without co-operation with each other, there will be a lack of achievement for the child, as he/she is struggling anyway because of the health problems and needs to be assisted in both home and education setting to keep pace with peers and not fall behind.

Several studies recommended using a key-person to coordinate the relationship better between the education setting and the family of a child. An article (Foley, Dunbar & Clancy, 2014) proposes that school nurses be the link or key-person between the education setting and the family, explaining that nurses have more time and varied interactions with the students and their families. Allowing them to provide consistent messages and education to empower families to talk about their health care problems and decrease misunderstandings. In this way, a key-person can improve communication by managing relations and keeping the child as the priority, so that everybody involved would have up-to-date information about the health condition. Moreover, that the family is covered by the information on homework and moving on with classes when the child needs to spend away from the education setting.

6.1.3 The communication between the professionals in health care and education

The difficulties in communication were reported by many of the studies in this review between the education and health care setting. It could be solved so that there would be ongoing partnership between the education and health care settings of the same district. This partnership would allow continuity of co-operation and develop patterns of action to use in case there will be a new child with a chronic condition. It is especially important that the team develops and embraces a truly interagency collaborative relationship, the representatives of the local school/kindergarten and the local hospital district could have the opportunity to present the concerns about the need for a more seamless approach for identifying children who would soon be in the process of transitioning back into their school (Chesire, Canto & Buckley, 2011). The education professionals should find the motivation to communicate with the child’s physician or discharge coordinator, which allows them to be ready to best meet the child’s educational needs (McCabe, P.C, 2007).

As in both of the previous chapters, it is again emphasized to have a key worker to coordinate the communication and relation in this case, between health care and education settings. Inversely a study (Aruda, Kelly & Newinsky, 2011) claims that families of the children are the primary coordinators between health care and education. This of course would hinder
coping of the families, who amongst the other responsibilities have a burden of taking care of the child with a chronic health condition anyway. The other question is the competence issue. The capability of parents picking up the information adequately from the health care team cannot be guaranteed, as clinicians were using the medical language which, as brought out before, makes the clear communication and information sharing even more complicated. So, if the family was in a role of the key-person between school/ kindergarten and the health care communication, there might be some important information missing (Strawhacker & Wellendorf, 2004).

6.2 Practical implementation

This literature review mainly concentrates on the communication between the professionals of health care, education and family in relation to a child with a chronic health condition. These aspects are pertained to the microsystems and mesosystems described by U. Bronfenbrenner’s bioecological model of human development. According to the Kliebenstein & Broome (2000) interpretation of the bioecological model, microsystem characteristics influence a child with a chronic health condition entering the education setting negatively or positively. It is dependent on the qualities of the teacher but also peer interactions and the instructional environment of the education setting. A child with a chronic health condition is participating in family relations, education and health care setting, of which each can provide different aspects for their development (Bronfenbrenner & Ceci, 1994). The mesosystem becomes critical for the professionals in health care, education and family to work together for the mutual goal. Kliebenstein & Broome (2000) indicate that before the child is discharged from hospital, the professionals of health care and education need to come together in which the mesosystem should be facilitated by effective communication, information sharing and future planning. This is also emphasized by Aruda, Kelly & Newinsky (2011). This literature review addresses the same issues highlighting the mesosystem between the professionals of health care, education and family, that is not a layer outside the microsystem, but a relationship between microsystems (Rosa & Tudge, 2013).

6.3 Limitations

Proportionally various samples from different locations of this literature review can be considered as strengths, however there are still multiple limitations. To begin with, only the articles in English were used and in narrow range of databases (CINAHL, ERIC. PsycINFO and ScienceDirect). A wider search using more languages would probably have increased the
number of hits and the diversity of articles. In that rate, a deeper understanding of the problems, good practices and suggestions would have been possible to reach. Also, search process consisted of terms “family” and “parents”. Term “caregiver” was not used while searching in any of the databases. This may have led to the limitation of the number of found articles.

The assessment of the articles was performed using the modified tool created in the basis of the measurement instrument, which originally was not meant to assess studies with different methodology and in addition was not tested previously. Even more, the author of this paper solely modified the assessment tool for articles, by reformulating questions to suit with different types of studies and by adding questions related to the topic of this review.

In addition, the process of choosing the articles was also done by the author of the paper and only a third of the chosen articles was randomly chosen for the peer-review process. During the peer-review, the second reviewer was asked for the full-text reading of the articles together with the aim of the paper and research questions, to confirm or oppose the choice that the author of the review had already done. But the majority of the articles were scanned only by the author of the review solely, which may have increased the possibility of bias in the process of choosing.

Thereto, the chosen 14 articles chosen will make an average sample for the review, but there was only one article among all others that reflected on all the research questions. The rest informed the reader only about the communication between certain parties only and even though the studies were represented differently using several different terms and addressed several different issues, the communication was only one part of it. Therefore, it is impossible to generalize and to compare the studies with each other.

6.4 Future research

To explore how the communication between the professionals in education, health care and family is constituted in case the family has a child with a chronic health condition, this literature review is provided. However, more specific and detailed analyses need to be conducted to discover the deeper issues concerning the problems, good practices and suggestions, which can lead to the development of a model for a successful communication in case the child has a chronic health condition. This can also become a handbook for education and health care professionals, but also for the parents of the child.

Secondly, as the review was lacking the studies related to all three parties of the child’s network, research could be done including all parties. For example, using focus groups so that
parents, health care professionals and school or kindergarten representors would be present. Including children themselves can also be an option, as there were only 2 articles out of 14, that considered the family not only as parents but also the child.

Thirdly, the understanding of communication- how it is expected to be and the settings of education and health care and the concept of family might vary in different cultures and ethnic groups. As different cultures are mixed together more and more, the future research should take it into account, planning the sample of the participants and building up questionnaires.

6.5 Conclusion

A chronic health condition demands a great deal from the person, but in case the person is a child, it places an extra pressure and burden of care on the parents, who are directly responsible for the welfare of their child. Caring for the child that needs to spend periods of time away from the natural setting, such as school, kindergarten or home to have needed treatments because of the health problems, is only one part of the parent’s commitment. Being away in health care can be facilitated by the effective communication between the professionals of health care, education and family. Therefore, a clear and honest communication plus the effort from key-workers coordinating communication can be beneficial to lower the burden of care for the parents. Even though this review has its limitations, it tried to give an overview of the current situation in the communication between the professionals in health care, education and family, bringing out the problems but also the examples of good practice and suggestions made. Regardless of the possible strategies suggested by this review to improve the situation, the constantly highlighted lack of communication cannot be ignored and needs to be dealt with.
7 References


Barbosa, V.M. (2013). Teamwork in the Neonatal Intensive Care Unit. *Physical & Occupational Therapy in Paediatrics, 33*(1), 5-26


Hopkins, A.F., Hughes, M.-a. (2016). Individualized Health Care Plans: Supporting Children with Chronic Conditions in the Classroom. *Young Exceptional Children, 19*(2); 33-44


Mccarthy, C. (2016). Why communication is the key to diabetes success. *Optometry Times, 8*(3), 1,5


# Appendix A. Protocol for full-text screening.

## Protocol used for full-text screening and data analyses

### General information
- Number of the article
- Author
- Year of publication
- Title
- Published by
- Country where the research was done
- Research questions/ aim
- Hypothesis
- Abstract/ summary of the article

### Children’s characteristics
- Diagnose
- Description of the condition
- Age range

### Participants of the study
- School workers/ health care workers/ family
- How many?
- Age range
- Mean age

### Method
- Quantitative/ qualitative/ mixed/ other
- Survey/ questionnaire/ interview/ focus group/ mixed/ other
- Data analysis method

### Study setting
- Recruitment, how?
- Recruitment, where?
- Sampling strategy
- Control group

### Results
- Communication between health care and education workers
- Communication between health care workers and family
- Communication between education workers and family
- Conclusion of authors

### Additional results
Communication between all 3 parties: health care and education workers and family
Problems brought out

<table>
<thead>
<tr>
<th>Limitations/suggestions</th>
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<tr>
<td>Limitations mentioned by authors</td>
<td></td>
</tr>
<tr>
<td>Suggestions made by authors</td>
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</table>

| Included? | Yes/ No |
Appendix B. Quality assessment questions modified using CASP (CASP checklist https://casp-uk.net/casp-tools-checklists/)

Maximum score- 20 points; Minimum score- 20 points

1. Did the study address a clearly focused issue? (yes-2; can't tell-1; no=0)
   Was it clear whether the study tried to detect a beneficial or harmful effect the outcomes considered?

2. Was it clearly stated, the study was a qualitative/quantitative/mixed methodology appropriate? (yes-2; can't tell-1; no=0)
   Is research methodology addressing the research goal?

3. Was the research design appropriate to address the aims of the research? (yes-2; can't tell-1; no=0)
   Has the researcher justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research? (yes-2; can't tell-1; no=0)
   Has the researcher has explained how the participants were selected and why was the selection like it was?
   Were there any discussions around recruitment (e.g. why some people chose not to take part)?

5. Was the data collected in a way that addressed the research issue? (yes-2; can't tell-1; no=0)
   Was setting for the data collection justified?
   Was is clear how data were collected (e.g. focus group, semi-structured interview etc.) and has the researcher justified the methods chosen?
   Has the researcher made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)?
   Were methods modified during the study. If so, has the researcher explained how and why?
   Was the form of data being clear (e.g. tape recordings, video material, notes etc.) and has the researcher has discussed saturation of data?

6. Have ethical issues been taken into consideration? (yes-2; can't tell-1; no=0)
   Are there sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained?
   Has the researcher discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)?
Has approval been sought from the ethics committee?

7. Was the data analysis sufficiently rigorous? (yes-2; can't tell-1; no=0)

Was there an in-depth description of the analysis process?

If thematic analysis is used was it clear how the categories/themes were derived from the data?

Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process?

Was sufficient data presented to support the findings?

Has the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?

8. Is there a clear statement of findings? (yes-2; can't tell-1; no=0)

Was there is adequate discussion of the evidence both for and against the researcher's arguments?

Has the researcher discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)?

Were the findings discussed in relation to the original research question?

9. Have the researchers discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used (yes-2; can't tell-1; no=0)?

10. Does the study describe communication between all three parties (2 p), or only between two parties (1 p)? None of the parties (0 p)
### Appendix C. Quality assessment scores

<table>
<thead>
<tr>
<th>Author of the study</th>
<th>Quality assessment questions (Appendix B)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Leger, 2014</td>
<td>1</td>
</tr>
<tr>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>2</td>
</tr>
<tr>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>2</td>
</tr>
<tr>
<td>Rodriguez, King, 2014</td>
<td>2</td>
</tr>
<tr>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp; Cohen, 2015</td>
<td>2</td>
</tr>
<tr>
<td>Paget, Mallewa, Chinguo, Mahebere-Chirambo &amp; Gladstone, 2016</td>
<td>2</td>
</tr>
<tr>
<td>Mostert, Gunawan, van Dongen, van de Ven, Sitaesmi, Wolters, Veerman, Mantik &amp; Kaspers, 2013</td>
<td>2</td>
</tr>
<tr>
<td>Poursanidou, Garner &amp; Watson, 2008</td>
<td>1</td>
</tr>
<tr>
<td>Bradley-Klug, Sundman, Nadeau, Cunningham &amp; Ogg, 2010</td>
<td>2</td>
</tr>
<tr>
<td>Mayer., Parsons, Terrin, Tighiouart ja Jeruss, 2005</td>
<td>2</td>
</tr>
<tr>
<td>Kirk &amp; Glendinning, 2002</td>
<td>2</td>
</tr>
<tr>
<td>Selekman, 2016</td>
<td>2</td>
</tr>
<tr>
<td>Asprey &amp; Nash, 2006</td>
<td>2</td>
</tr>
<tr>
<td>Sullivan, Fulmer &amp; Zigmond, 2001</td>
<td>1</td>
</tr>
<tr>
<td>Strong &amp; Sandoval, 1999</td>
<td>2</td>
</tr>
</tbody>
</table>
## Appendix D. Characteristics of the included studies

<table>
<thead>
<tr>
<th>Number of the study</th>
<th>Study</th>
<th>Country</th>
<th>Study is about</th>
<th>Type of the study</th>
<th>Data generation+ analysis</th>
<th>Quality assessment rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>Australia</td>
<td>How do health professionals and teachers make decisions about supporting young people whose lives are disrupted by chronic health conditions to stay in touch with schooling</td>
<td>Qualitative</td>
<td>Interviews and focus groups. The framework used to analyse transcriptions from the interviews and focus groups was adapted from Davison’s compilation of knowledge translation indicators.</td>
<td>High</td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>Australia</td>
<td>To explore ethical issues encountered by social workers in their everyday practice communicating with families and other health professionals in a paediatric hospital context in Australia.</td>
<td>Qualitative</td>
<td>Interviews (semi structured), phenomenology was used, analysed thematically.</td>
<td>High</td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>Israel</td>
<td>This study explores factors related to parents’ expectations and assessments of care in a new born intensive care unit (NICU) in Israel.</td>
<td>Mixed</td>
<td>Interviews, but part of it was close- end question, based on questionnaires and analysed as quantitative material.</td>
<td>High</td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King, 2014</td>
<td>United Kingdom</td>
<td>To explore the lived experience of caring and care planning for a child with a life-limiting condition (LLC).</td>
<td>Qualitative</td>
<td>The interpretive/ hermeneutic phenomenological research methodology of van Manen. Focus group discussions and interviews were used.</td>
<td>Very high</td>
</tr>
<tr>
<td>5</td>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp; Cohen, 2015</td>
<td>Canada</td>
<td>This study explores the implementation process of the Integrated Complex Care Model: a voluntary partnership between acute, rehabilitative and community care aimed at system integration through a key worker model to improve care co-ordination for CMC (children with medical complexity).</td>
<td>Qualitative</td>
<td>First, basic questionnaire, and in base of it semi-structured interviews, focus groups, document review and audit of administrative databases.</td>
<td>High</td>
</tr>
<tr>
<td>6</td>
<td>Paget, Mallewa, Chinguo, Mahebere-Chirambo &amp; Gladstone, 2016</td>
<td>Malawi</td>
<td>This study explores perspectives and experiences of caregivers of children with disabilities (CWD) from acquired brain</td>
<td>Qualitative</td>
<td>In depth interviews were completed with parents/carers and health care workers+</td>
<td>Very high</td>
</tr>
<tr>
<td>Study Number</td>
<td>Authors</td>
<td>Country</td>
<td>Study Background</td>
<td>Methodology</td>
<td>Data Analysis</td>
<td>Level of Evidence</td>
</tr>
<tr>
<td>--------------</td>
<td>---------</td>
<td>---------</td>
<td>------------------</td>
<td>-------------</td>
<td>--------------</td>
<td>------------------</td>
</tr>
<tr>
<td>7</td>
<td>Mostert, Gunawan, van Dongen, van de Ven, Sitaresmi, Wolters, Veerman, Mantik &amp; Kaspers, 2013</td>
<td>Indonesia</td>
<td>Study investigates health-care providers’ perspectives on childhood cancer treatment in Indonesia. Their health beliefs and attitudes toward parental financial difficulties, protocol adherence, parental education, and communication were explored.</td>
<td>Quantitative</td>
<td>Questionnaires. This was a cross-sectional study using a self-administered semi-structured questionnaires. Frequency distributions were calculated. Reliability of items in the questionnaire was established. Cronbach’s alpha coefficient was calculated. Mann–Whitney test was used to compare differences in health beliefs between doctors and other health care professionals. Data management and analysis were performed with SPSS for Windows version 17.0.</td>
<td>Very high</td>
</tr>
<tr>
<td>8</td>
<td>Poursanidou, Garner &amp; Watson, 2008</td>
<td>United Kingdom</td>
<td>This article explores collaboration between health and education staff as a key aspect of educational provision for children with chronic medical conditions, drawing upon material from interviews with eight health professionals (paediatric nephrologists and specialist renal nurses) and 11 mainstream schoolteachers involved in the care and schooling of children with renal transplants.</td>
<td>Qualitative</td>
<td>Interviews with families + interviews with teachers + individual semi-structured interviews with health care professionals.</td>
<td>High</td>
</tr>
<tr>
<td>9</td>
<td>Bradley-Klug, Sundman, Nadeau, Cunningham &amp; Ogg, 2010</td>
<td>United States of America</td>
<td>The overall goal of this study was to inform the development of specific strategies applicable to the daily practice of school psychology practitioners and trainers to facilitate communication and collaboration across systems.</td>
<td>Quantitative</td>
<td>Surveys were mailed. Data were analysed using SAS software, Version 9.1 of the SAS System for Windows</td>
<td>High</td>
</tr>
<tr>
<td>10</td>
<td>Mayer., Parsons, Terrin, Tighiouart ja Jeruss, 2005</td>
<td>United States of America/Japan</td>
<td>Study is about school re-entry for children with cancer hallmarks a return to age-appropriate activities; a process fraught with adjustment challenges. To understand physicians’ attitudes and behaviours</td>
<td>Quantitative</td>
<td>Surveys were used. Survey contained of hypothetical scenario of the case. Descriptive statistics were calculated for all survey responses. Variables were tested for significance using the likelihood ratio test.</td>
<td>High</td>
</tr>
</tbody>
</table>
regarding school re-entry will provide insight into these practices.

<table>
<thead>
<tr>
<th>Study Number</th>
<th>Authors</th>
<th>Country</th>
<th>Methodology</th>
<th>Data Collection</th>
<th>Analysis</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Kirk &amp; Glendinning, 2002</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>Face-to-face, in-depth qualitative interviews were conducted with parents.</td>
<td>SAS version 8.2 was used for all analyses.</td>
<td>High</td>
</tr>
<tr>
<td>12</td>
<td>Selekman, 2016</td>
<td>United States of America</td>
<td>Mixed</td>
<td>Focus groups (1st phase) and electronic surveys (2nd stage). The tapes were transcribed by a paid service and then all transcriptions were checked against the original tapes by the primary researcher. Surveys were analysed using Pearson's and Likert-type scale.</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Asprey &amp; Nash, 2006</td>
<td>United Kingdom</td>
<td>Qualitative</td>
<td>Semi-structured interviews were conducted</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Sullivan, Fulmer &amp; Zigmond, 2001</td>
<td>United States of America</td>
<td>Qualitative</td>
<td>Interviews were performed, and medical records of the children were used as the background information. Audiotaped</td>
<td>High</td>
<td></td>
</tr>
</tbody>
</table>
young survivors approach the process of living each day. Attendance obstacles are discussed, along with guidelines for maintaining school as a priority.

interviews were transcribed into Microsoft Word 6.0. Two additional sets of documents (medical profile information and summary documents) were also transcribed.
## Appendix E. Characteristics of the participants

<table>
<thead>
<tr>
<th>Number</th>
<th>Study</th>
<th>Participants</th>
<th>n</th>
<th>Gender (male/female)</th>
<th>Mean age</th>
<th>Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>Education workers</td>
<td>12</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Health care workers</td>
<td></td>
<td>12</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>Health care workers (social workers in hospitals)</td>
<td>9</td>
<td>0/9</td>
<td>41</td>
<td>25-56</td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>Families (couples)</td>
<td>63</td>
<td>63/63</td>
<td>31.8 (fathers);</td>
<td>?</td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King, 2014</td>
<td>Health care workers</td>
<td>21</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td></td>
<td>20</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>5</td>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp; Cohen, 2015</td>
<td>Health care workers</td>
<td>21</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td></td>
<td>23</td>
<td>?</td>
<td>38</td>
<td>?</td>
</tr>
<tr>
<td>6</td>
<td>Paget, Mallewa, Chinguo, Mahebere-Chiramo &amp; Gladstone, 2016</td>
<td>Health care workers</td>
<td>33</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Families (one member per family)</td>
<td></td>
<td>14</td>
<td>2/12</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>7</td>
<td>Mostert, Gunawan, van Dongen, van de Ven, Sitaresmi, Wolters, Veerman, Mantik &amp; Kaspers, 2013</td>
<td>Health care workers</td>
<td>222</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>8</td>
<td>Poursanidou, Garner &amp; Watson, 2008</td>
<td>Health care workers</td>
<td>8</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Education workers</td>
<td></td>
<td>11</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td></td>
<td>14</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>9</td>
<td>Bradley-Klug, Sundman, Nadeau, Cunningham &amp; Ogg, 2010</td>
<td>Health care workers</td>
<td>561</td>
<td>253/308</td>
<td>39.8</td>
<td>35-44</td>
</tr>
<tr>
<td>10</td>
<td>Mayer., Parsons, Terrin, Tighiouart ja Jeruss, 2005</td>
<td>Health care workers (Japan) + 348 (USA)</td>
<td>358</td>
<td>289 (Japan) + 205 (USA)/69 (Japan) + 143 (USA)</td>
<td>43.8</td>
<td>?</td>
</tr>
<tr>
<td>11</td>
<td>Kirk &amp; Glendinning, 2002</td>
<td>Health care workers</td>
<td>41</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Families</td>
<td></td>
<td>24</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>12</td>
<td>Selekman, 2016</td>
<td>Education workers</td>
<td>14</td>
<td>(focus group) + 1280 (surveys)</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>13</td>
<td>Asprey &amp; Nash, 2006</td>
<td>Families (parents + children)</td>
<td>46</td>
<td>(parents)+</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>47</td>
<td>(children)</td>
<td>24/23</td>
<td>4-19</td>
</tr>
<tr>
<td>14</td>
<td>Sullivan, Fulmer &amp; Zigmond, 2001</td>
<td>Families (including children)</td>
<td>10</td>
<td>(parents)+</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8</td>
<td>(children)</td>
<td>3/5</td>
<td>11.4</td>
</tr>
</tbody>
</table>
## Appendix F. Characteristics of the children

<table>
<thead>
<tr>
<th>Number</th>
<th>Study</th>
<th>Diagnose, special need</th>
<th>Description of the special need</th>
<th>Gender; male (n)/ female (n)</th>
<th>Mean age; Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>Chronic disease</td>
<td>Leukaemia, cancer.</td>
<td>?</td>
<td>Until the age 18</td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>Children with medical complexity</td>
<td>Patients in oncology, rehabilitation, general medicine, adolescent health and emergency department.</td>
<td>?</td>
<td>Not specified</td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>Infants with very low birth weight</td>
<td>Weighs less than 1750 grams.</td>
<td>?</td>
<td>Infants</td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King, 2014</td>
<td>LLC (life-limiting condition)</td>
<td>LLCs are those for which there is currently no available cure and the condition is likely to lead to the child dying prematurely. Of these children, 4 had been given cancer diagnoses (1 brain tumour, 1 bone cancer, 2 leukaemia) and the remaining 16 had been given other diagnoses (3 cerebral palsy, 1 muscular dystrophy, 1 congenital, 1 neurological, 10 rare genetic issues).</td>
<td>?</td>
<td>Not specified</td>
</tr>
<tr>
<td>5</td>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp; Cohen, 2015</td>
<td>Children with medical complexity</td>
<td>Neurological impairment (61%), technical assistance (87%)- mostly gastronomy tube.</td>
<td>12 M/11 F</td>
<td>7.5; under 18 years of age</td>
</tr>
<tr>
<td>6</td>
<td>Paget, Mallewa, Chinguo, Mahebere-Chirambo &amp; Gladstone, 2016</td>
<td>Neuro disability</td>
<td>Caused by illnesses such as meningitis, cerebral malaria, encephalitis, but also trauma and birth asphyxia. Most children had suffered the episode of brain infection/injury in the previous 3 months (range from 2 weeks to 2½ years).</td>
<td>?</td>
<td>8 months-11 years</td>
</tr>
<tr>
<td>8</td>
<td>Poursanidou, Garner &amp; Watson, 2008</td>
<td>Children with chronic renal failure</td>
<td>Children having renal transplants.</td>
<td>?</td>
<td>Not specified</td>
</tr>
<tr>
<td>9</td>
<td>Bradley-Klug, Sundman, Nadeau, Cunningham &amp; Ogg, 2010</td>
<td>Chronically ill children</td>
<td></td>
<td>?</td>
<td>Not specified, school aged children</td>
</tr>
<tr>
<td>10</td>
<td>Mayer., Parsons, Terrin, Tighiouart ja Jeruss, 2005</td>
<td>Children with cancer</td>
<td></td>
<td>?</td>
<td>10-17 years</td>
</tr>
<tr>
<td></td>
<td>Author</td>
<td>Description</td>
<td>Needs of</td>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-------------------</td>
<td>--------------------------------------------------</td>
<td>----------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Kirk &amp; Glendinning, 2002</td>
<td>Technology-dependent children</td>
<td>of changing tracheostomy tubes or administering intravenous medications regularly.</td>
<td>?</td>
<td>4 months- 17 years</td>
</tr>
<tr>
<td>12</td>
<td>Selkman, 2016</td>
<td>Children with different chronic conditions</td>
<td></td>
<td>School aged children</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Asprey &amp; Nash, 2006</td>
<td>LLC (life-limiting conditions) and LTC (life-threatening conditions)</td>
<td>Children with muscular dystrophy, heart disease, cystic fibrosis and cerebral palsy.</td>
<td>24 M/ 23 F</td>
<td>4-19 years</td>
</tr>
<tr>
<td>14</td>
<td>Sullivan, Fulmer &amp; Zigmond, 2001</td>
<td>Children with ALL (acute lymphoblastic leukaemia)</td>
<td></td>
<td>11,4; 10-12</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix G. Findings of the studies- communication between health care and family.

<table>
<thead>
<tr>
<th>Number</th>
<th>Author of the study</th>
<th>Description of the current situation</th>
<th>Current problems</th>
<th>Current good practices</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>In case child have been in hospital care long time, health care workers have close relationships with families.</td>
<td>Health professionals reported feeling torn between the development of family-focused role of providing counsel, which requires time that does not necessarily fit into schedules and budgets of the hospital.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Delan, Richards, Stewart &amp; Kosta, 2017</td>
<td>Often some members of health care teams in hospital already have an information about the child's health situation, but it is not their authority to deliver it to parents, so family needs to wait until the professional comes to talk to them. Misunderstandings between clinical staff and parents with a hospitalized child. Parents do not understand the meaning of information about medical situations given by medical professionals. Often there is many medical workers and only one parent in the meeting, which may lead to feeling too stupid to ask questions.</td>
<td>Building a relationship between medical staff and family is often the work of social worker, who acts as a middle-man in communication, interpreting information in a sensitive way, giving a context to a situation and explaining medical situations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Auslander, Netzer &amp; Arad, 2003</td>
<td>Some families are likely to prefer an indirect approach, whereas others may prefer direct and detailed information about the child’s condition.</td>
<td>Wrong expectations towards hospital staff: failure to provide information was the most commonly cited criticism of the physicians. Nurses, on the other</td>
<td></td>
<td>In settings that serve a multicultural patient population, staff needs to be available that speak the patients’ language. If no native speakers are on staff,</td>
</tr>
<tr>
<td></td>
<td>Authors</td>
<td>Description</td>
<td>Notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------</td>
<td>-------------</td>
<td>-------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Rodriguez, King, 2014</td>
<td>Professionals are expected to share information about the child's situation, but also to help with decision making. Parents desire to be involved in care planning and care decisions but not always to be the ones who had to flag issues or be making the final decisions.</td>
<td>The burden of care is so great that parents feel it is too much of energy needed forward planning or 'second guessing' or just to orchestrate required discussions. Family members need to introduce the situation to many professionals, visiting their home. As there are no predictions, how long would the child live, families are left with little assistance. Hospital staff are expected to deliver good service against all odds, work longer than paid hours and being involved in tasks outside their competence.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Kingsnorth, Lacombe-Duncan, Keilty, Bruce-Barrett &amp;</td>
<td>For example, a team member at each organization is responsible for addressing issues related to the sharing of patient information. Some parents do not trust key-workers completely to trust them care co-ordination. In some cases, care plans of children are not physically</td>
<td>Communication between families and key workers, between key workers themselves and between key workers and other healthcare providers involved was felt to be strong, enabling care co-ordination at the family level. Parents noted a variety of positive ways that hospitals should make basic language training available. Medical care staff should be aware of differences in communication norms and preferences in their patient population. It is important to individually assess preferences, being attuned to differences without assuming they exist. Key-worker, who would act as a middle-man between medical care staff and families is necessary. Medical care workers should share the information amongst themselves if working with one family, so that family should not tell their story every time from the beginning. Parents want to feel reassured that their children were in 'good hands', even if they were aware of a lack of provision, would ease their day-to-day burden.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohen, 2015</td>
<td>Review of meeting minutes identified the accomplishment of key deliverables as a direct result of strong working relationships. Families use care plans for numerous reasons across multiple settings. Families who did not feel that care had changed, were those who believed that communication between health care settings was already adequate and/or families whose children were stable during the research. distributed to families and exist only at hospital setting. key workers impacted the life of their child and family, including connecting them to new, altering existing and/or referral to additional services, co-ordinating outpatient visits, attaining funding and offering emotional support. Half of families felt that care had changed since enrolment citing examples of increased communication and collaboration between healthcare providers and decreased parental burden. Families identified care plans as helpful, for reasons of not having to repeat information within a clinic or emergency department setting, helping them feel at ease that providers have accurate, up-to-date information about the care of their child and assisting with the provision of timely and appropriate care.</td>
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<td>Paget, Mallewa, Chinguo, Mahebere - Chirambo &amp; Gladstone, 2016</td>
<td>Communication between health care providers and parents/carers generally is reported as poor. Parents saw acquiring information about their child’s condition as a privilege rather than a right; hence, it was unusual to get requests for clarification. Health workers normally provided information on diagnosis, management, investigations, prognosis, and how to care for the child at home. Health care workers try to counsel parents about the future, that the child will grow, but will stay the same. Parents/carers often find it hard to believe and blame magic and so on. As lot of parents still do not understand, that their child will not heal from this condition, they blame hospital of releasing the child too soon, because child it not well enough. To prevent good communication between health care workers and families, the barriers such as lack of adequate time for counselling, lack of knowledge and confidence of health care workers and lack of ability of parents to understand information about their children’s health condition needs to decrease.</td>
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but this needed tailoring to the educational level of the carer. Explanations were sometimes considered too "biological" or "too basic" for carers.

| 7 | Mostert, Gunawan, van Dongen, van de Ven, Sitaresmi, Wolters, Veerman, Mantik & Kaspers, 2013 | Clear explanations to patients and parents are crucial to ensure cooperation and adherence with chemotherapeutic regimen according to 86% of health care providers (HCP). Parents are always warned for recurrence of cancer if they do not complete treatment by 21% of HCPs. Communication with parents is hindered by differences in status and social hierarchical structures according to 83% of HCPs. Poor communication between patients, parents, and doctors decreases the prognosis of children with cancer according to 81% of HCPs. | In total, 88% of HCPs admitted using medical vocabulary with parents and patients whom they knew parents and patients would not understand. Information about cancer and its treatment makes parents more afraid or depressed about the future and they prefer not to know, according to 27% of HCPs, 20% are uncertain about this statement, and 53% disagree. Only 1% of HCPs always verified if parents understand the information they provide about disease, treatment, and medication. Important information was always rehearsed by 2% of HCPs. Some difficulties in openly discussing the disease with parents and patients are encountered according to 57% of HCPs, and more severe difficulties are experienced according to 14% of HCPs. This study illustrated that many health care providers (HCP) believe that parental financial difficulties influence beliefs, attitude, and behaviour of medical professionals. There was a distinction reported in |
the quality of care towards families with poor versus prosperous socioeconomic backgrounds, that receive more time, accuracy, thoroughness, and attention according to a considerable minority of HCPs. Poor families receive less explanation and cooperation from the medical team, and encounter more difficult vocabulary according to approximately half of all HCPs. It is the more striking that almost all HCPs denied differences in the quality of medical care between poor and prosperous patients. Before a problem can be solved, HCPs first need to recognize that there is one.

<table>
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<tr>
<th></th>
<th>Mayer., Parsons, Terrin, Tighiouar t ja Jeruss, 2005</th>
<th>The most striking difference between the two countries was related to explicitly telling the child about their diagnosis. Most Japanese physicians (61.8%) did not explicitly tell the child their diagnosis; only 9.5% (34/359) always told. Conversely, 65% (227/349) of the US physicians always explicitly told the child the diagnosis.</th>
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<td>11</td>
<td>Kirk &amp; Glendinni ng, 2002</td>
<td>Parents’ expertise was rooted in both the knowledge they had derived from the training programs they had undergone before their child’s discharge from hospital and in the experiential and intuitive knowledge derived from their Both parents and professionals reported problems in relation to type of support, where the provision of equipment and medications, and obtaining a break from caring, were concerned. Problems arose in both areas first, because it was not clear who was responsible for funding these services in the community and only a small minority of professionals reported feeling threatened by parent’s expertise, although some parents felt that some generic community-based professionals had avoided them because they felt threatened by parents’ superior knowledge. Honesty in relation to professional limitations, as described in the data extract below was seen an important factor in promoting a more trusting, egalitarian relationship between parents and professionals.</td>
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subsequent experience of caring for their child.

Working with parents was acknowledged by professionals to be different, as it was often parents rather than professionals who were the experts in the child’s care. This could transform the nature of the parent-professional relationship as well as roles of professionals themselves.

secondly because services appropriate for children who needed very specialised care were often simply not available in the community.

Families criticised local community nursing services for their poor arrangements for obtaining equipment and consumable supplies. These parents consequently continued to rely on the specialist hospital from which their child had been discharged to provide supplies if none were available from local community nursing services; this was particularly problematic for families living far from the specialist regional hospital or who had no transport of their own.

For many families, problems in obtaining adequate supplies was a source of considerable stress; some parents reported having had disputes with nurses and general practitioners over the quantity of consumables needed. The provision of equipment appeared to be particularly problematic for children with a tracheostomy.

Few parents reported that any local healthcare professional had assumed responsibility for co-ordinating the supply of equipment and services which they needed for their child. Consequently, parents had to adopt

Parents valued having their expertise acknowledged by professionals in this way; however, this was not always the case, leading to conflictual relationships.

In addition, nurses considered that part of their role was to ensure that parents performed clinical procedures safely. Parents found it reassuring to know that there was someone who was familiar with their child’s circumstances, who was easy to contact and personally approachable if they needed help, advice or information- someone who “was there for them”. Parents felt that this type of support promoted their confidence and helped them to cope with caring for their child. Having an easily accessible source of professional advice and help could also reduce the intrusion of professionals into the home as parents could seek help when they needed it.

Parents valued the practical help they received from professionals as this could make a considerable difference to the work involved in caring for their child.

An element of emotional support was being able to talk to and share with a professional who was familiar with the family, any worries or anxieties they might be experiencing. Professionals also recognized that enabling parents to express their feelings and concerns was an important aspect of providing

Continuity in parent-professional relationships was identified by both parents and professionals as being important in developing a relationship characterized by mutual recognition of respective knowledge and expertise.

Professionals could also act as an intermediary with other workers on the family’s behalf and thus take the pressure off parents who were considered to have enough to cope with in just looking after their child without having to organise professional services as well.

Both parents and professionals identified how professionals could act as an advocate on the family’s behalf, for example, by writing to charities, supporting parents’ applications for disability benefits and trying to obtain appropriate support services.
this co-ordination role themselves, in addition to the other aspects of their child’s care.

Information which was offered by health care was often insufficient or conflicting, so that parents felt confused and uncertain. Inappropriate information, which did not take account of the child’s needs, was also sometimes provided.

Parents assessed and made judgements about the level of expertise and knowledge that professionals possessed. They assessed that health visitors and district nurses (and generalist family doctors and local general hospitals as well) lacked specialist knowledge and consequently had few expectations of them being able to provide advice relating to their child’s clinical care.

emotional support. Indeed, some nurses remarked that they would like additional training in counselling skills to enable them to perform this aspect of their role more effectively.

Learning to judge whether to adjust the child’s medication or when to call out a doctor, if the child seemed unwell, was not easy. A wrong judgement could have serious even fatal consequences. Nurses therefore recognised they had an important role to play in developing parents’ confidence by providing reassurance and reinforcing their decisions.

Although parents were the main providers of care for their child, nurses provided some elements of “hands-on” care, usually in relation to procedures that were either only intermittently required or where it was anticipated that over time the parents would assume responsibility. Examples included taking blood samples, dressing wounds, administering injections, passing nasogastric tubes and flushing intravenous lines. In addition, a small number of nurses provided “hands-on” support in order to give the parents a break from caring, this support was considered very helpful.
## Appendix H. Findings of the studies- communication between school staff and family.

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<tr>
<th>Number</th>
<th>Author of the study</th>
<th>Description of the current situation</th>
<th>Current problems</th>
<th>Current good practices</th>
<th>Suggestions</th>
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<tbody>
<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>Regular parent support meetings at school, many education professionals also made themselves available for informal meetings at other times. Teachers replaced missing child with photograph or teddy bear and parents sent photos and e-mails from the child, which were read out loud in class. It increased the connection between child and peers but also between families.</td>
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<td>12</td>
<td>Selekman, 2016</td>
<td>Teachers have concerns about discussing the child’s health-care needs when the parents are not English speakers and/or not having legal citizenship. Teachers express frustration with parents, especially those who do not advocate for their own children and those who refuse the development of IEPs (individualised education plan). Teachers reported they have kids who are identified as needing services in the first grade, but parents disagree because they do not want them to have special education. And they wait until fourth grade, child is still not reading and then parents decide they want child to have services, but the teachers have to make up 3 years by the time. Teachers expressed frustration about finding out which students had health conditions, but this is not always legal.</td>
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Lack of and a desire for information about the conditions their students have, especially what they should look for that indicated the child was in trouble and what they should do while they are waiting for help to arrive. It often takes weeks or months until someone shared with them that a student in their classroom had a chronic health condition that required their attention. Little help comes from school nurse who is working half time and it's impossible to reach.

| 13 | Asprey & Nash, 2006 | Even the contact with support assistants, although often much appreciated by parents, as they were reportedly more often available than teachers, was not always enough. As a result of lack of contact, schools and colleges often did not seem to be sufficiently aware of the problems associated with absence among this group of young people. Children also reportedly had to move down a set in specific subjects while others had needed to drop one or more subjects because they were unable to maintain the required standard. For many parents, high standard of communication was not experienced and therefore awareness and provision sometimes suffered. Parents complained, that the lack of communication between themselves and the school setting meant that they were sometimes unable to keep teachers up to date with their child’s needs, so they consequently felt that they had very little influence over the nature of their child’s support in school setting. Parents commented that not enough use was made of home-school diaries, which, if used regularly, could provide an efficient channel of communication. Parents of students in colleges also frequently complained of the lack of liaison between themselves and the college. They felt that the practice of treating young people of college age | The link between awareness and communication: when communication with school or college was rated as ‘very good’, in nearly two-thirds of cases (60%) it was felt that the school or college was well informed about their child’s health needs. |
(over 16 years) as adults could be inappropriate at times for those with complex medical conditions.

The parents of 34% of the children said that the school or college did not keep in touch during periods of absence and a further 6% said that any communication during these times was initiated by themselves.

Parents felt that they are giving information to their child’s school or college about their medical condition but expressed doubt as to whether this information had been read or understood.

| 14 | Sullivan, Fülmer & Zigmond, 2001 | Absence and re-entering process is seen as a dominant problem. | School personnel fostered support by providing students with a comfortable return to the classroom setting. In six of the eight cases, young survivors were eased into the transition. Some parents actively start the communication with teacher before a child needs to return to school, to give teacher enough information about leukaemia and so teacher can also share it with the child's classmates. | Establishing and maintaining communication between home and school will ensure the best possible outcomes for children recovering from childhood cancer and other chronic illnesses. With the many variables that affect children's success in school, it is imperative that survivors of childhood cancer receive ongoing support as they progress through the educational system and make transitions from one level to the next and, ultimately, into adult life. |
|   |   |   |   | Ongoing collaboration between the family, school, and medical team will encourage positive school experiences for young survivors. |   |   |   |
## Appendix I. Findings of the studies- communication between school staff and health care.

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<th>Number</th>
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<tr>
<td>1</td>
<td>Leger, 2014</td>
<td>Educational consultant plays key role in multi-disciplinary team to be middle man between school and hospital.</td>
<td>Health workers supported a young person with a visiting teacher, parents and the young persons, as a coordinated effort to enable a young person to connect back to school. This involved a team approach to identify a student’s needs and to clarify the medical condition for teachers so that they were aware of potential challenges and ways in which they could support the student including what information to give to other students. A team approach may include a qualified nurse, an integration aide, a visiting teacher and an assistant principal or a student welfare coordinator. Education professionals organised groups of children, usually special friends, to visit the hospital or the student’s home. However, visits need to be arranged sensitively and prepared thoroughly. Weekly session also served as a communication channel for connecting what was happening to the young person in hospital and for the young person to keep up with what was happening at school.</td>
<td>Both health professionals and education professionals mentioned that approach having a support person means that there is a choice for the young person to ‘make a link with someone in particular who they felt really comfort-able with and to build a relationship with that person’. In the hospital, that person could be a clinician or an administrator. Within the school, the person may be an assistant principal or a teacher.</td>
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<td>Poursanidou, Garner &amp; Watson, 2008</td>
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<td>The findings suggest that a complex interplay of attitudinal, institutional and wider political and economic factors is likely to undermine the effectiveness of collaboration between health and education staff. Attitudinal factors involve teachers’ attitudes towards collaboration with health staff characterized by defensiveness, lack of interest and reluctance. Institutional factors comprise: the type of school attended by transplanted children, as it is suggested that on the whole, liaison with health staff tends to be less effective and spread with more difficulties in the case of secondary and mainstream schools, compared to their primary and special counterparts; a lack of knowledge and clarity on the part of health staff and teachers as regards each other’s roles and responsibilities in relation to transplanted children; and conditions of professional work for health professionals and teachers, namely increased caseloads and time pressures. Wider political and economic factors involve problems about resources or staffing faced by hospitals. Some teachers’ apparent reluctance to liaise with health staff to what they perceived as defensiveness, which may be precipitated by fears</td>
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<td>The findings draw attention to the critical importance of hospital–school liaison that is of a proactive, preventative and hence systematic and strategic nature, for the provision of effective educational support to transplanted children, whereas they highlight the limitations of liaison occurring merely in a reactive and ad hoc fashion. They also throw light on teachers’ need for enhanced communication with health staff at times of medical crises.</td>
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and anxieties to do with potential criticism from health practitioners. Communicating and updating information about transplanted children’s medical needs becomes problematic due to the large numbers of teaching staff and frequent staff changes.

Lack of knowledge and clarity on both health staff and teachers’ part about each other’s roles and responsibilities in relation to transplanted children is likely to augment liaison difficulties.

More than 50% of the sample reported that communication with the school was for the purposes of requesting patient information, providing diagnostic information, and discussing an intervention or treatment plan (69.5%, 66.6%, and 56.4%, respectively).

When paediatricians did contact schools, the primary individuals who were contacted were the school nurse (39.5%) and the classroom teacher (35.3%). School psychologists were reported as the primary contact by 8.5% of the respondents.

When questioned as to which school personnel serve as contacts for collaboration, the of respondents, 53.9% reported that they communicated with the schools a few times per year or less and most did not participate in a specific, school-based role (e.g., school health advisory council, consultant to schools).

The most commonly cited barriers to collaboration were not having enough time in the day (79.77%), finding school personnel inaccessible (49.53%), not being able to obtain reimbursement for collaborating (39.32%), not knowing with whom to collaborate (20.60%), differing views on child development (12.10%), other barriers (10.78%), and a belief that collaboration was not beneficial to their practice (1.51%). Of the “other barriers” listed by respondents, the

Collaborating with school personnel was ranked as very beneficial by most of the paediatricians (75%). In fact, 60% of paediatricians indicated that they were currently collaborating with educational personnel. However, the most commonly reported frequency of collaboration with school personnel were only a few times per year (38.3%).

Paediatricians indicated that they would prefer communicating through phone calls (37.0%) and written reports (22.2%), as is reflected in their current practice, where the most effective and efficient form of communication reported was a phone call (41.9%).
most common responses were classroom teachers (68.3%), school nurses (62.4%), school psychologists (40.4%), guidance counsellors (31.1%), and social workers (23.6%). Other personnel cited less often as regular collaboration contacts were speech/language pathologists (18.3%), principals (18.3%), and physical or occupational therapists (14.9%).

leading concern was compliance with the Health Insurance Portability and Accountability Act (HIPAA).

Among US physicians, no statistically significant predictors were found for beliefs about school re-entry because there was little variability in their responses to the scenario.

In response to the school re-entry scenario, 294 (84.5%) of the US physicians overwhelmingly endorsed telling the school officials and classmates, option ‘D’) about the girl’s diagnosis and treatment.

Both US (98.3%) and Japanese (91.3%) physicians agreed with the statement that knowledge within the community would enhance the psychosocial support of the child.

In the Japanese sample, several patterns emerged. Japanese physicians were more likely to endorse telling everyone if they agreed it was their responsibility to tell the child the truth at diagnosis; if they disagreed that awareness of cancer dashes hope; and if an actual child’s
| diagnosis did not influence their willingness to communicate directly. |   |   |