Aus dem Institut für
Medizin-/Pflegepädagogik und Pflegewissenschaft
Der Medizinischen Fakultät der Charité-Universitätsmedizin Berlin

DISSERTATION

Pflegeabhängigkeit bei Kindern in Deutschland und Ägypten-eine vergleichende Studie

Zur Erlangung des akademischen Grades
Doctor rerum curae (Dr. rer. cur.)

Vorgelegt der Medizinischen Fakultät der Charité –
Universitätsmedizin Berlin

Von

Hanan Tork
aus Alexandria,
Ägypten

Gutachter: 1. Prof. Dr. Theo Dassen
2. Prof. Dr. rer. cur. Christa Lohrmann
3. Prof. Dr. med. Renate Bergmann

Datum der Promotion: 15.Oktober 2007

Care Dependency of Children in Germany and in Egypt-a Comparative Study

Thesis

Submitted in Partial Fulfillment of
The Doctoral Degree
In
Pediatric Nursing

By

Hanan Mohamed Mohamed Tork

(M.Sc. Nursing)

Supervisor

Prof. Dr. Theo. W. N. Dassen

Professor and Chairman of Nursing Science Department
Centre for Humanities and Health Sciences,
Charité -Universitätsmedizin
Berlin, Germany

Charité-Universitätsmedizin
Berlin, Germany

2007

Contents

List of Tables

List of Figures

CHAPTER 1

Introduction

The segment of the life span extending from the age of 6 years to 12 years has a variety of labels, each of which describes an important characteristic of this period. These middle years of childhood are most often referred to as school age (1).

During the school years, dramatic changes occur in the child's thought process, social skills, activities, attitudes and use of language. Children move from the small family circle to school and community (2).

School-age children gain great satisfaction from independent behaviour in exploring and manipulating their environment and interacting with peers. The danger inherent in this period of personality development is the occurrence of situations that might result in a sense of inferiority, therefore, the problem of care dependency or the feeling of having failed in mastering self-care activities at that age may lead to children thinking they are inferior (3). On the other hand, children with competent social and self-care skills are better integrated in the community and have wider social networks. The development of independent self-care skills influences the entire life (4). Therefore, the school age is considered the appropriate stage for maximizing children's care independency .

Dijkstra et al. (5, P.15) defined the care dependency as "a process in which the professional offers support to a patient whose self-care abilities have decreased and whose care demands make him/her to a certain degree dependent, with the aim of restoring this patient's independence in performing self care".

Although the problem of care dependency is predominant among very young, very old, very ill or impaired people (6), several studies (7, 8, 9) addressed the phenomenon of care dependency among the elderly, but paid less attention to children. According to Day (10), child dependency is not solely related to age and biological development, but it also appears that sub-cultural as well as wider society norms with regard to child rearing play an important role in determining the degree of dependency. In order to estimate the extent of the problem, data from different countries are required. There is currently little known about the care dependency of children, particularly from an international perspective. The present study aimed at exploring the problem of care dependency among children from two countries with distinctive cultural contexts: Germany and Egypt. Germany is a highly developed country with well-resourced hospitals, and Egypt is a major representative of a developing country with hospitals which necessarily function with limited resources. A comparison between the two countries, with different backgrounds of cultures and experiences in dealing with the problem of care dependency, will lead to results that both countries can benefit

from. With the right assessment appropriate care can be offered and the independence of children can be supported instead of strengthening their dependent behaviour. Therefore, a precise assessment tool providing data for children's care needs is required. A valid and reliable instrument for the assessment of care dependency was developed in the Netherlands in 1996 for demented and mentally handicapped people. It was tested psychometrically in various European countries (9).

Care Dependency Scale (CDS)

The Care Dependency Scale (CDS) is an instrument for use in psychogeriatric nursing homes to assess a patient's care dependency. The CDS was developed by Dijkstra et al. in 1996 based on Virginia Henderson's human needs. It was tested in psychogeriatric nursing homes in the Netherlands, and some time later in other European countries (7) as well. In addition, the CDS was tested in Germany as to its use in hospitals in different disciplines; one of them was the paediatric ward (11, 12).

The CDS measures 15 human needs: eating and drinking, continence, body posture, mobility, day/ night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, recreational activities and learning ability. Each of the 15 items has an item description and five care dependency criteria. Nurses rate all items by selecting one criterion out of the five. Low scores on the items indicate that patients are completely dependent on care and high scores mean that patients are almost independent on care (8). The present study is significant as it modifies the CDS to a paediatric version which is called Care Dependency Scale for Paediatrics (CDS-P). Subsequently, the validity and reliability of the CDS-P were tested in different hospital disciplines for school-age children. This age group has been frequently selected and recommended in previous children's research studies (14, 15). Ideally, a cross-cultural CDS-P assessment can be performed, so we can get a better understanding of the actual intercultural differences.

Cultural variations of care dependency

Cross-cultural differences in care dependency were documented in literature (8, 15). Wong and colleagues (16) revealed that Chinese children of all ages in Hong Kong had better results in their care ability than their American counterparts. The present study aimed at comparing the

care dependency among school-age children from two countries with different backgrounds: Germany and Egypt.

To get an insight into the care dependency of children in Germany, data sets from the annual prevalence studies from the Department of Nursing Science, Charité-Universitätsmedizin Berlin (2001-2005) were analysed. Only the data from children aged between 6 and 12 years (n= 191) were used. The results showed that more than 50 % of those children were dependent regarding patterns like eating and drinking, continence, body posture and mobility.
Due to the scarcity of literature in Egypt there were no statistical data available about the care dependency of children. On the other hand, different studies show that the care dependency is one of the prominent features of disability and many physical, cognitive and mental disabilities of children resulted in those children being dependent on their caregivers (17). Disability in Egypt constitutes a major problem among children and it has health, economic and social consequences. According to local authorities, Egypt has an estimated population of 60 million people with 39.4% of them being children (0-15 years) and about 6% of those children having significant disabilities (18).

Research questions

The overall aims of the study were to develop the paediatric version of the Care Dependency Scale (CDS-P), to test its validity and reliability in Germany and in Egypt in order to assess the psychometric properties of the CDS-P in both countries and, additionally, to compare the care dependency of school-age children in both countries. The following research questions are discussed to achieve these aims.

Chapter 2

- What factors influence children's care dependency?
- Are there any instruments to assess a child's care dependency?

Chapter 3

- Is the modified version of the Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency of hospitalised school-age children?
- To what extent are the school-age children in Germany care dependent?

Chapter 4

- Is the modified Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency among children in Egypt?
- What are the differences between disabled and non-disabled school-age children in Egypt regarding their care dependency?

Chapter 5

- What are the differences between school-age children in Germany and in Egypt regarding their care dependency?
- Is the Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency of children of different cultures?

Outline of the thesis

Chapter Two of this thesis presents an overview of the research literature dealing with the care dependency among children and the factors possibly influencing their dependency on care. Additionally, it focuses on the available instruments for measuring children's care dependency. Chapter Three reports the psychometric properties of the Care Dependency Scale for Paediatrics (CDS-P) in a paediatric setting. It also describes the care dependency of hospitalised school-age children in Germany. Chapter Four provides comparable data of psychometric properties of the CDS-P and the care dependency of disabled and non-disabled school-age children in Egypt. Chapter Five shows the differences in the care dependency of children in Germany and Egypt with regard to the cultural variations.
Chapter Six summarizes and discusses the results of the study project and gives recommendations, which can be considered as relevant for both clinical research and nursing practice.

Chapter 2 and chapter 4 of this thesis are based on articles that have already been accepted for publication in scientific journals and they were written with the intention of being read independently. This is the reason why a certain extent of overlaping material between those two chapters and the remaining chapters of the thesis was inevitable.

References

1. Wong DL. Whaley and Wong's essentials of pediatric nursing. 5th ed, St. Louis: Mosby-Year Book Inc., 1997.

2. Marks, M. Counselling and psychotherapy with children and adolescents. 3rd ed., New York: John Wiley and Sons, Inc., 1998.

3. Erikson E. Childhood and Society. New York: Norton 1963.

4. Lewis S, Iselin S. A comparison of the Independent Living skills of Primary Students with Visual Impairments and Their Sighted Peers: A pilot Study. Journal of Visual Impairment & Blindness 2002; 96: 335-44.

5. Dijkstra A. Care dependency: An assessment instrument for use in long-term care facilities. Stichting Drukkerij C. Regenboog, Groningen 1998.

6. Kittay E, Jennings B, Wasunna A. Dependency, difference and the global ethic of longterm care. J. Polit. Philos. 2005; 13: 443–469.

7. Dijkstra A, Tiesinga L, Goossen W, Dassen T. Further psychometric testing of the Dutch Care Dependency Scale on two different patient groups. International Journal of Nursing Practice 2002; 8: 305-314.

8. Dijkstra A, Coleman M, Tomas C, Välimäki M, Dassen T. Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing 2003; 43 (2): 181-187.

9. Lohrmann, C. Dijkstra, A. & Dassen, T. An Assessment Instrument For Elderly Patients in German Hospitals. Geriatric Nursing. 2003a; 24 (1): 40-43.

10. Day B. Dependency: personal and social relations. Athenaeum Press Ltd., Newcastleupon Tyne.Great Britain,1992

11. Dassen T, Balzer K, Bansemir G, Kühne P, Saborowski R, Dijkstra A. Die Pflegeabhängigkeitsskala, eine methodologische Studie. Pflege, 2001; 14: 123-127.

12. Lohrmann C, Dijkstra A, Dassen T. Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scandinavian Journal of Caring Science. 2003b ; 17: 51-56.

13. Palermo T, Childs G, Burgess E, Kaugars A, Comer D, Kelleher K. Functional limitations of school-aged children seen in primary care. Child Care Health Dev. 2002; 28: 379-389.

14. Patton S, Graham J, Varlotta L, Holsclaw D. Measuring Self-Care independence in children with Cystic Fibrosis: The Self-Care Independence Scale (SCIS). PediatrPulmonol. 2003; 36: 123-130.

15. Dijkstra A, Buist G, Moorer P, Dassen T. A reliability and Utility Study of the Care Dependency Scale. Scandinavian Journal of Caring Science. 2000; 14: 155-161.

16. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

17. Limperopoulos C, Majnemer A, Michael S, Rosenblatt B, Rohlicek C, Tchervenkov C, Darwish H. Functional Limitation in Young Children with congenital heart defects after cardiac surgery. Pediatrics 2001; 108: 1325-1331.

18. Shukrallah A (1997) Childhood Disability Project: Final Progress Report. Cairo: Association for Health and Environmental Development.

CHAPTER 2

Care Dependency among School-Age Children: Literature review

Published: Tork H, Dassen T, & Lohrmann C. Care Dependency among School-Age Children: Literature review. Nursing and Health Sciences 2007; 9(2): 142-149

Abstract

Many disabilities and chronic illnesses of children result in those children being dependent on their caregivers. The higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers and on care-providers in the health-care system, especially nurses. The objectives were to gain an overview of the literature dealing with care dependency among children and the factors possibly influencing their dependency on care, and to obtain instruments for measuring children's care dependency. MEDLINE, CINAHL, and PsychINFO were searched for different publications from 1995 to 2005. The literature reveals four categories of factors associated with care dependency of the child. With respect to instruments, a variety of instruments were identified but most of them were restricted to children with specific health conditions. For this reason, the paper suggests the development of a new instrument for assessing children's care dependency that is applicable to healthy children.

2. 1 Introduction

According to a World Health Organization (WHO) report, dependent people currently represent a share of 4–5% of the total world population (1). In spite of the problem of care dependency predominant among very young, very old, very ill or impaired people (2), several studies addressed the phenomenon of care dependency among the elderly, but paid less attention to children. Dependency regarding self-care activities, which the WHO defines as the inability to perform the key activities of daily life, such as maintaining personal hygiene, eating, and safety awareness, is considered to be one of the greatest problems (1).

The term "self-care" is usually applied to children of school age who are expected to gradually master an increasing level of responsibility for their own safety and well-being (3). Erikson's stage theory describes the school-aged years, that is, the segment of life between the ages of six and 12 years, as the time of industry and activity, which means that children gain a lot of satisfaction from independent behaviour when exploring and manipulating their environment and interacting with peers. The danger inherent in this period of personality development lies in the occurrence of situations that might result in a sense of inferiority (4). Therefore, the problem of care dependency or the feeling of having failed to master self-care activities at that age might lead to the sense of inferiority.

However, children with competent social and self-care skills are better integrated in the community and have an expanding social network. The development of independent self-care skills influences their entire life (5). Furthermore, the American Academy of Paediatrics recommended a transition plan including opportunities for children and adolescents to gain more independence regarding their self-care prior to their transition to adult care (6).

Learning to be as independent as possible by means of self-care activities does not necessarily mean to do things without any help. On the contrary, the differentiation between the time and extent of assistance required is an indication of mature decision-making for many children with chronic conditions or disabilities. Ideally, the development of self-care skills that began at home and continued throughout school was directed towards the ultimate goal of an independent way of living (7).

2. 2 Concept of self-care and dependency

Self-care denotes the ability to initiate and perform one's own actions directed towards the care of oneself (8). In the area of clinical nursing, self-care is the focus and goal of nursing care, being aimed at improving the health status, coping, and functioning of clients, as well as at achieving favourable consequences of self-care, such as an increased sense of responsibility, control, independence, autonomy, and the reduced burden of a chronic illness (9). In contrast to this, a self-care deficit might cause the problem of dependency.

Dependency is placed within the framework of common human relationships and care dependency is placed within the framework of professional and formal care assistance. Dependent behaviour is supported and promoted by nurses; however, independent behaviour is often not supported but ignored instead. Ignoring independence means promoting dependency, which leads to a decreased exercise of self-care abilities.

The problem of care dependency among children is currently underestimated in clinical settings and requires additional attention to be paid by nursing practitioners, paediatricians, and developmental specialists (10). Therefore, the purposes of this review are:

1 To gain an overview of the literature dealing with care dependency among children and the factors possibly influencing their dependency on care.

2 To obtain instruments for measuring children's care dependency.

Research questions

1 Which factors influence children's care dependency?
2 Are there any instruments to assess a child's care dependency?

2. 3 Methods

2.3.1 Search strategy

A literature search covering the period from 1995 to 2005 was carried out using the databases, MEDLINE, CINAHL, and PsychINFO. In addition, a search of several online Internet journals and websites was performed. In order to increase the likelihood of identifying all relevant studies, the reference lists of all retrieved articles were searched. The key words used in the search were "care", "dependency", "literature review", "school-age", and "self-care deficit" in various combinations. Self-care deficit was used as a synonym for the term, care dependency, because of the scarcity of available literature. This resulted in 201 publications, 22 of which were potentially relevant; upon further reading and evaluation, 11 articles were selected as most relevant to the inclusion criteria and corresponding most to the aims of the review. Only a small amount of papers were reviewed, which was related to the exclusion of those papers that focused on special areas of dependency, such as substance or technology dependency. The same applied to measures of care dependency: papers without available data about their validity and reliability were excluded.

2.3.2 Selection criteria

Papers were included as long as they had been published from January 1995 to February 2005 and had been written in Arabic, English or German. Furthermore, articles were included if they focused on the following:

2.3.3 Types of participants

All school-aged children from 6–12 years of age with chronic illnesses, with or without special needs, irrespective of the setting (hospitalised, unhospitalised or institutionalised) were included.

2.3.4 Types of studies

Owing to the fact that not much has been written about care dependency among children, the authors decided to use all available publications for this review, which meant that no restrictions on the types of studies (qualitative and quantitative) were made during the search.

2.3.5 Types of outcome measures

The care dependency outcome measures were: concept analysis, its burden on the child's family, related factors, and measurements and their psychometric properties.

2.3.6 Review process

The authors independently assessed the titles and abstracts of the potentially relevant studies identified by using the search strategy. All abstracts were checked to determine whether they fulfilled the selection criteria. All studies that potentially or definitely met the criteria were retrieved completely. Each study was then assessed independently for inclusion by all three authors. If there was disagreement about whether a study met the criteria or not, it was retrieved completely and the three authors then decided together to either include it or not.

2.3.7 Data extraction and analysis

The evaluation of the methodology drew from multiple sources so as to be commensurate with the design of each study (11). Following the quality assessment, 11 studies remained for data extraction. The first author extracted details from the eligible studies and placed them into the data extraction form. The extracted data were then checked by the other two authors. Each paper was read through several times to identify the main concepts, design, purpose, participants, findings, and conclusion of the study. Those details were entered into a grid to establish the similarities and differences in scope and the findings across the studies. The characteristics of the included studies are summarized in Table 1.

Table 1. A summary of the research articles

Author, year	Purpose	Design	Measuring instrument	Participants	Findings
Azaula *et al*. (2000)	To compare a paediatric and an adult version of a functional status measuring instrument for assessing school-aged children with cerebral palsy	A longitudinal, prospective study design	Three instruments were used: WeeFIM, FIM, and AAQ	47 children aged 2–12 years with cerebral palsy	A paediatric (WeeFIM) and an adult (FIM) version of a functional status instrument can be used to monitor the functional status throughout adolescence for children with cerebral palsy
Lewis & Iselin (2002)	To determine the performance of daily life skills among children with visual impairments and sighted peers of the same age	Interviews with parents were conducted face-to-face or by telephone	The questionnaire was designed by the second author; it consisted of 101 items in the area of daily life skills, such as hygiene, dressing, clothing care, and home care	Parents of 20 children, 10 children with visual impairments, and 10 sighted children	Children with visual impairments performed only 44% of the tasks independently, while the sighted children performed 84% of them independently
Msall & Tremont (1999)	To describe the use of functional assessment in children with genetic impairments	Analyses of the studies that assessed the functional status of children with genetic impairments using different scales	WeeFIM, VABS, Batelle, and AAQ	No participants	Appropriate use of functional assessment tools allows clinicians to describe children's strengths and challenges across health, developmental, educational, and community settings
Msall *et al*. (2003)	To examine the contribution of medical impairments towards functional disabilities and school activity limitations	Cohort study	Data from the National Health Interview Survey (1995, 1996) were used	Children between 5 and 17 years of age (n = 41 300)	Chronic health impairments and functional limitations in essential activities form part of the complexity of disabilities in school-aged children
Ottenbacher *et al*. (1999)	To compare the performance of children with developmental disabilities	Comparative descriptive design	WeeFIM, BDI, and VABS	Children with different developmental disabilities (n = 205)	The three instruments provide important information regarding childhood performance in motor, self-care, communication, and social skills
Ottenbacher *et al*. (1997)	To examine the inter-rater agreement of WeeFIM	Relational design	WeeFIM	Disabled children (n = 205)	The WeeFIM ratings were consistent regarding raters and time
Patton *et al*. (2003)	To describe the development and psychometric properties of a survey tool designed to evaluate children's level of	Descriptive design	SCIS	Parents of 76 patients with cystic fibrosis (aged 4–17 years)	The self-care independence scale has acceptable internal consistency and good test-retest reliability

	independence with their cystic fibrosis treatment				
Palermo *et al*. (2002)	To assess the prevalence of functional limitations in children, to identify sociodemographic, family, and psychosocial factors related to functional limitations	Cross-sectional analysis	The Functional Limitations index, the Family Apgar test, and the PSC	School-aged children, aged 6–12 years (n = 14 630) and their caregivers	15% of the surveyed children had some limitation in their daily functioning and more children had physical functional limitations than personal and self-care limitations
Schmidt (2003)	To describe mothers' perceptions of the diabetes-related self-care abilities and practices of their school-aged children with type I diabetes	Descriptive, qualitative study	Semi-structured interview (self-developed measurement instrument)	12 mothers of children between 11 and 12 years of age	Mothers reported that their children with diabetes had learned skills in a predictable sequence and there were considerable gender differences in the children's self-care development
Wong *et al*. (2002)	To examine the utility of the WeeFIM in Chinese children and to create a normative WeeFIM profile suitable for Chinese children	Direct interviews with Chinese children in the community	WeeFIM for children	445 Chinese children, aged 6 months – 7 years	The total WeeFIM sub-scores of self-care, mobility, and cognition independence increased progressively with age
Zhimin (2003)	To identify the levels of self-care in Chinese school-aged children with primary nephritic syndrome	Descriptive design	Interview sheet for demographic data and information about nephritic syndrome self-care	66 school-aged children hospitalized at least once for nephritic syndrome	High levels of self-care found in 83% of the 6–8 year old children, 95% of the 9–10 year old children, and in all of the 11–12 year old children

AAQ, Amount of Assistance Questionnaire; BDI, XXX; FIM, Functional Independence Measure; PSC, Paediatric Symptom Checklist; SCIS, Self-Care Independence Scale; VABS,Vineland Adaptive Behaviour Scale; WeeFIM, Functional Independence Measure.

2.4 Findings

2.4.1 Factors relating to children's care dependency

Various factors influence the self-care behaviour of children. They were classified into four categories: (i) demographic (e.g. age, gender, socioeconomic status); (ii) sociocultural (e.g. cultural differences, social support); (iii) psychosocial (e.g. self-concept, self-esteem, and personality traits); and (iv) physical category (e.g. activity level, health functional state, disability) (12). Some studies examined the effects of the children's demographic factors on self-care behaviour and established that older children had a higher level of care independence than younger children (13,14). In the same context, Zhimin (2003) conducted a research study among Chinese school-aged children with nephritic syndrome to assess their self-care ability and reported that self-care practice was found in 83% of the 6–8 year olds, in 95% of the 9–10 year olds, and in all of the 11–12 year olds (n = 66) (15).

In the analysed studies, we found a relationship between gender and self-care. The results of the study conducted by Wong *et al*. on 445 Chinese children indicated that girls mastered self-care and communication competencies earlier than boys did (14). This finding is supported by Schmidt's (2003) study, which attributed it to the fact that the mothers of male children were much more involved in the care of their offspring than the mothers of female children, leaving girls under more pressure than boys to take over their self-care (28).

With regard to the effect of socioeconomic factors, the present review revealed that one study investigated this aspect and reported that the socioeconomic status correlated negatively with children's self-care practice (8).

Cultural difference is also one of the important factors that can affect children's care dependency. Wong and colleagues revealed that Chinese children of all ages in Hong Kong had better results in their care ability than their American counterparts (14).

Regarding the psychosocial factors, the influence of self-concept on children's self-care practices was supported. In the analysed studies, a significant, positive correlation between self-care and self-concept was found. It suggests that psychosocial interventions that enhance children's self-concept are likely to improve self-care and, in turn, that a participation in self-care activities strengthens the self-concept (16).

Disability might lead to a need for individual help in the basic activities of daily life, to a need for adaptation to the physical environment, and for the health services to cure, palliate, and prevent the deterioration of a condition or development of complications (1). Children with

disabilities are a heterogeneous population consisting of children with complex medical conditions, including chronic illnesses, developmental disabilities, and related disorders requiring special educational services (17).

When assessing the influence of children's disability on their care dependency, Leonard *et al*. (18) found that children with Down's syndrome were completely independent in changing positions, mobility, and bowel continence.

Some analysed studies compared the self-care performance of children with disabilities to the self-care performance of children without disabilities to demonstrate the effect of a disability on the children's care dependency. One of those studies was that of Msall and Tremont (19), who examined the differences between children with major neurological impairments and children without disabilities regarding their care dependency. They established that 13% of the children without disabilities had self-care limitations and 12% had communication limitations, while 41% of the children with disabilities showed low scores in self-care skills and 35% had communication limitations (n = 156).

Furthermore, in a comparison between sighted and visually impaired children, the sighted children's parents indicated that their offspring performed 84% of their daily life skills without any assistance, while the parents of the children with visual impairments claimed that their children only performed 44% of those tasks independently (5).

2.4.2 Instruments measuring children's care dependency

In order to optimise children's independent way of living, measurements of dependency in daily activities are essential. These activities include communication, socialization, locomotion, hand skills, eating, dressing, and toileting. It is important to measure children's self-care autonomy as it might have a direct effect on children's active independence in their treatment and their adherence to it (20).

The literature showed the researchers' interest in assessing the children's care independency behaviour by developing several instruments. The reviewed instruments were limited, which was related to the exclusion of those tools that were developed for adults and those that were not sufficiently tested. Some assessment instruments, such as the Physical Self-Maintenance Scale (PSMS) and the Barthel Index, were developed to estimate the activities of daily living. However, these instruments were not developed from a nursing perspective. In addition, there is only a little known about the psychometric properties of the PSMS and the Barthel Index is limited because it does not account for the patient's psychological and sociological aspects. The

instruments used to measure children's self-care differ; most of them were developed for examining self-care in children with a specific health condition or disease, especially with conditions restricting independent self-care, such as a disability or chronic illness. Only a few of them were developed for behaviour specific to healthy or normal children.

A variety of instruments for children's self-care are available, but only a few of them are worth mentioning. The Functional Independence Measure (WeeFIM) for children is based on the conceptual framework of the Functional Independence Measure for adults and is designed to assess the performance in self-care, mobility, and learning of children without disabilities between the ages of 6 months and 7 years and of children of all ages suffering from developmental disabilities and having a mental age of < 7 years (21). The advantages of the WeeFIM are its conciseness (simple scoring of 1–7), its comprehensiveness (covering all developmental aspects), a shorter administration time, and the discipline-free requirements (can be administered by trained health, developmental or educational professionals) (14). The WeeFIM was tested thoroughly in several studies and showed an excellent test-retest and inter-rater reliability and content validity (21, 13, 14). The Self-Care Independence Scale (SCIS) is a disease-specific, self-care behaviour scale developed by a team of cystic fibrosis clinicians and researchers from Hahnemann University, Pennsylvania, USA. The SCIS is a 44-item questionnaire that is completed by parents (20).

Table 2. Psychometric properties of PEDI, SCIS, WeeFIM, and VABS

Purpose	PEDI	SCIS	WeeFIM	VABS
Author, year	Haley et al. 1992	Team of CF clinicians & researchers, 1999	A multidisciplinary team of health, education, and Rehabilitation professionals, 1990	Sparrow et al., 1998
Domains	Self-care, social functional, motoric	Self-care, treatment	Self-care, mobility, communication, and social cognition	Daily life skills, motoric, communication, & socialization
Application	Children with cerebral palsy	Children with cystic fibrosis (CF)	Disabled and non-disabled children	Disabled and non-disabled children
Target population	Children from 6 months to 7.5 years	Children from 4–17 years	Non-disabled: 6 months to 7 years Disabled: 6 months to 21 years	Children from birth - 18 years
Method of administration	Administered by a clinician	Administered by the parent	Discipline-free requirements (can be administered by trained health, developmental or educational professionals)	Administered by the child's caregiver
Reliability	Excellent test retest and interrater reliability	Acceptable internal consistency, good testretest	Excellent test-retest and interrater reliability, equivalence reliability	Excellent test-retest and interrater reliability
Validity	Concurrent validity with Battelle and WeeFIM	Concurrent validity with a measure of patient self-care Knowledge & HDQ	Content validation by expert group, concurrent validity With VABS, AAQ	Excellent correlation with school-age IQ
Administration time	45 min	45 min	15 min	45 min

HDQ, Highland Dependency Questionnaire; PEDI, Paediatric Evaluation of Disability Index; SCIS, Self-Care Independence Scale; VABS, Vineland Adaptive Behaviour Scale; WeeFIM, Functional Independence Measure.

The Vineland Adaptive Behaviour Scale (VABS) measures adaptive behaviour in children and adults, communication (receptive, expressive, written), daily life skills (personal self-care), socialization (interpersonal skills, playing, learning, and coping), and motor skills (gross and fine) (19). The psychometric properties of the Paediatric Evaluation of Disability Index (PEDI), SCIS, WeeFIM, and VABS are illustrated in Table 2.

2.5 Discussion and conclusions

This review was conducted with two objectives: to gain an overview of the literature dealing with care dependency among children and the factors possibly influencing their dependency on care, and also to obtain the instruments that are available for measuring children's care dependency. A higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers (10); therefore, care dependency has been described as a problem that needs to be addressed (22).

The present literature review tried to identify factors relating to children's care dependency. In the analysed studies, four categories of factors were reported, out of which two major findings emerged. First, older children had a significantly higher self-care ability than younger children. It is assumed that as children grow older, their ability to cope with responsibility towards their personal care increases and so does the amount of time children spend on self-care. Second, cultural differences are important factors influencing the children's self-care behaviour. The findings appear to be in accordance with those of Wong *et al*. (14), who showed that Chinese children of all ages in Hong Kong had better results in their self-care than their American counterparts. They also stated that the differences might be attributable to the fact that Chinese children attended preschool settings, where they were taught to tend to their needs at an earlier stage than their American counterparts did.

Concerning the influence of a disability on children's care dependency, some authors argue that there is a difference between children with disabilities and those without disabilities in performing self-care, while others argue that there is a difference in the ability of children with a certain type of disability, such as physical or mental disability, in performing self-care. According to Lewis and Iselin (5), sighted children performed 84% of daily life activities without any assistance, while children with the physical disability of a visual impairment only performed 44% of those tasks independently. The aforementioned differences might be related to the fact that the visually impaired children are unable to watch in detail how the tasks had to be

performed; therefore, the acquisition of competence is delayed owing to the lack of direct instruction and frequent opportunities to practise the tasks.

Furthermore, Msall and Tremont (23) stated that children with Down's syndrome (as a mental disability) were completely independent in changing positions, mobility, and bowel continence, and only a little supervision and assistance were required for bladder continence and dressing. The previous studies concluded that a disability might have a direct effect on many care-dependent children, but appropriate training and guidance through counselling programs at schools can improve the ability of children with disabilities to take over the responsibility of their care.

In order to determine the problem of care dependency among children, instruments for assessing the children's self-care are required. The present review revealed a variety of instruments for this purpose; the majority were restricted to the assessment of self-care for specific diseases, such as the SCIS, which was designed for children with cystic fibrosis only, and the PEDI, which was used for children with cerebral palsy between the ages of 6 months and 7.5 years.

Following an analysis of the findings of the above studies, we concluded that there is no appropriate instrument in terms of validity and reliability that can be used for healthy children in the same way as for children with illnesses or chronic conditions at different stages of their childhood. Therefore, one of the potential objectives for future research is to develop a new instrument for assessing children's care dependency that is applicable to normal or healthy children and to continue research on the reliability, validity, and responsiveness of the present instruments.

This review showed a gap in the literature where care dependency among school-aged children is concerned. Further research is recommended to be able to evaluate the impact of care dependency among children and to assess the extent of the problem in terms of prevalence. The factors influencing children's self-care ability should be taken into consideration in studies that are aimed at optimising care independence.

2.6 Limitations

Although a rigorous approach was taken when conducting this literature review, its limitations must be acknowledged. In some instances, an abstract was unavailable, which inevitably meant that some papers were overlooked. The restriction to school-aged children led to the exclusion of some papers dealing with other age groups. Furthermore, measures of self-care were excluded if there was no information available about their validity and reliability. Nonetheless, a considerable amount of data was retrieved and reviewed.

2.7 Nursing implications

An appropriate assessment of children's care dependency can help nurses in clinical practice to conduct a nursing care plan in accordance with the children's needs. The practical nursing implications of the findings emphasize the importance of appropriate training and guidance for children, which are aimed at maximizing their ability to take over the responsibility of their self-care.

An implication for nursing research is the need to develop further measurements of care dependency for healthy children. One way of doing this is to construct a measurement tool and test the tool in practice.

References

1. World Health Organization (WHO). Current and future long-term care needs: An analysis based on the 1990 WHO study. [Cited 18 Feb. 2006] Available from: http://www.who.int/entity/chp/knowledge/publications/ltc_needs.pdf.

2. Kittay E, Jennings B, Wasunna A. Dependency, difference and the global ethic of longterm care. J. Polit. Philos. 2005; 13: 443–469.

3. Kerrebrock N, Lewit E. Child indicators: children in self-care. Future Child. 1999; 9: 151–160.

4. Erikson E. Childhood and Society. New York: Norton, 1963.

5. Lewis S, Iselin S. A comparison of the independent living skills of primary students with visual impairments and their sighted peers: a pilot study. J. Visual Impair. Blin. 2002; 96: 335 –344.

6. American Academy of Pediatrics, Committee on Children with Disabilities. Transition of care provided for adolescents with special health care needs. Pediatrics 1996; 98: 1203–1206.

7. Jackson P, Vessey J. Primary Care of the Child with a Chronic Condition. St Louis, MO: Harcourt Health Sciences, 2000.

8. Sidani S. Nursing-sensitive Outcomes. State of the Science. Boston: Jones and Bartlet, 2003.

9. Slusher L. Self-care agency and self-care practice of adolescents. Issues Compr. Pediatr. Nurs. 1999; 22: 49–58.

10. Limperopoulos C, Majnemer A, Michael S et al. Functional limitation in young children with congenital heart defects after cardiac surgery. Pediatrics 2001; 108: 1325–1331.

11. Burns N, Grove S. Understanding Nursing Research. Philadelphia: Saunders, 2003.

12. Gaffney KF, Moore JB. Testing Orem's theory of self-care deficit: dependent care agent performance for children. Nurs. Sci. Q. 1996; 9: 160–164.

13. Palermo T, Childs G, Burgess E, Kaugars A, Comer D, Kelleher K. Functional limitations of school-aged children seen in primary care. Child Care Health Dev. 2002; 28: 379–389.

14. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

15. Zhimin L. Self-care in Chinese school-age children with nephritic syndrome. Am. J. Matern. Child Nurs. 2003; 28: 81–85.

16. Mosher RB, Moore JB. The relationship of self-concept and self-care in children with cancer. Nurs. Sci. Q. 1998; 11: 116–122.

17. Msall ME, Avery R, Tremont M, Lima J, Rogers M, Hogan D. Functional disability and school activity limitations in 41 300 school-age children: relationship to medical impairments. Pediatrics 2003; 111: 548–553.

18. Leonard S, Msall M, Bower C, Tremont M, Leonard H. Functional status of school-aged children with Down syndrome. J. Paediatr. Child Health 2002; 38: 160–165.

19. Msall ME, Tremont MR. Measuring functional outcomes after prematurity:developmental impact of very low birth weight and extremely low birth weight status on childhood disability. Ment. Retard. Dev. Disabil. Res. Rev. 2002; 8: 258–272.

20. Patton S, Graham J, Varlotta L, Holsclaw D. Measuring self-care independence in children with cystic fibrosis: the Self-Care Independence Scale (SCIS). Pediatr. Pulmonol. 2003; 36: 123–130.

21. Azaula M, Msall ME, Buck G, Tremont MR, Wilczenski F, Rogers BT. Measuring functional status and family support in older school-age children with cerebral palsy: comparison of three instruments. Arch. Phys. Med. Rehabil. 2000; 81: 307–311.

22. Flanagan J, Holmes S. facing the issue of dependence: some implications from literature for the hospice and hospice nurses. J. Adv. Nurs. 1999; 29: 592–599.

23. Msall ME, Tremont MR. Measuring functional status in children with genetic impairments. Am. J. Med. Genet. 1999; 89: 62–74.

24. US Department of Health and Human Services. Current Estimates From the National Health Interview Survey. Washington, DC: US Government Printing Office; 1995 (Vital and Health Statistics Series 10-193)

25. US Department of Health and Human Services. National Health Interview Survey on Disability, Phase 1. Washington, DC: US Department of Health and Human Services; 1996 (Machine Readable Data, CD-ROM Series 10-8, SETS Version 1.22a)

26. Ottenbacher KJ, Msall ME, Lyon NR, Duffy LC, Granger CV, Braun S. Measuring developmental and functional status in children with disabilities. Dev Med Child Neurol. 1999; 41: 186- 194.

27. Ottenbacher KJ, Msall ME, Lyon NR, Duffy LC, Granger CV, Braun S. Interrater agreement and stability of the Functional Independence Measure for children (WeeFIM): Use in children with developmental disabilities, Arch. Phys. Med. Rehabil. 1997; 78: 1309- 1315.

28. Schmidt C. Mothers' perceptions of self-care in school-age children with diabetes. Am. J. Matern. Child Nurs. 2003; 28: 362–370.

29. Haley SM, Coster WJ, Ludlow LH, Haltiwanger JT, Andrellos PJ. (1992) Pediatric Evaluation of Disability Inventory (PEDI). Version 1.0 Boston, MA: New England Medical Center Hospitals

30. Sparrow S, Balla D, Cicchetti D. (1984) Vineland Adaptive Behavior Scale Interview Edition: Survey Form Manual. Circle Pines, MN: American Guidance Service.

CHAPTER 3

Psychometric testing of the modified Care Dependency Scale among Hospitalized school-age children in Germany

Tork H, Dassen T, & Lohrmann C. (2007) Accepted for publication in Nursing and Health Sciences

3.1 Introduction

In 2004, more than 12 million children (under fifteen years) were treated in hospitals in Germany (1); the care of those children represents a burden on care providers and children's care dependency may be considered as an enormous challenge for all care providers in health care systems, especially for nurses. Despite the fact that care dependency predominantly is a problem among very young, very old, very ill or impaired people (2), several studies (3, 4, 5) addressed the phenomenon of care dependency among the elderly but paid less attention to children.

Dijkstra et al. (6) (p.144) define nursing care dependency as "a nurse-patient relationship resulting from a person's decrease in self-care and simultaneous increases in dependency on nursing care whenever needs must be satisfied".

To get an insight into the care dependency of children in Germany, data sets of the annual prevalence studies carried out by the Department of Nursing Science, Charité Universitäts-medizin Berlin (2001-2005) were analyzed. Only data of the sub-sample children, aged 6-12 years (n= 191), were used. The results gave a first impression of the care dependency of children, 50.9 % of children were dependent regarding patterns like eating and drinking, continence, body posture and mobility. A higher dependence of children in daily tasks undoubtedly places a greater burden on caregivers (7). Therefore, the literature describes care dependency as a problem that needs to be addressed (8). According to Erikson's theory of psychosocial development school-age children belong to the same developmental stage, i.e. industry versus inferiority. At this stage, children need to cope with new social and academic demands and gain great satisfaction from an independent behaviour. Success leads to a feeling of competence (9). Therefore, school age is considered the appropriate stage to maximise children's care independence. In addition, this age group was frequently selected in previous research studies on children (10, 11).

On the other hand, failures result in a feeling of inferiority. The children themselves perceive this sense of inferiority or unworthiness in their social environment or when they are chronically ill or disabled (12). The feeling of having failed in mastering their self-care activities or of their dependency on others may at that age lead to this sense of inferiority. Ignoring independence means promoting dependency (13), which leads to a decreased use of self-care abilities and, consequently, to a sense of inferiority. With the right assessment appropriate care can be offered and the independence of children can be supported instead of strengthening dependent behaviour. Therefore, a precise assessment tool is required, which provides data regarding

children's care needs. A valid and reliable instrument for the assessment of care dependency was developed in the Netherlands in 1996 for demented and mentally handicapped people and was tested psychometrically in various European countries (13). In 2004, the modified version of the CDS for children was developed in Germany and named the Care Dependency Scale for Paediatrics (CDS-P)

Prior to this study, the psychometric properities of the CDS-P had never been tested. Thus, it was particularly important to test the CDS-P.

Background

Care Dependency Scale (CDS)

Dijkstra et al. (1996) developed the original CDS based on Virginia Henderson's 14 human needs but added the item 'communication'. The 15-item scale measures the care dependency regarding the following needs: eating and drinking, continence, body posture, mobility, day/ night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, recreational activities and learning ability. Each of those 15 items has an item description and five care dependency criteria. The psychometric testing of the CDS is described in several studies (4, 5, 6, 13). The theoretical range of the CDS sum score is from 15 to 75. Low scores on the items indicate that patients are completely dependent on care and high scores mean that patients are almost independent on care (6).

Research questions

This chapter deals with two questions: first, is the modified version of the Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency of hospitalized school-age children? Second, to what extent are the school-age children in Germany care dependent?

3.2 Methods

3.2.1 Participants and setting

The age range of children included in the study was 6–12 years. The researcher excluded children with severe medical conditions, which might interfere with the children's independence toward their care, and also those who were identified as having cognitive and learning problems. The study was conducted in four wards: general paediatrics**,** nephrology**,** cardiology and oncology in a university hospital in Germany. Four hundred questionnaires were handed to the nurses in the participating wards. A response rate of 88% was obtained and forty-six returned data sets were excluded because data was missing or the children observed did not meet the above-mentioned criteria. Consequently, a total of 130 valid data sets were included in the final analysis.

Forty nurses operated as raters for the reliability test and all raters were practicing nurses directly involved in the daily care of the participating children.
Two scales, the modified Visual Analog Scale (VAS) and the modified Care Dependency Scale for Paediatrics (CDS-P), were used in data collection. Practicing nurses, who had been involved in the care of the children for at least one day, filled in the CDS-P and the VAS. Each child was assessed by two different raters, i.e. paediatric nurses of the morning and the afternoon shifts, to prove the interrater reliability. The data were collected over a period of 4 months, from May to August 2005.

3.2.2 Ethical considerations

Approval to conduct the study was obtained from the Research Ethics Committee of the university as well as the nursing director of the hospital. The nursing supervisors of the four participating wards were fully informed of the purpose, nature and duration of the study. Written informed consent was obtained from the parents of all participating children. Furthermore, the children and their parents were also informed that they had the right to withdraw from the study at any time and were assured of the confidentiality of the study.

3.2.3 Research instruments

3.2.3.1 Care Dependency Scale for Paediatrics (CDS-P)

The CDS was modified using Delphi technique to be applicable for children. The present study applied the modified version of the Care Dependency Scale, which is called the Care Dependency Scale for Paediatrics (CDS-P). In addition, all items descriptions that could be appropriate for children were modified.

3.2.3.2 Visual Analogue Scale (VAS)

In order to verify the criterion-related validity, a modified VAS was used as a control. Nurses administered the CDS-P and the Visual Analog Scale (VAS) at the same time and the criterion-related validity of the CDS-P was assessed by investigating the relationship between the CDS-P and the VAS scores. The VAS is used in many clinical and research settings to assess the strength of perceptions of both children and adults. Polit & Beck (14) reported that the VAS measures certain clinical symptoms (e.g. pain, fatigue) by making people indicate the intensity of the symptom on a straight line. One reason for favouring the VAS for the present study was that the literature recommended it as a more appropriate tool for evaluating complex human performance (15). In addition, the VAS has some advantages, such as its simplicity, sensitivity and universality (e.g. independent from language).

The VAS is a 10-cm line with a descriptor at either end. For the present study, the descriptors were amended to “dependent regarding self-care” and “independent regarding self-care”. The assessment was performed by marking the line at a certain location, which was then quantified by measuring its distance from the descriptor “dependent regarding self-care”. The nurse involved in the care of the child for at least 24 hours filled in both the CDS-P and the VAS at the same time.

3.2.4 Data analysis

Children’s baseline characteristics were presented using average values and standard deviations. The effect of sex and age on the performance of the mean CDS-P sum score was investigated using t-test. The present study assessed the reliability of the CDS-P in terms of internal consistency using Cronbach’s alpha and interrater reliability using Cohen’s Kappa. As the study sample was relatively small, the percentage agreement between the two raters was also presented in addition to the Kappa values. The Kappa statistics were interpreted as recommended by

Landis & Koch (16), where K-values higher than 0.80 were considered as almost perfect, 0.61–0.80 as substantial, 0.41–0.60 as moderate, 0.21–0.40 as fair and < 0.20 as slight. Percentage agreement is defined as the percentage of full agreement between corresponding item criteria that nurses of the morning and afternoon shifts rated using the five response criteria, while Kappa is described as the ratio of the observed agreement beyond chance and the maximal potential agreement beyond chance (17).

The criterion-related validity was determined by investigating the relationship between the CDS-P scores and the VAS scores. Furthermore, construct validity was tested using the principal component factor analysis. The statistical package SPSS 12.0 for Windows was used for the analysis.

3.3 Results

3.3.1 Reliability aspects of the CDS-P

The Reliability of the CDS-P was tested in terms of internal consistency using Cronbach's alpha and interrater reliability. Cronbach's alpha was calculated at scale level and the result was 0.91, which indicates a high internal consistency. Cohen's Kappa and percentage agreement were used to calculate the interrater reliability.

Table 1. Measuring agreement between the two raters in CDS-P scores at item level for school-age children (n=130)

CDS-P items	Percentage Agreement	Kappa	Strength of agreement
Eating and drinking	73.1	0.69	substantial
Continence	83.8	0.75	substantial
Body posture	75.4	0.59	moderate
Mobility	82.3	0.73	substantial
Day and night pattern	83.1	0.72	substantial
Getting dressed and undressed	76.9	0.74	substantial
Body temperature	67.7	0.61	substantial
Hygiene	73.1	0.73	substantial
Avoidance of danger	71.5	0.62	substantial
Communication	72.3	0.62	substantial
Contact with others	70.8	0.59	moderate
Sense of rules and values	64.6	0.57	moderate
Daily activities	67.7	0.60	moderate
Play and hobbies	84.6	0.80	substantial
Learning ability	77.7	0.73	substantial

Table 1 shows substantial agreement at item level (64.6 - 84.6%) between the paediatric nurse of the morning shift and her colleague of the afternoon shift when using the five response criteria on each of the 15 CDS-P items. Cohen's Kappa ranged from 0.57 to 0.80 indicating a moderate to substantial interrater reliability.

3.3.2 Validity aspects of the CDS-P

Criterion-related validity is the degree to which the scores of an instrument correlate with another external criterion (14). This was examined by comparing the sum scores of the CDS-P and VAS; the Pearson correlation was 0.86 and significant ($P < 0.001$).

In order to verify the construct validity, a factor analysis was carried out and a principal component factor analysis resulted in a one-factor solution. The determination of the number of factors to be extracted depends on how strongly the variables load on the factors (18); the variable will load strongly on a particular factor if loading is ≥0.40 (19). Factor extraction demonstrated that all 15 items fell in factor 1 and none of the items had a factor loading lower than 0.40 (table 2). Three of the CDS-P items (learning ability, mobility and sense of rules and values) had a loading of ≥0.40 in factor 2, but factor loading was higher with regard to factor 1. The first factor eigenvalue was 7.5 and accounted for 49.9 % of the total variance.

Table 2. Rotated component matrix, eigenvalue and percentage variance of the CDS-P

CDS-P items	Components	
	1	2
Daily activities	0.87	0.15
Getting dressed and undressed	0.83	-0.34
Hygiene	0.82	-0.26
Play and hobbies	0.79	0.35
Body posture	0.76	-0.34
Eating and drinking	0.74	0.02
Learning ability	0.70	0.46
Avoidance of danger	0.69	0.16
Continence	0.68	-0.39
Mobility	0.67	-0.59
Contact with others	0.62	0.28
Body temperature	0.62	0.11
Sense of rules and values	0.61	0.47
Day and night pattern	0.58	-0.17
Communication	0.53	0.30
Eigenvalue	7.5	1.7
% Variance	49.9	10.8

3.3.3 Is a school-age child care dependent?

Concerning the second research question, more than two thirds of the children were dependent to a limited extent to almost independent regarding the CDS-P items (table 3).

Moreover, the same table showed that the mean values of all the CDS-P items were approximately high, indicating that the school-age children were not care dependent. In order to gain a better insight into children's performance on the CDS-P items, body posture and mobility obtained the highest means of the CDS-P, which indicates that school-age children were mostly independent regarding the two items. In contrast to this, hygiene and daily activities were the items with the lowest independence means.

Table 3. Percentage of the performance of children regarding different items of the CDS-P

CDS-P items	Completely dependent	To a great extent care dependent	Partially care dependent	To a limited extent care dependent	Almost independent	Mean (SD) (n=130)
	%	%	%	%	%	
Eating and drinking	6.2	1.5	12.3	33.8	46.2	4.1 (1.1)
Continence	1.5	1.5	6.9	28.5	61.5	4.5 (0.8)
Body posture	0.8	1.5	4.6	22.3	70.8	4.6 (0.7)
Mobility	0.8	2.3	6.2	23.1	67.7	4.6 (0.9)
Day and night pattern	2.3	1.5	3.8	23.1	69.2	4.5 (0.9)
Getting dressed and undressed	1.5	4.6	10.8	40.8	42.3	4.2 (0.9)
Body temperature	4.6	2.3	15.4	35.4	42.3	4.1 (1.0)
Hygiene	4.6	6.2	20.0	44.6	24.6	3.8 (1.1)
Avoidance of danger	3.8	2.3	16.2	51.5	26.2	3.9 (0.9)
Communication	0.8	1.5	7.7	33.1	56.9	4.4 (0.9)
Contact with others	2.3	1.5	11.5	32.3	52.3	4.3 (1.0)
Sense of rules and values	6.2	3.1	15.4	39.2	36.2	3.9 (1.2)
Daily activities	3.1	3.1	29.2	41.5	23.1	3.8 (0.9)
Play and hobbies	2.3	1.5	6.2	43.1	46.9	4.3 (0.8)
Learning ability	1.5	3.1	10.0	48.5	36.9	4.2 (0.8)

3.3.4 Sex and age

The mean age of the children (n = 130) was 9.1 (SD 1.8) years. Slightly more girls (53.8%) than boys took part in the study. The total sample distribution according to the children's age and gender is shown in table 4.

Table 4. Sample distribution according to the children's gender and age

Age								Gender
Total	**12 years**	**11 years**	**10 years**	**9 years**	**8 years**	**7 years**	**6 years**	
60	5	12	7	9	6	17	4	Boys
70	10	7	16	10	11	13	3	Girls
130	15	19	23	19	17	30	7	**Total**

With regard to the effect that the age and sex of children has on care dependency, figure 1 showed that the most significant decrease in independence occurred between the age of 6 and 7 years. There was also a progressive increase in care independence between the age of 11 and 12 years, whereas the means of the total CDS-P for children aged 8 to 10 years were approximately the same.

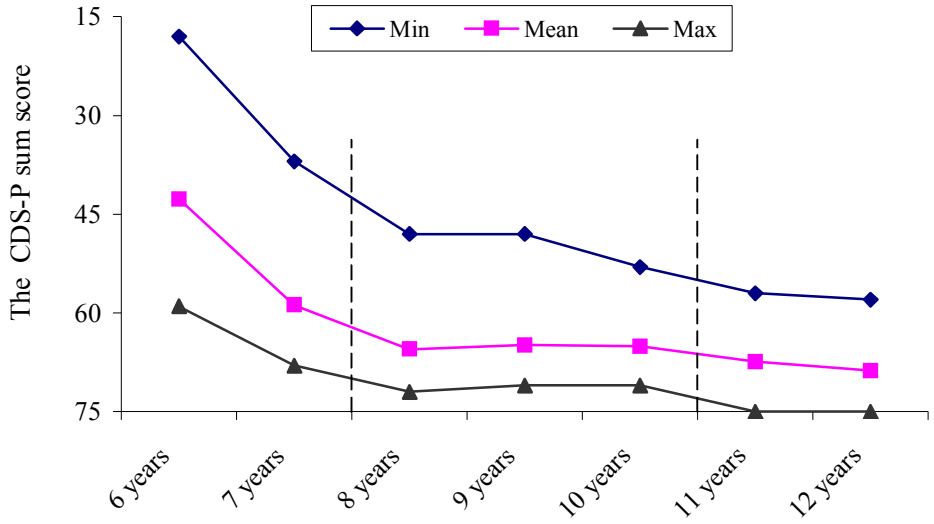


Figure 1. Minimum, mean & maximum of the CDS-P score according to children's age

A significant correlation was found between the age of children and the mean of the total CDS-P ($P < 0.001$). An interesting fact was that there was no significant difference between boys and girls regarding the mean CDS-P sum scores (table 5). The CDS-P sum score was calculated by adding the 15 CDS-P item scores.

Table 5. The mean and standard deviation of the CDS-P sum score of children

Sex	CDS-P sum score		
	Mean	**SD**	**N**
Boys	61.7	9.8	60
Girls	64.6	8.1	70
Total	63.3	9.0	130

3.4 Discussion and Conclusion

The descriptive findings highlight that care dependency correlates significantly with the child's age. The mean scale scores increased progressively with age (figure 1), which suggests that the CDS-P is appropriate for the detection of consistent age-related gains in care independency.
The findings of the present study do not support the effect of gender on the children's care dependency. This finding is inconsistent with those of the study of Jongjit and colleague's (20) (N=569), who established that girls in Thailand are more capable of self-care whereas boys are stronger in mobility and manual work. This discrepancy may partially be explained by cultural differences; the authors mentioned that it is well-accepted in the traditional Thai culture that girls master self-care skills before boys do.

3.4.1 Psychometric properties of the CDS-P

Based on the four investigated aspects of reliability and validity (internal consistency, interrater reliability, criterion-related validity and construct validity of the CDS-P), it can be stated that the CDS-P is a valid and reliable instrument for assessing the care dependency of school-age children.
Concerning the reliability and validity of the modified version of the Care Dependency Scale, there are no published studies about the scale quality in paediatric settings. This study is the first one to use the CDS-P in paediatric wards and revealed results similar to those of the original CDS in nursing homes and hospitals. Consistent with previous findings (3, 4, 5, 13) provides further evidence of the reliability and validity of the CDS-P with school-age children.

The internal consistency of the whole CDS-P instrument was determined by means of Cronbach's alpha. An internal consistency greater than the required value of 0.90 means that the scale may be applied on an individual level (14). The coefficient alpha was found to be high enough (0.91) to use the CDS-P in clinical practice on group and individual level.
Regarding the interrater reliability the Kappa values ranged from 0.57 for 'sense of rules and values' to 0.80 for 'play and hobbies'. According to Landis and Koch (16) the verbal interpretations of these Kappa statistics indicate a moderate to substantial agreement. The lowest agreement was found for 'sense of rules and values', however, a possible explanation could be that it is difficult to describe the key concept of 'sense of rules and values' to young children, which leads to nurses interpreting responses in different ways.

The construct validity of the CDS-P was explored by factor analysis, which resulted in a one-factor solution. Theoretically, possible clusters of somatic and psychosocial items cannot be clearly distinguished. Therefore, no somatic and psychosocial subscales were constructed. The obtained results support the holistic approach of nurse theorists that somatic and psychosocial needs are inseparable (21, 22).

3.4.2 Care dependency of school-age children

With regard to the second research question, the results demonstrate that the majority of children ranged from being care dependent to a limited extent to being almost independent regarding all items of the CDS-P. The findings are not surprising when looking at the findings of some previous studies, such as Marks (23) who reported that children reach school age with the necessary skills, abilities and independence to function successfully in the environment. They can feed and dress themselves and use the primary language of their culture to communicate their needs and feelings.

Along the same line, Wong and colleagues (24) revealed that children at toddler age achieved mobility, walking, toileting transfers, stairs and social interactions independently. At pre-school age, continence independence, getting in and out of showers, dressing and other aspects of personal hygiene were performed independently. These results lead to the conclusion that children enter school age with the ability to master many self-care activities independently.

Furthermore, the results showed more independence among school-age children regarding mobility and its consequences and less independence regarding hygiene and daily activities, which may be explained by the fact that mobility is easier for children than performing aspects of self-care. This may also be due to the fact that mobility is fully developed by the point of school age but that it takes longer to master the tasks of self-care, such as hygiene and daily activities.

In conclusion, the psychometric properties of the CDS-P support its use in measuring the care dependency of hospitalised school-age children. It shows a good internal consistency and a strong evidence for content validity and criterion-related validity. In addition, Kappa statistics indicated a moderate to substantial agreement supporting the interrater reliability. Based on these results, the CDS-P can be used with confidence as an appropriate tool in clinical research to assess the care dependency of children.

Furthermore, school-age children showed more independency regarding mobility and its consequences than regarding any other aspects of the CDS-P.

3.5 Implications for nursing practice

A higher dependence of children with regard to their daily tasks undoubtedly places a greater burden on their caregivers. The present study intends to provide information regarding the care dependency of school-age children. It seems important in nursing practice to assess the degree of care dependency of children in respect to their developmental stage because this may help nurses to improve the care dependency among dependent children and encourage children's independence on care. The CDS-P is a valid and reliable measurement instrument that offers a comprehensive assessment from a nursing perspective and enables nurses to help children acquire independence.

References

1. Statistisches Bundesamt Deutschland. International Children's Day: statistics of illness diagnoses. Available at: http://www.destatis.de/basis/d/gesu/gesutab10.php 2006; Cited [Accessed 10 Feb. 2007].

2. Kittay E, Jennings B, Wasunna A. Dependency, difference and the global ethic of longterm care. J. Polit. Philos. 2005; 13: 443–469.

3. Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T, Heuvel W. An International Psychometric testing of the Care Dependency Scale. Journal of Advanced Nursing 2000; 31 (4): 944-952.

4. Dijkstra A, Coleman M, Tomas C, Välimäki M, Dassen T. Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing. 2003; 43 (2): 181-187.

5. Lohrmann C, Dijkstra A, Dassen T. Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scandinavian Journal of Caring Science. 2003a; 17: 51-56

6. Dijkstra A, Buist G, Dassen T. A criterion-related validity study of the Nursing-Care Dependency (NCD) scale. International Journal of Nursing Studies 1998; 35(3): 163-70

7. Limperopoulos C, Majnemer A, Michael S, Rosenblatt B, Rohlicek C, Tchervenkov C, Darwish H. Functional Limitation in Young Children with congenital heart defects after cardiac surgery. Pediatrics 2001; 108 (6): 1325-1331.

8. Strandberg G, Jansson L. Meaning of dependency on care as narrated by nurses Scand J Caring Sci 2003; 17: 84–91.

9. Erikson E. Childhood and Society. 2nd edn. New York: Norton 1963.

10. Palermo T, Childs G, Burgess E, Kaugars A, Comer D, Kelleher K. Functional limitations of school-aged children seen in primary care. Child Care Health Dev. 2002; 28: 379-389.

11. Patton S, Graham J, Varlotta L, Holsclaw D. Measuring Self-Care independence in children with Cystic Fibrosis: The Self-Care Independence Scale (SCIS). PediatrPulmonol. 2003; 36: 123-130.

12. Igoe JB, Speer S. Community health nurse in the schools: Process and practice for promoting health 4th ed. St. Louis: Mosby-Year Book 1996

13. Lohrmann C, Dijkstra A. Dassen T. The Care Dependency Scale: An Assessment Instrument For Elderly Patients in German Hospitals. Geriatric Nursing. 2003b; 24 (1): 40-43

14. Polit D, Beck C. Nursing Research: Principles and Methods. 7 th edn. Philadelphia: Lippincott, 2004; p.716.

15. McAllister S. Competency based assessment of speech pathology students' performance in the workplace. PhD thesis. University of Sydney, 2006.

16. Landis J, Koch G. The measurement of observer agreement for categorical data. Biometrics 1977; 33:159-74.

17. Cohen JA. Coefficient of agreement for nominal scales. Educational and psychological Measurement. 1960; 20:37-46.

18. Youngblut J. Comparison of factor analysis options using the home/employment orientation scale. Nursing Research 1993; 42: 122–124.

19. Nunnally JC, Bernstein IH. Psychometric Theory. McGraw-Hill, New York, 1994.

20. Jongjit J, Komsopapong L, Saikaew T, Wanich U, Chewapanich S, Udomsubpayakul U, Ruangdarganon N. Reliability of the Functional Independence Measure for children in Normal Thai children. Pediatric International 2006; 48: 132-137.

21. Henderson V. The nature of Nursing: A Definition and its Implications for Practice, Research and Education. New York: MacMillan Press, 1966.

22. Neuman B. The Neuman Systems Model 3rd edn. Appleton & Lange, Norwalk, Connecticut. 1995.

23. Marks, M. Counselling and psychotherapy with children and adolescents. 3rd ed., New York: John Wiley and Sons, Inc., 1998.

24. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

CHAPTER 4

Care dependency of children in Egypt

Tork H, Lohrmann C, & Dassen T. (2007) Accepted for publication in

Journal of clinical Nursing

Abstract

Aims: This study aimed to modify the Care Dependency Scale (CDS) so that it could be used for children, to apply its Arabic version to Egyptian children to test the reliability and validity of the modified scale and to compare the care dependency of disabled and non-disabled Egyptian children.

Background: A higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers. To estimate the extent of the problem of care dependency, data from different countries and proper standard instruments are required.

Method: The CDS was modified for children by Delphi technique. This study assessed the care dependency of non-disabled children compared to children with physical and mental disabilities using the modified version of the Care Dependency Scale (CDS-P). The total sample included 260 Egyptian school-age children (50.8 % of whom were disabled and 49.2 % were non-disabled).

Results: Reliability was examined in terms of internal consistency using Cronbach's alpha (0.91). Interrater reliability revealed moderate to very good Kappa statistics between 0.57 - 0.89. Content validity and criterion validity were evaluated. Differences regarding care dependency were found between disabled and non-disabled children.

Conclusion: The psychometric properties of the CDS-P support its usefulness in measuring the care dependency of children in Egypt. This study provides an Arabic version of the CDS-P that is easy to administer and may be useful to measure the care dependency in various Arabic countries.

Relevance to clinical practice: The findings raise concerns regarding the extent to which disabled and also non-disabled school-age children are care dependent leading to an increased burden of care on nurses or on caregivers in general. The CDS-P can help nurses to conduct an appropriate assessment of children's care dependency so that any nursing care can be planned according to the children's needs.

4.1 Introduction

Disability is a worldwide problem. The 2003 World Health Organization (WHO) reports pointed out that 10% of the world's population, or 600 million people, are disabled. About a quarter of these 600 million, i.e. 150 million people are children (1). The International Classification of Functioning, Disability and Health (ICF) defined disability as 'an umbrella term for impairments, activity limitation and participation restrictions' (2). In Egypt, disability constitutes a major problem among children and it has health, economic and social consequences. According to local authorities Egypt has an estimated population of 60 million people with 39.4% of them being children (0-15 years) and about 6% of those children having significant disabilities (3).

Many physical, cognitive and mental disabilities of children result in those children being dependent on their caregivers. On the other hand, a higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers (4). Therefore, in the literature about nursing, care dependency has been described as a problem that needs to be addressed (5, 6).

In spite of the burden of care that the families of disabled children have to face, the problem of care dependency among children has not received the appropriate attention yet. To estimate the extent of the problem, data from different countries are required. The present study aimed at exploring the problem of care dependency among Egyptian children. There is no standard instrument to assess the care dependency of children in Egypt. The Care Dependency Scale (CDS) was widely used in various European countries to assess patients' care dependency in nursing homes and hospitals. In Germany it was also used and psychometrically tested in different hospital disciplines, one of which was the paediatric discipline (7, 8). However, due to cultural differences it might be psychometrically inappropriate and even problematic, to apply this tool to a different cultural group, such as Egyptian children. Some concepts or items contained in the original instrument might be inappropriate for people of another culture (9). It was therefore decided to modify and test the CDS for its use in Egypt. This modified scale has been translated into Arabic and named the Care Dependency Scale for Paediatrics (CDS-P). The present study is significant as it tests the CDS in an additional language and modifies the scale for a specific age group, i.e. school-age children, so that nurses can give a reliable and validated judgment regarding children's care dependency. In addition, it examines the extent to which a disability influences the child's self-care ability by comparing the care dependency of disabled and non-disabled children.

AIMS: The objectives of this study were to modify the Care Dependency Scale (CDS) so that it could be used for children, to apply its Arabic version to Egyptian children to test the reliability and validity of the modified scale and to compare the care dependency of disabled and non-disabled Egyptian children.

Research questions:

Is the modified Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency among children in Egypt?

What are the differences between disabled and non-disabled school-age children in Egypt regarding their care dependency?

4.2 Instruments

4.2.1 The Care Dependency Scale (CDS)

Some assessment instruments, such as the Physical Self-Maintenance Scale (PSMS), the Barthel Index and the Functional Independence Measure (FIM), were developed to estimate the activities of daily living. However, these instruments were not developed from a nursing perspective. In addition, there is only little known about the psychometric properties of the PSMS, the Barthel Index is limited because the patient's psychological and sociologic aspects are not accounted for (10) and the FIM is complex and takes a long time to learn and be administered (11). Lohrmann et al. (8) recommended the CDS as a better instrument for assessing the care dependency due to the psychometric properties and because it covers all aspects of care needs. This instrument was developed in the Netherlands in 1996 by Dijkstra et al. for demented and mentally handicapped people and has been psychometrically tested in different European countries.

The CDS has a theoretical framework; it is based on Henderson's (1966) human needs theory. The CDS items are therefore related to fundamental human needs independent from the cultural background. In addition, the CDS was tested in Germany for its use in hospitals in different disciplines; one of them being the paediatric ward (7, 8). It also showed a good validity and reliability in several studies (12, 13, 14, 8, 15), that it is easy to use and can be completed quickly, usually within less than 5 minutes (14). These are also the reasons why the current study applied the Care Dependency Scale.

The CDS measures 15 human needs: eating and drinking, continence, body posture, mobility, day/night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of

danger, communication, contact with others, sense of rules and values, daily activities, recreational activities and learning ability. Each of the 15 items has an item description and five care dependency criteria. For an example see Figure 1. Nurses rate all items by selecting one of the five criteria. The theoretical range of the CDS sum score is from 15 - 75. Low scores on the items indicate that patients are completely dependent on care and high scores mean that patients are almost independent on care (14).

4.2.2 Visual Analog Scale (VAS)

The VAS is a scaling procedure used to measure certain clinical symptoms (e.g. pain, fatigue) by making people indicate the intensity of their symptoms on a straight line (16). This is a 10-cm long line with the descriptors 'no pain' and 'severe pain' at either end. For the present study, the descriptors were amended to 'dependent regarding self-care' and 'independent regarding self-care'. The assessment was carried out by marking the line and then quantifying the position by measuring its distance from the descriptor 'dependent regarding self-care'. For normal children, the nurse having been involved in the care of the child for at least 24 hours filled in the modified Care Dependency Scale (CDS-P) and Visual Analog Scale (VAS). For disabled children, their teachers were responsible to complete the relevant scales.

4.3 Methods

This study was conducted in two phases; the first one included the modification of the German version of the CDS and its translation into Arabic. The second phase involved the data collection of a convenient sample of 260 disabled and non-disabled school-age children in Egypt from primary schools and university hospitals respectively.

4.3.1 First phase

4.3.1.1 Modification of the CDS by Delphi technique

The Delphi technique as defined by Polit & Beck (16) is a specific method of obtaining judgments from a panel of experts. The experts are questioned individually and a summary of the individual judgments is then distributed to the entire panel. The experts are questioned again and further iterations are introduced as required until a minimum of 75% agreement or more is obtained as the criterion of consensus. The panel size in the present study comprised 12 experts. The experts in this study were graduated nurses with a minimum of three years experience in paediatric care, who were presently involved in nursing education and/or practice.

The Delphi process consists of two rounds; in round one the questionnaires are mailed to the experts to ask each participant questions about the relevancy of items for children to be able to assess the content validity. Participants respond anonymously within one month. The researcher then summarizes the responses, develops a modified questionnaire and again mails it to the same respondent group. In round two the respondents provide their written judgment about the modified questionnaire and return the responses using a stamped and self-addressed envelope supplied by the researcher.

Table 1. Example of an item of the modified Care Dependency Scale

Item	**Eating and drinking**
Description	The extent to which the child is able to satisfy his/her need for food and drink unaided
Criteria	(1) The child is unable to take food and drink unaided
	(2) The child is unable to prepare food and drink unaided; (e.g. He can not put the butter on the bread); child is able to put food and drink into his/her mouth unaided
	(3) The child is able to prepare and put food and drink into his/her mouth unaided; He has difficulties to determine the quantity 'per spoon/ per meals'.
	(4) The child is able to eat and drink unaided; He/she need some support
	(5) The child is able to prepare his/her meals and to satisfy his/her need for eating and drinking unaided.

4.3.1.2 Translation Procedure

The next step was the translation of the modified Care Dependency Scale for Paediatrics (CDS-P) into Arabic so that it could be used in Egypt. The most common and highly recommended procedure of verifying the translation of an instrument is the back translation (17, 18, 19). The translation process of the Arabic version followed this back translation method. First, the CDS-P was translated from German into Arabic by the researcher. An independent translator then translated the Arabic version back from Arabic into German. To establish the accuracy of the Arabic version, the following statistical analyses were employed: Cronbach's alpha reliability coefficients, Kappa to determine item-to-item agreement, Pearson's correlation between the Arabic version of the CDS-P and VAS to assess the criterion-related validity and factor analysis to determine the construct validity.

4.3.1.3 Pilot study

The Arabic version was presented to a group of nurses in Egypt to assess its clarity and appropriateness for clinical settings. A pilot study was conducted on 20 children, 10 normal school-age children and 10 children with different types of disabilities to test the appropriateness of the measurement tool and to estimate the time required to complete it.

4.3.2 The second phase

4.3.2.1 Informed Consent

The study protocol and the measurement tools were reviewed and approved by the nursing manager at the hospital. Other permissions were obtained from the managers of each educational region that the relevant school was allocated to. The permissions were handed to the headmaster of each school to allow the collection of data pertinent to the study. The parents of all participants provided written informed consent before completing the instruments, which were filled in by the nurses responsible for the child's care. Furthermore, information was simplified for the children and a separate consent form was provided.

4.3.2.2 Data collection

Sample: Two hundred and sixty convenient samples of Egyptian children aged 6-12 years participated in the study (50.8 % of whom were disabled and 49.2 % were non-disabled). The disabilities involved were of physical (blindness, deafness, speech disorders) and mental (intellectual disability, slow learning) nature. The extent of the disability ranged from a mild to a moderate disability. Data collection took place from January to April 2005.

Setting: This study was conducted in Egypt. Data of non-disabled children were collected from different wards at a university hospital.

Data of disabled children were collected from institutionalised governmental schools as follows: Primary school for blind children, primary school for deaf children and those with speech disorders and a school for children with intellectual disabilities. However, these three schools are the only schools for disabled children in the area.

4.3.2.3 Data analysis

The present study assessed the reliability of the CDS-P in terms of internal consistency using Cronbach's alpha and each child was assessed by two different raters, i.e. paediatric nurses in the

morning and afternoon shifts at the hospital in the case of non-disabled children and teachers in the case of disabled children were involved to proof the interrater reliability.

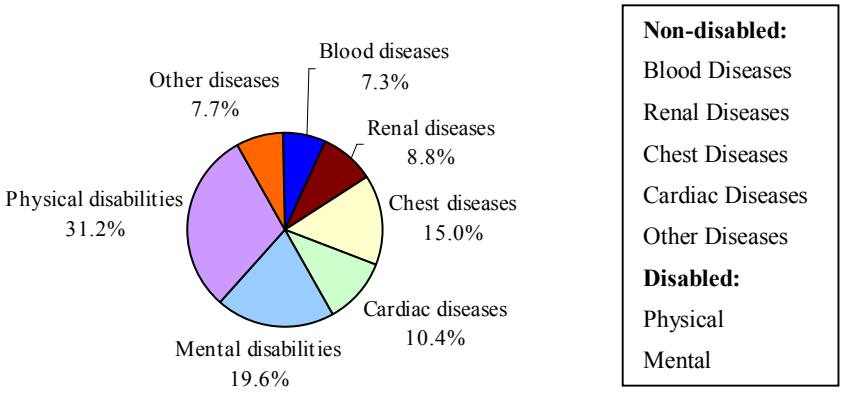
To verify the validity, nurses administered the CDS-P and the Visual Analog Scale (VAS) at the same time and the criterion-related validity of the CDS-P was assessed by investigating the relationship between the CDS-P and VAS scores. Furthermore, construct validity was tested using the principal component factor analysis. To analyse for statistical significant differences between each type of disability, a scheffé post-hoc test for each item was performed. The statistical package SPSS 12.0 for Windows was used for this analysis.

4.4 Results

4.4.1 Descriptive statistics

The average age of the children was nine years and five months (SD one year and nine months). Slightly more male children (54.6%) were involved in the study than female children. The sample distributions according to the setting are reported in Figure 1.

Figure 1. Percentage distribution of the sample according to the main diagnosis



More than half of the disabled children ranged from being completely dependent to being care dependent to a great extent regarding the items of body temperature, communication, contact with others, daily activities and learning ability (Table 2).

Table 2. Percentage of the performance of disabled children regarding different items of the CDS-P

CDS-P Items	Completely dependent	To a great extent care dependent	Partially care dependent	To a limited extent care dependent	Almost independent
	%	%	%	%	%
Eating and drinking	22.8	28.5	18.5	22.7	7.6
Continence	8.3	9.8	11.4	20.5	50.0
Body posture	1.5	4.5	13.6	44.7	35.6
Mobility	3.0	7.6	12.1	53.0	24.2
Day and night pattern	4.5	20.5	22.0	36.4	16.7
Getting dressed and undressed	19.7	22.0	24.2	24.2	9.8
Body temperature	18.2	35.6	26.5	15.9	3.8
Hygiene	10.6	31.8	32.6	15.9	9.1
Avoidance of danger	12.9	27.3	31.8	25.0	3.0
Communication	18.2	34.1	22.0	16.7	9.1
Contact with others	24.2	34.1	23.5	15.2	3.0
Sense of rules and values	14.4	34.1	21.2	23.5	6.8
Daily activities	22.0	31.8	22.7	17.4	6.1
Play and hobbies	6.8	22.0	14.4	13.6	43.2
Learning ability	25.8	28.8	21.2	12.9	11.4

More than half of the non-disabled children ranged from being care dependent to a limited extent to being almost independent regarding the majority of the CDS-P items (eating and drinking, continence, body posture, mobility, day and night pattern, hygiene, avoidance of danger, communication, play and hobbies and learning ability) (Table 3).

Table 3. **Percentage of the performance of non-disabled children regarding different items of the CDS-P**

CDS-P Items	Completely dependent	To a great extent care dependent	Partially care dependent	To a limited extent care dependent	Almost Independent
	%	%	%	%	%
Eating and drinking	13.3	19.8	15.6	27 .9	23.4
Continence	3.9	13.3	12.5	13.3	57.0
Body posture	5.5	22.7	10.2	21.9	39.8
Mobility	3.1	25.8	4.7	18.8	47.7
Day and night pattern	2.3	23.4	3.9	40.6	29.7
Getting dressed and undressed	16.4	23.4	13.3	25.8	21.1
Body temperature	16.4	30.5	24.2	20.3	8.6
Hygiene	12.5	22.2	13.3	34.8	17.2
Avoidance of danger	10.2	18.8	13.3	33.6	24.2
Communication	5.5	24.2	19.5	25.8	25.0
Contact with others	8.6	20.8	17.2	27.3	26.1
Sense of rules and values	8.6	28.9	21.1	23.4	18.0
Daily activities	12.8	24.6	11.7	25.8	25.1
Play and hobbies	3.1	21.1	16.4	7.0	52.3
Learning ability	6.3	24.2	9.4	18.0	42.2

4.4.2 Reliability and validity of the CDS-P

Reliability aspects. Reliability of the CDS-P was analysed in terms of internal consistency using Cronbach's alpha and interrater reliability. Cronbach's alpha was calculated at scale level and the result was 0.91, which indicates a high degree of internal consistency.

Cohen's Kappa was used to calculate the interrater reliability. The Kappa value ranged from 0.57 for sense of rules and values to 0.89 for play and hobbies (Table 3). The Kappa statistics were interpreted in the way recommended by Landis & Koch (20), where K-values higher than 0.80 were considered as almost perfect, 0.61–0.80 as substantial, 0.41–0.60 as moderate, 0.21–0.40 as fair and < 0.20 as poor.

Table 4. Interrater reliability of the CDS-P items (Kappa)

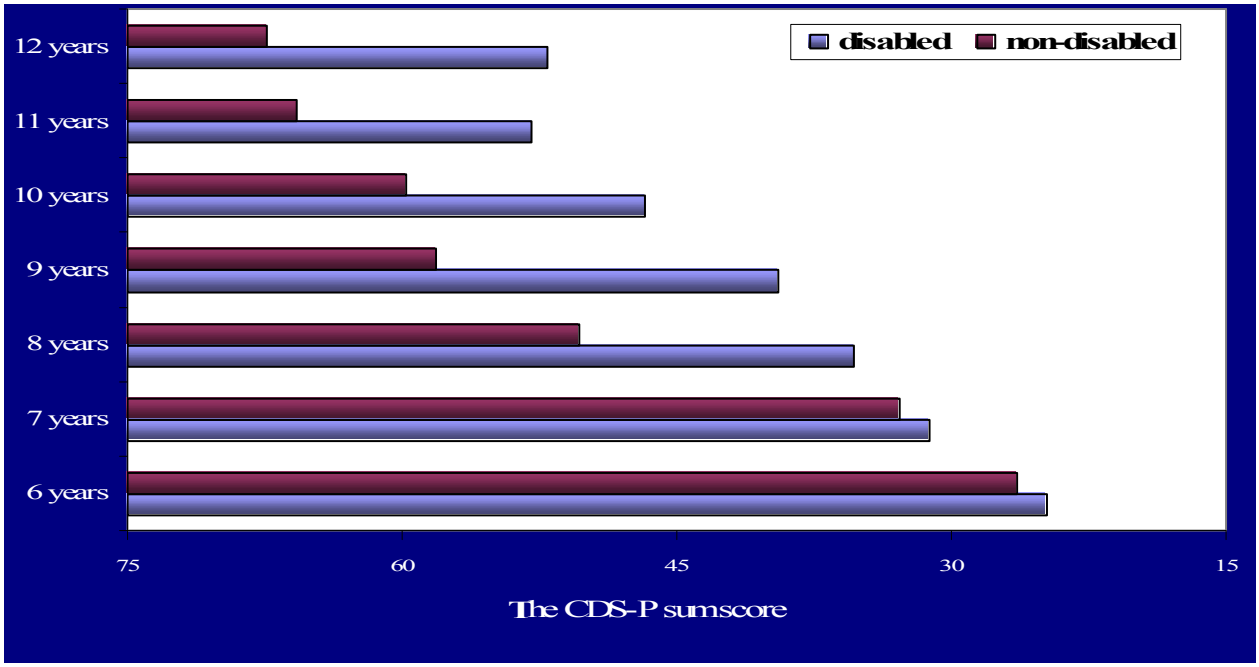
CDS-P items	Kappa
Eating and drinking	0.78
Continence	0.85
Body posture	0.86
Mobility	0.88
Day and night pattern	0.69
Getting dressed and undressed	0.86
Body temperature	0.66
Hygiene	0.74
Avoidance of danger	0.58
Communication	0.66
Contact with others	0.61
Sense of rules and values	0.57
Daily activities	0.58
Play and hobbies	0.89
Learning ability	0.76

Validity aspects. The content validity was proved by experts in a Delphi survey, which was conducted in two rounds. The response rates were 92% for the first round and 85% for the second round, which means it obtained a good consensus. The indication for criterion validity was found by comparing the CDS-P with the VAS (Pearson's correlations, $r = 0.67$, $p<0.001$).

Factor analysis (principal component analysis) was employed to verify the construct validity. The factor analysis yielded two factors with eigenvalues greater than 1, which combined accounted for 60.6% of the variance (separately, 51.6%, 9.0%). Factor 1 (eigenvalue = 7.8) included seven items representing the psychosocial cluster of items, such as contact with others, communication. Factor 2 (Eigenvalue = 1.3) included eight items representing the somatic cluster of items, e.g. body posture and mobility. A factor extraction demonstrated that all 15 items channelled into factor 1. Factor loadings ranged from 0.58 to 0.83. As none of the items had a factor loading lower than .40 an item reduction did not take place.

Pearson's correlations were computed from age and CDS-P sum scores. The correlation between age and the CDS-P sum score was statistically significant for the disabled and non-disabled children respectively ($r =0 .79$, $p<0. 0001$; $r =0 .88$, $p<0. 0001$).

Figure 2. The Care Dependency of children according to their age



4.4.3 Care dependency of disabled and non-disabled children

The differences between disabled and non-disabled children were statistically significant in the items avoidance of danger, communication, contact with others, sense of rules and values, daily activities and learning ability (Table 5).

Table 5 Mean, standard deviation, t-test items of the CDS-P

CDS-P Items	Disabled children (n =132) Mean (SD)	Non-disabled (n =128) Mean (SD)	t-test p ≤ 0.01 (two-tailed)
Eating and drinking	2.7 (1.3)	3.2 (1.4)	n.s
Continence	3.9 (1.3)	4.1 (1.3)	ns
Body posture	4.0 (0.9)	3.7 (1.4)	ns
Mobility	3.9 (0.9)	3.8 (1.4)	ns
Day and night pattern	3.4 (1.3)	3.7 (1.2)	n.s
Getting dressed and undressed	2.8 (1.3)	3.1 (1.4)	ns
Body temperature	2.5 (1.1)	2.7 (1.3)	ns
Hygiene	2.8 (1.1)	3.2 (1.4)	ns
Avoidance of danger	2.8 (1.1)	3.4 (1.3)	0.01
Communication	2.6 (1.3)	3.4 (1.3)	0.01
Contact with others	2.4 (1.1)	3.3 (1.3)	0.01
Sense of rules and values	2.7 (1.2)	3.1 (1.3)	0.01
Daily activities	2.5 (1.2)	3.1 (1.4)	0.01
Play and hobbies	3.6 (1.4)	3.8 (1.3)	ns
Learning ability	2.6 (1.4)	3.7 (1.4)	0.001
CDS-P sum score per sex			
Male	45 (10.2)	50.8 (16.6)	
Female	45.0 (10.7)	51.9 (15.2)	

According to the one-way analysis of variance the item analysis revealed that the mean values of all the CDS-P items apart from 'continence' and 'play and hobbies' were significantly different for the five types of disabilities (see Table 6).

Table 6. Mean, Standard deviation and F-test of the CDS-P among disabled children

CDS-P Items	Mental disabilities (n =51)		Physical disabilities (n =81)			Analysis of variance F- test
	Slow Learning (n =27) Mean (SD) A	Intellectual Disability (n =24) Mean (SD) B	Deafness (n =28) Mean (SD) C	Speech Disorders (n =25) Mean (SD) D	Blindness (n =28) Mean (SD) E	
Eating and drinking	2.8 (1.2)	1.8 (1.2) [C]	2.9 (1.0)	3.5 (1.4) [B]	2.4 (1.2)	6.25*
Continence	3.9 (1.6)	3.4 (1.2)	4.1 (1.1)	4.1 (1.2)	4.0 (1.4)	1.29†
Body posture	4.5 (0.7) [E]	3.9 (0.9)	4.2 (0.8)	4.0 (0.9)	3.7 (0.9)	3.53*
Mobility	4.2 (0.7) [E]	3.9 (0.8) [E]	4.1 (0.7) [E]	4.2 (0.6) [E]	3.0 (1.2)	9.77*
Day and night pattern	3.3 (0.9)	2.6 (1.1) [C, D]	4.0 (1.1) [E]	4.0 (0.8) [E]	3.0 (0.9)	8.86*
Getting dressed and undressed	2.6 (1.2) [D]	2.7 (1.3)	2.8 (1.1)	3.8 (1.4) [E]	2.3 (1.0)	5.26*
Body temperature	2.3 (0.8) [D]	1.8 (0.8) [D, E]	2.0 (0.7) [D]	3.4 (1.1)	3.0 (1.0) [C]	13.67*
Hygiene	2.6 (1.1) [D]	2.7 (1.0) [D]	2.5 (1.0) [D]	3.6 (1.2) [E]	2.7 (0.9)	5.03*
Avoidance of danger	2.6 (0.9) [D]	3.0 (1.3)	2.4 (0.6) [D]	3.6 (1.1) [E]	2.5 (1.0)	6.37*
Communication	3.6 (0.9) [C]	2.5 (0.9) [A, C]	1.3 (0.6) [D, E]	2.2 (0.5) [A, E]	3.5 (1.1) [D, B]	36.26*
Contact with others	3.0 (0.7) [C]	2.0 (0.8) [A, E]	1.2 (0.5) [D, B]	1.9 (0.2) [A, E]	3.7 (0.9) [A, C]	58.91*
Sense of rules and values	2.9 (1.0) [B]	1.5 (0.8) [C]	2.7 (1.0) [D]	3.7 (1.3) [B]	2.9 (0.7) [B]	14.91*
Daily activities	2.2 (0.7) [D]	2.2 (1.0) [D]	2.0 (0.7) [D]	3.4 (1.5)	2.9 (1.2)	8.51*
Play and hobbies	3.6 (1.5)	3.0 (1.4)	3.4 (1.3)	4.2 (1.2)	3.9 (1.2)	2.75†
Learning ability	1.7 (0.9) [D]	1.6 (0.6) [D, E]	2.5 (1.0) [B]	3.4 (1.3)	3.4 (1.4) [A]	17.49*

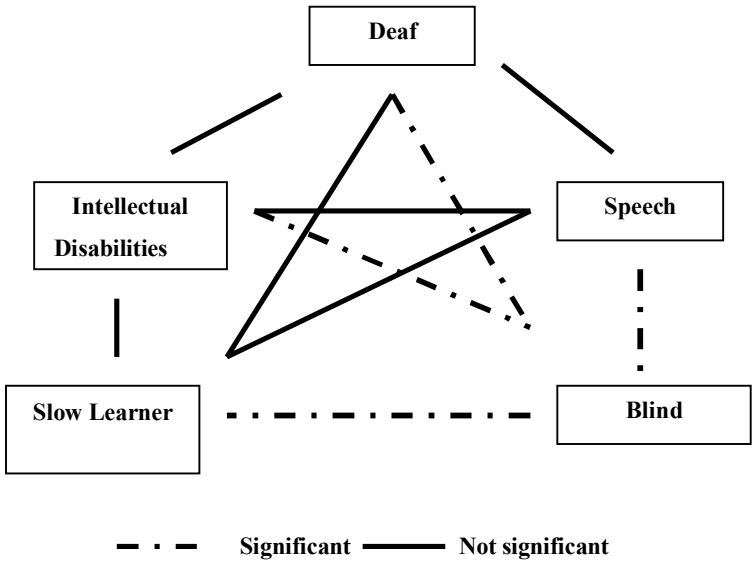
A, B, C, D, E: significant correlation between the above mentioned groups.

* $P \leq 0.01$.

†$P > 0.01$.

To obtain a greater insight into differences between each type of disability, a scheffé post-hoc test for each item was performed, which showed that slow learning, intellectual disability, deafness, speech disorders and blindness significantly correlate with each other regarding the 13 items of the CDS-P (Table 6). For example, blindness correlates significantly with the other four types of disability regarding mobility (figure 3).

Figure 3. Example of the correlation between the types of disabilities regarding mobility



4.5 Discussion and conclusion

A higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers (4). The objectives of the present study were to modify the Care Dependency Scale (CDS) in such a way that it could be used for children and to develop its Arabic version to allow it to be applied to Egyptian children, to test the reliability and validity of the modified scale and to compare the care dependency of disabled and non-disabled Egyptian children. A random sampling design is easy to describe, but it sometimes is quite difficult to achieve in practice. Therefore, the present study employed a convenient sample rather than a random sample. The sample selection was based on certain criteria: the children were 6-12 years old, the extent of the disability of disabled children ranged from a mild to a moderate disability and non-disabled children did not suffer from a major illness or disability that could interfere with the child's performance on the CDS-P.

In relation to reliability, the internal consistency of the modified version of the Care Dependency Scale (CDS-P) was determined by means of Cronbach`s alpha and showed a very good result. Other reliability aspects were examined with regard to the raters' agreement showing moderate to almost perfect results. This means, the guidance provided for the application of the scale was successful and the evaluation criteria of the items were clear enough for nurses to assess the children in practice.

With regard to validity, the content validity was proved by the Delphi technique and obtained a good consensus. An instrument is valid if its scores correlate with other criteria (16). In the

present study, the scores of the CDS-P correlate with the scores of the VAS ($r = .67$, $P<0.001$). The analysis revealed two factors regarding the construct validity. However, according to the principle of discontinuity (16), the abrupt drop in the percentage of explained variance between the first and second factors in the sub-sample indicates that an appropriate termination point was specified, making it advisable to only extract the first factor. The high factor loadings of items in the factor analysis indicated that all 15 items had a positive orientation towards the care dependency concept.

The results proved that the CDS-P is a reliable and valid measurement. They also were in accordance with those previously reported (13, 14, 8, 15). The gender did not make a significant difference in relation to the children's care dependency. This finding is contradictory to that of Wong et al. (21), who stated that girls are more capable of self-caring than boys ($n = 445$). The total CDS-P scores increased progressively with the age for both disabled and non-disabled children (Figure 3).

Table 4 shows that statistically significant differences were detected between disabled and non-disabled children in the items avoidance of danger, communication, contact with others, sense of rules and values, daily activities and learning ability. These results were in accordance with Lewis & Iselin (22) who examined the level of independency in relation to the daily living activities of children with a normal and those with an impaired vision aged 6-9 years ($n= 20$) and revealed that children with an impaired vision only performed 44% of the tasks independently, while children with normal vision performed 84% of their tasks independently. There are several viable explanations for the previously mentioned differences between disabled and non-disabled children. Firstly, children with disabilities included deaf and blind children and those with speech disorders all of which impede the child's communication and contact with others and the avoidance of danger. Secondly, it is possible that disabled children do not master these tasks to the same extent as non-disabled children, because they need longer for the completion of theses tasks due to the nature of their disability. Thirdly, care dependency among disabled children may have a cultural background and/or be supported by the children's environment as mentioned by Francisco & Carlson, (23) who reported that care independency in children in areas such as eating, drinking and dressing etc. was less valued in some cultures. Some parents viewed themselves as always being there for their disabled children and therefore performed many of the daily tasks for them.

On the other hand, we also found differences between the disabled children themselves in all the different types of disabilities. Slow learning, intellectual disability, deafness, speech disorders and blindness significantly correlate with each other regarding all the CDS-P items apart from

'continence' and 'play and hobbies' (table 5). This finding is congruent with that of Smith & Smith (24) and Bruschini et al. (25), who established that the acquisition of bowel and bladder control is almost the same in non-disabled children and those with mild disabilities and correlates with the grade of mental disability. If taking into consideration that the grade of disability for the present study ranged from mild to moderate these findings are quite comprehensible.

A quite interesting aspect of the findings was that there was no significant difference between children in the different types of disability with regard to the area 'play and hobbies'. This could be explained by the fact that during playing children follow their abilities and not their disabilities. No child is ever taught how to play. Long before children use language to express their needs or to explain their actions they play; playing is a child's natural activity.

In general, the Arabic version of the Care Dependency Scale can be recommended to be used for school-age children. In Egypt, there is no standard instrument for measuring care dependency. This study provides an Arabic version of the CDS, which may be useful to measure the care dependency in various Arabic countries.

In conclusion, the findings carry important clinical and research implications; they describe the extent to which disabled and also non-disabled school-age children are care dependent, which possibly increases the burden of care on nurses or on caregivers in general. The CDS-P offers clinicians a valid and reliable assessment instrument of care dependency. With the right assessment it is possible to offer the appropriate care. Nurses then have an instrument, which is easy to handle and not as time-consuming. Furthermore, this instrument can be used as a research tool for comparing the care dependency of children in Arabic speaking countries and elsewhere.

4.6 Limitations and recommendations

The present study has, however, certain limitations, which need to be taken into account: the sample was selected on convenience rather than random sampling; in addition, for non-disabled children, the sample size per disease was too small (n=7) to detect the influence of the children's diagnoses on the CDS-P performance. A further limitation is the fact that the data were restricted to school-age children. Further studies are needed to test the applicability of the CDS-P to other age groups, such as pre-school age or adolescence and to assess the influence of the children's diagnoses on the CDS-P performance.

References

1. World Health Organization. international consultation to review community based Rehabilitation (CBR) Available at: http://www.who.int/ncd/disability, 2003 (Accessed 28 March 2004).

2. World Health Organization. International Classification of Functioning, Disability and Health. (ICF), Geneva; 2001.

3. Shukrallah A Childhood Disability Project: Final Progress Report. Cairo: Association for Health and Environmental Development, Cairo; 1997.

4. Limperopoulos C, Majnemer A, Michael S, Rosenblatt B, Rohlicek C, Tchervenkov C, Darwish H Functional Limitation in Young Children with congenital heart defects after cardiac surgery. Pediatrics 2001; 108: 1325-1331.

5. Flanagan J, Holmes S. facing the issue of dependence: some implications from literature for the hospice and hospice nurses. Journal of Advanced Nursing 1999; 29: 592 - 9.

6. Seale CF, Addington-Hall J. Euthanasia: why people want to die earlier. Social Science & Medicine 1994; 39: 647-54.

7. Dassen T, Balzer K, Bansemir G, Kühne P, Saborowski R, Dijkstra A [The Care Dependency Scale, an assessment instrument] Pflege 2001; 14: 123-127.

8. Lohrmann C, Dijkstra A, Dassen T. The Care Dependency Scale: An Assessment instrument for elderly Patients in German Hospital. Geriatric Nursing 2003a ; 24: 40-43.

9. Ferraz MB. Cross-cultural adaptation of questionnaires: What is it and when should it be performed? Journal of Rheumatology 1997; 24: 2066–2068.

10. Shelkey M, Wallace M. Katz Index of Independence in Activities of Daily Living (ADL). Best Practices in Nursing Care to Older Adults. New York: Hartford Institute for Geriatric Nursing 1998; 1: 1–2.

11. Dromerick A, Edwards D, Diringer M Sensitivity to changes in disability after stroke: A comparison of four scales useful in clinical trials. Journal of rehabilitation research & development 2003; 40: 1 – 8.

12. Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T, Heuvel W. An international psychometric testing of Care Dependency Scale. Journal of Advanced Nursing 1999; 31: 944 - 952.

13. Dijkstra A, Buist G, Moorer P, Dassen T. A reliability and utility study of the Care Dependency Scale. Scandinavian Journal of Caring Science 2000; 14: 155-61.

14. Dijkstra A, Coleman M, Tomas C, Välimäki M, Dassen T. Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing 2003; 43: 181-187.

15. Lohrmann C, Dijkstra A & Dassen T (2003b) Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scandinavian Journal of Caring Science 2003b; 17: 51-56.

16. Polit D, Beck C. Nursing Research: Principles and Methods. 7th ed., Lippincott, Philadelphia, 2004.

17. Jones E. Translation of quantitative measures for use in cross-cultural research. Nursing Research 1987; 36: 324-327.

18. Chang AM, Chau JC, Holroyd E. Translation of questionnaires and issues of equivalence. Journal of Advanced Nursing 1999; 29: 316-322.

19. Hilton A, Skrutkowski M Translating instruments into other languages: Development and testing Processes. Cancer Nursing 2002; 2: 1-7.

20. Landis J, Koch G. The measurement of observer agreement for categorical data. Biometrics 1977; 33: 159-74.

21. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

22. Lewis S, Iselin S. A comparison of the Independent Living skills of Primary Students with Visual Impairments and Their Sighted Peers: A pilot Study. Journal of Visual Impairment & Blindness 2002; 96: 335-44.

23. Francisco I, Carlson G. Occupational therapy and people with intellectual disability from Culturally diverse backgrounds. Australian Occupational therapy Journal 2002; 49: 200-211.

24. Smith L, Smith P. promoting continence training for people with learning difficulties Part One. Journal of community Nursing 1998;12: 18-25.

25. Bruschini H, Faria N, Garcez E, Srougi M. Development of blazer control in mentally handicapped children. International Brazilian Journal of Urology 2003; 29: 455-8.

CHAPTER 5

Children's care dependency: a cross-cultural comparison between Germany and Egypt

5.1 Introduction

The problem of care dependency is not only influenced by age, severity of illness and disability but also by cultural and social factors (1). Little is known about the similarities and differences in care dependency among children across the cultures. This study attempted to compare the care dependency among school-age children of two countries with distinctive cultural contexts: Germany and Egypt. Germany is a highly developed country with well-resourced hospitals, and Egypt is a major representative of a developing country with hospitals which necessarily function with limited resources. A comparison between the two countries, with different backgrounds of cultures and experiences in dealing with the problem of care dependency, will lead to results that both countries can benefit from. In Germany, more than 12 million children (under fifteen years) were treated in hospitals in 2004 (2). The care dependency of those children in their daily tasks undoubtedly places a greater burden on their caregivers. In Egypt, more than 18 million children were treated in hospitals in 2000 (3). It has to be noted that Egypt suffers from a considerable shortage in the number of nurses at hospitals and public clinics, which increases the burden of care in clinical settings. There are about 276 nurses for a population 100,000 people; a relatively low ratio compared to international levels with 425 nurses per 100,000 people (4). Therefore, the care of those children represents a great challenge for all care providers in health care systems, especially for nurses. In order to conduct the present comparative study of care dependency among children in both countries, a valid and reliable instrument is required.

Therefore, the present study started with the modification of the CDS to be appropriate for children. In 2004, the modified version of the CDS for children was developed in Germany and named the Care Dependency Scale for Paediatrics (CDS-P) (chapter 3). However, due to cultural differences it might be psychometrically inappropriate, and even problematic, to apply this tool to a different cultural group, such as Egyptian children. Some concepts or items contained in the original instrument could be inappropriate for people of a different culture (5). It was therefore decided to translate the CDS-P into Arabic to use it in Egypt (chapter 4).

The aims of this chapter were to describe the psychometric properties of the CDS-P in Germany and Egypt in order to determine whether CDS-P scores were comparable for both countries and to compare the care dependency of school-age children in Germany and Egypt.

5.2 Methods

5.2.1 Study population and settings

A total of three hundred and ninety children participated in the study. (Egypt: 128 non-disabled, 132 disabled children & Germany: 130 non-disabled children). For practical reasons it was impossible to include children with disabilities in the German sample, therefore the comparison between the two countries was restricted to only non-disabled children. In the end, two hundred and fifty eight children (128 from Egypt and 130 from Germany), aged between 6 and 12 years participated in this comparative study. A detailed description of the sampling procedure in both countries has already been described (chapter 3, 4). In brief, data were collected from one university hospital in each country. The study was conducted on four wards: general paediatrics**,** nephrology**,** cardiology and oncology in Germany as well as in Egypt.

5.2.2 Ethical Considerations

The study protocol was approved by the Research Ethics Committee of the Charité-Universitätsmedizin, Berlin, Germany. In Egypt, approval was obtained from the nursing manager at the hospital. In Germany as well as in Egypt, parents were also provided with contact telephone numbers to enable them to obtain further details regarding the study. Parents were asked to sign a consent form to indicate that they agreed for their children to participate in the study.

5.2.3 Instruments

5.2.3.1 Care Dependency Scale for Paediatrics (CDS-P)

As previously mentioned (chapter 4), the present study started with the modification of the CDS using Delphi technique so that it was appropriate for children. The modified version of the CDS was called Care Dependency Scale for Paediatrics (CDS-P) and translated into Arabic using the back translation technique to be able to apply it to children in Egypt. The CDS-P is a 15-item scale measuring the child's care dependency in the following needs: eating and drinking, continence, body posture, mobility, day/night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, play and hobbies and learning ability. Nurses have to select one of the five criteria; accordingly, values between 15 and 75 points can be obtained, i.e. the lower the value, the more care dependent is the child.

5.2.3.2 Visual Analogue Scale (VAS)

The Visual Analogue Scale was applied to verify the criterion-related validity of the CDS-P by investigating the correlation between the CDS-P and VAS sum scores. The Visual Analogue Scale (6) has been used in clinical research for many years and was found to be sensitive, valid and reliable (7, 8). The VAS is a 100 mm long, horizontal line with two descriptors. For the present study the descriptors were marked as 'dependent' at the left hand side end and 'independent' at the right hand side end. Nurses were asked to indicate the child's care dependence by marking the appropriate location on the line. Interval scores were obtained by counting the number of millimetres from zero to the dependence mark set by each nurse. Higher values indicated an increased level of care independence.

5.2.4 Data collection

Practicing nurses, who had been involved in the care of children for at least one day, filled in the CDS-P and the VAS at the same time. Each child was assessed by two different raters, paediatric nurses of the morning and afternoon shifts, to prove the interrater reliability. Prior to rating the raters were verbally informed of the background and purpose of the study and the use of the CDS-P. Forty nurses in Germany and twenty-nine in Egypt operated as raters for the reliability test and all raters were practicing nurses directly involved in the daily care of the participating children. In Germany, the data were collected in the year 2005.

5.2.5 Statistical analysis

The internal consistency of both language versions of the CDS-P was evaluated using Cronbach's alpha (α) coefficients. Cronbachs's alpha measures the average correlation of items within an instrument. Internal consistency is considered to be acceptable when Cronbach's alpha exceeds 0.70, indicating a good correlation (9). Kappa statistics were calculated to prove the interrater reliability. In order to verify the validity, a factor analysis (principal components analysis) was performed to test the validity of the internal structure of the CDS-P.

Correlation coefficients between the CDS-P total score and the scores of the Visual Analogue Scale (VAS) were calculated to assess the criterion-related validity of the CDS-P. All analyses were carried out using the SPSS for Windows (SPSS Inc., Chicago, IL, USA) version 12.

5.3 Results

Both samples had a similar average age but varied slightly in their sex ratio (table 1). There was a considerably greater difference between the two national samples with regard to the mean of the CDS-P (51.3 for the Egyptian and 63.3 for the German sample, respectively) and this difference was statistically significant. The sample distribution among the medical disciplines was similar for the German and Egyptian participants (table 2).

Table 1. Sample characteristics in Germany and Egypt

	Germany (n=130)	Egypt (n=128)	*P*-value
Gender (%)			
Male	46.2	50.8	ns
Female	53.8	49.2	ns
Age in years			
Mean (SD)	9.1 (1.8)	9.0 (1.9)	ns
Age in number			
6 - 7 years	37	38	
8 - 10 years	59	59	
11 - 12 years	34	31	

ns, not significant

Table 2. Sample distribution across the medical disciplines

	Country	
Discipline	**Germany (n=130)**	**Egypt (n=128)**
Internal medicine	48 (36.9)	39 (30.5)
Oncology	14 (10.8)	19 (14.8)
Cardiology	27 (20.7)	27 (21.1)
Nephrology	30 (23.1)	23 (18)
Others	11 (8.5)	20 (15.6)
Total	130 (100)	128 (100)

5.3.1 Psychometric Properties of the CDS-P

5.3.1.1 Reliability

Reliability was investigated through internal consistency and interrater reliability assessment.

Internal consistency The internal consistency is the extent to which the questions in each underlying concept domain interrelate with each other. An alpha score of > 0.7 is acceptable, > 0.81 is good and > 0.91 is excellent (10).

The CDS-P showed to have a good internal consistency for both countries, indicated by Cronbach's alpha. The results were 0.91 and 0.85 for the German and Egyptian versions respectively.

Interrater reliability Cohen's Kappa was used to calculate the interrater reliability. The Kappa statistics were interpreted as recommended by Landis & Koch (11), where K-values higher than 0.80 were considered as almost perfect, 0.61–0.80 as substantial, 0.41–0.60 as moderate, 0.21–0.40 as fair and < 0.20 as slight.

For the German sample, Cohen's Kappa ranged from 0.57 to 0.80 indicating a moderate to substantial interrater reliability. A wider range in Kappa between 0.53 and 0.90 was found in the Egyptian sample indicating a moderate to almost perfect interrater reliability (Table 3).

Table 3. **Interrater reliability of the 15 items of the CDS-P (Cohen's Kappa)**

	Kappa	
CDS-P Items	**Germany**	**Egypt**
Eating and drinking	0.69	0.82
Continence	0.75	0.89
Body posture	0.57	0.84
Mobility	0.73	0.88
Day and night pattern	0.72	0.77
Getting dressed and undressed	0.74	0.90
Body temperature	0.61	0.65
Hygiene	0.73	0.83
Avoidance of danger	0.62	0.65
Communication	0.62	0.61
Contact with others	0.59	0.63
Sense of rules and values	0.57	0.66
Daily activities	0.60	0.53
Play and hobbies	0.80	0.67
Learning ability	0.73	0.70

5.3.1.2 Validity

The validity of the CDS-P was tested in terms of criterion-related validity, content validity and construct validity.

Criterion-related validity was examined by comparing the sum scores of the CDS-P and VAS; the Pearson correlation was significant for both the German and the Egyptian data (0.86, $P < 0.001$ & 0. 77, $P < 0.001$)

Content validity was proved by experts in a Delphi survey, which was conducted in two rounds. The response rates were 92% for the first round and 85% for the second round, which means there was a good consensus (chapter 2).

Construct validity. Factor analysis (principal component analysis) was employed in both countries in order to verify the construct validity. All 15 items of the CDS-P had the highest loadings on the first factor (loading ≥ 0.53). Only three items (for each version) also had a loading of > 40 on the second factor (table 4). The total explained variance was satisfactory and accounted for 49.9 % in the German and 64.6% in the Arabic version.

Table 4. Rotated component matrix, eigenvalue, and percentage variance of the CDS-P

CDS-P Items	Germany (n=130) Factor		Egypt (n=128) Factor	
	1	2	1	2
Eating and drinking	0.74	0.02	0.77	0.44
Continence	0.68	-0.39	0.82	-0.13
Body posture	0.76	-0.34	0.70	0.35
Mobility	0.67	-0.59	0.86	-0.03
Day and night pattern	0.58	-0.17	0.70	-0.16
Getting dressed and undressed	0,83	-0.34	0.86	0.24
Body temperature	0.62	0.11	0.73	0.46
Hygiene	0.82	-0.26	0.84	-0.21
Avoidance of danger	0.70	0.16	0.87	-0.27
Communication	0.53	0.30	0.84	-0.07
Contact with others	0.62	0.28	0.84	-0.14
Sense of rules and values	0.61	0.47	0.75	-0.41
Daily activities	0,87	0.15	0.76	-0.05
Play and hobbies	0.79	0.35	0.81	0.23
Learning ability	0.70	0.46	0.90	-0.14
Eigenvalue	7.5	1.7	9.7	1.0
% Variance	49.9	10.8	64.6	6.7

5.3.2 Comparison of Germany and Egypt

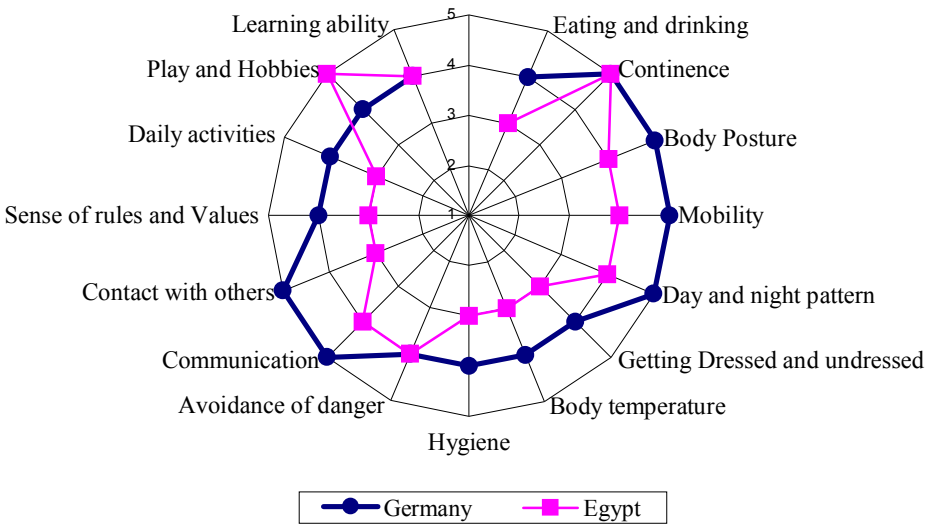
Statistically significant differences between the participating German children and their Egyptian counterparts were detected regarding the mean sum score of the CDS-P [mean (SD): 63.9 (9.0) & 51.3 (15.8) respectively]. The results showed that the majority of the Egyptian children (82%) are substantially to slightly care dependent, whereas the majority of the German children (87.7%) are partially care dependent to almost independent. The distribution of the dependency levels is represented in detail in table 5.

Table 5. Distribution of the care dependency levels of the two country samples

Level of care dependency	Germany (n= 130)		Egypt (n= 128)	
	N	%	N	%
Completely care dependent	5	3.8	13	10.2
Substantially care dependent	11	8.5	44	34.4
Partially care dependent	29	22.3	31	24.2
Slightly care dependent	58	44.6	30	23.4
Almost independent	27	20.8	10	7.8
Total	130	100	128	100

Figure (1) demonstrates the performance of the school-age children in both countries for each of the CDS-P items. A rating from 1 to 4 indicates that the child requires some level of assistance from another person to complete the task. A rating of 5 means that the child can complete the task independently, but may require supervision or adult advice to set up the task. The same figure shows that Egyptian children lag behind German children in most of the CDS-P items, except for "play and hobbies" and that the children of both countries are at the same performance level for three of the CDS-P items (continence, avoidance of danger and learning ability).

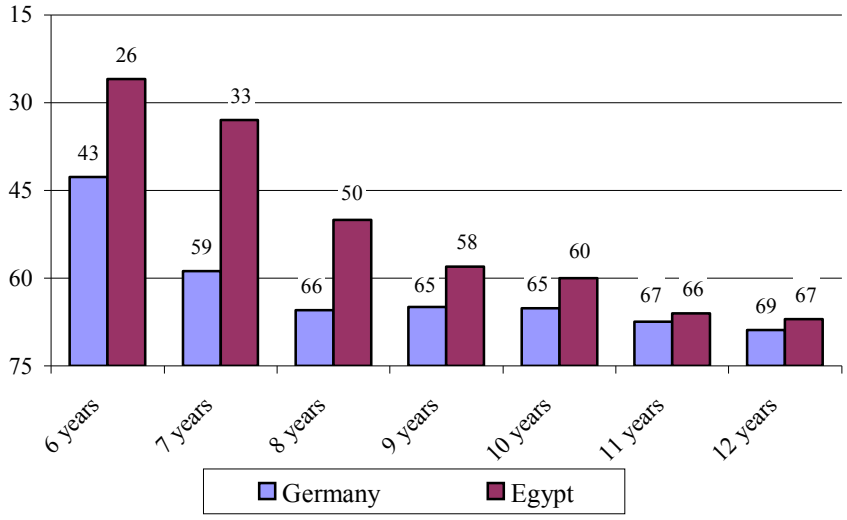
Figure 1. Median of the CDS-P items for German and Egyptian children (1 = completly dependent, 2 = substantially dependent, 3 = partially dependent, 4 = slightly dependent, 5 = almost independent)



For a better insight figure 2 illustrates that the differences in care dependency between German and Egyptian children decreased with a progressing age until they are at approximately the same

performance level at the age of twelve. The same figure shows that the CDS-P sum scores increased progressively with the age in both samples.

Figure 2. The mean CDS-P sum scores of children in Germany and in Egypt according to their age



5.4 Discussion and Conclusion

The aims of this chapter were to describe the psychometric properties of the CDS-P in Germany and Egypt to determine whether CDS-P scores were comparable for both countries. Furthermore, to compare the care dependency of school-age children in Germany and Egypt.

5.4.1 Psychometric Properties of the CDS-P

The first results indicate that both the German and Arabic versions of the CDS-P have satisfactory psychometric properties for German and Egyptian school-age children. The high Cronbach`s alpha indicates a good internal consistency (0.91 for German and 0.85 for Egyptian data).

With regard to the interrater Kappa, the item 'daily activities' produces a moderate agreement both in the German as well as in the Egyptian data. As the meaning of the item may vary depending on the interpretation of the participants, a possible explanation can be that the core concept of "daily activities" was not clear interpreted to nurses and it was difficult to understand what the concept of "daily activities" means for children.

The factor analysis resulted in a one-factor solution for both countries. The high factor loadings for both countries confirmed that all items were affected by the same underlying care

dependency concept. When comparing German and Egyptian findings, higher eigenvalues and percentages of variance were found in the Egyptian sample.
The results demonstrated that the CDS-P is a reliable and valid instrument. The findings were in accordance with those previously reported (12, 13, 14). Thus, this study shows again that Henderson's theory of human needs is empirically testable.

5.4.2 Care dependency of German and Egyptian children

The German sum score of the CDS-P had a higher mean value than the Egyptian score. Therefore, Egyptian children may be described as more care dependent than German children. These findings may be explained by the study of Francisco & Carlson'study (15) which was conducted in different cultures of non-English speaking and indigenous backgrounds (as in Egypt) and reported that the care independency of children in certain areas, such as eating, drinking and dressing etc., is not appreciated as much in some of these cultures. Some parents viewed themselves as always being there for their children and therefore performed many daily tasks for them. In contrast, the parent who wanted their children to be totally independent, attempted to do so by removing all support. In Egypt, children also attend nurseries when they are about 4 years old, whereas in Germany, children attend nurseries earlier and are then trained to attend to their functional needs to help themselves in gaining independence in all aspects of self-care. This might account for the differences observed in Egyptian children as compared to German children. Cultural and educational emphases are factors that can affect performance. Further research is necessary to investigate the reasons for the poorer performance of Egyptian children on the CDS-P. The present baseline data for Egyptian children may be used as a guideline for a further assessment of children.

5.5 Application of the CDS-P

The results provide evidence that the scale components of basic care are measurable and can be used to assess the degree of care dependency of school-age children. A comprehensive assessment from a nursing perspective enables nurses to help children acquire their care independence. Therefore, the CDS-P can be used with confidence as an appropriate tool in clinical settings to assess the care dependency of children.

References

1. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

2. Statistisches Bundesamt Deutschland. International Children's Day: statistics of illness diagnoses. 2006, Available at: http://www.destatis.de/basis/d/gesu/gesutab10.php Cited [Accessed 10 Feb. 2007].

3. Central Agency for Public Mobilization and Statistics. Distribution of Egyptian population, Children under 15 years, (census). 2002, Table 2-14.

4. Centre for Development Services. Egypt Human Development Report. 2005, Available at: http://www.undp.org.eg/publications/NHDR.htm [Accessed 25 Feb. 2007].

5. Ferraz MB. Cross-cultural adaptation of questionnaires: What is it and when should it be performed? Journal of Rheumatology 1997; 24: 2066–2068.

6. Huskisson EC. Measurement of pain. Lancet 1974; 9: 1127-1131.

7. Price DD, McGrath PA, Rafii A, Buckingham B. The validation of visual analogue scales as ration scale measures for chronic and experimental pain. Pain1983; 17: 45–56.

8. Stephenson NL, Herman JA. Pain measurement: a comparison using horizontal & vertical analogue scales. Applied Nursing Research 2000; 13: 157–158.

9. Campbell MJ, Machin D. Designs Medical Statistics: A Commonsense Approach,Wiley, Chichester, New York, 1999.

10. Chinn S, Burney PG. On measuring repeatability of data from Self-administered questionnaires. Int J Epidemiol 1987; 16:121–7.

11. Landis J, Koch G. the measurement of observer agreement for categorical data. Biometrics 1977; 33: 159-74.

12. Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T, Heuvel W. An International Psychometric testing of the Care Dependency Scale. Journal of Advanced Nursing 2000; 31 (4): 944-952.

13. Dijkstra, A. Coleman, M. Tomas, C. Välimäki, M. & Dassen, T. (2003): Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing, 43 (2), 181-187.

14. Lohrmann C, Dijkstra A, Dassen T. Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scandinavian Journal of Caring Science. 2003; 17: 51-56.

15. Francisco I, Carlson G. Occupational therapy and people with intellectual disability from culturally diverse backgrounds. Australian Occupational therapy Journal 2002; 49: 200-211.

CHAPTER 6

General discussion

The main objectives of the present study were to develop a paediatric version of the Care Dependency Scale (CDS-P), to test it psychometrically among school-age children in Germany and Egypt and to compare the care dependency of children in both countries. The following general discussion contains the main findings and will finally conclude with implications for practice and recommendations for future research.

There are several instruments for assessing the care dependency, but almost none of them have been psychometrically tested, therefore the CDS was chosen, although originally developed for demented elderly. The reason for choosing the CDS instead of, for example, the Functional Independence Measure (WeeFIM) or Self-Care Independence Scale (SCIS), is subject to discussion. Both instruments were not developed from a nursing perspective and there is only little known about the psychometric properties of the SCIS. The CDS, however, has a theoretical framework; it is based on Henderson's human needs theory (1). Therefore, the CDS items are related to fundamental human needs independent from the cultural background. In addition, the CDS was tested in Germany for its use in hospitals in different disciplines, one of them being the paediatric ward. It also showed a good validity and reliability in various international studies (2, 3).

Reliability and validity of the CDS-P

For measures to become clinically and scientifically meaningful, they must be reliable and valid (4). Based on the investigating aspects of the validity and reliability (internal consistency, interrater reliability, content validity, criterion-related validity and construct validity), the findings support the reliability and validity of the CDS-P, a modified version of the CDS; which was developed by Dijkstra et al. (5). The CDS-P was tested psychometrically in Germany as well as in Egypt. In relation to the reliability, the internal consistency of the whole CDS-P instrument was determined by means of Cronbach's alpha. All values of Cronbach's α (0.85 to 0.91) exceeded the generally accepted criterion of 0·7 (6). This tends to indicate a high level of correlation amongst items and correspondingly a good reliability. Cohen's Kappa was used to calculate the interrater reliability. The Kappa statistics were interpreted as recommended by Landis & Koch (7), indicating a moderate to substantial agreement, which supports the interrater reliability. The lowest agreement among the raters in both countries was detected for 'daily activities', a possible explanation can be that it may have been difficult to describe the core

concept of ‘daily activities’ to young children, which leads to nurses interpreting responses in different ways.
The types of validity most frequently referred to in the literature are content, criterion-related and construct validity (6, 8).
The use of expert models is the most common method for the evaluation of content validity, i.e. how comprehensively and representatively the selected indicators and the items they comprise describe the studied phenomenon (9, 10). The content validity of the CDS-P was proven by an expert panel in Germany. Factor analysis resulted in a one-factor solution for both countries. The high factor loadings for both countries prove that all items were affected by the same underlying care dependency concept. These results were in accordance with those previously reported for the original CDS (3,11) and provide further evidence for the reliability and validity of the CDS-P.

Care dependency of children

The results of this study demonstrate that there are similarities as well as differences between German and Egyptian children regarding their care independence. In Germany (chapter 3), there was a significant correlation between the age and the total CDS-P scores for children aged six to twelve years, which means that care independence of children increased progressively with their age. The results of the Egyptian sample were similar. This suggests a trans-cultural applicability of the CDS-P in detecting the consistent age-related gains in care independency.

A second similarity was found for the aspect of gender (chapter 3, 4). In both countries gender did not evoke a significant difference in relation to the children’s care dependency. This finding is contradictory to some cross-cultural studies (12, 13) which state that girls in China or Thailand respectively, are more capable of self-caring than boys. Some of the discrepancies may be attributed to cultural differences; the authors mentioned that it is well accepted in traditional Thai and Chinese cultures that girls master self-care skills before boys do.

With regard to children with disabilities (chapter 4), there were quite interesting findings, in that there was no significant difference between children suffering from different types of disabilities regarding the area of ‘play and hobbies’ This could be explained by the fact that during playing children follow their abilities and not their disabilities. No child is ever taught how to play. Long before children use language to express their needs or to explain their actions they play; playing is a child’s natural activity.

The third similarity was detected when we analysed the order of achieving independency regarding the 15 items of the CDS-P (chapter 5, figure 1): we found that achieving independency in mobility and body posture was easier than in performing the aspects of self-care (hygiene, getting dressed and undressed) followed by "daily activities". It can be explained by the developmental trajectory if we study human development by plotting the percentage of developmental acquisition against age. The order for achieving a plateau level of development would be gross motor followed by fine motor development. Mobility and self-care are representative of gross motor and fine motor development respectively.

Despite the forementioned similarities, there are still differences between both countries. In the German-Egyptian comparison of care dependency among children (chapter 5), some remarks about the differences between the two countries need to be discussed. The findings show that the sum score of the German sample on the CDS-P had higher mean values than the score of the Egyptian sample. Thus, the participating Egyptian children may be described as more care dependent than their German counterparts. These findings can be explained by the study of Francisco & Carlson (14) which was conducted in different cultures and reported that the care independency in children in certain areas, such as eating, drinking and dressing etc., is not appreciated as much in some cultures. Some parents viewed themselves as always being there for their children and therefore performed many daily tasks on their behalf. In contrast, those parents who wanted their children to be totally independent, attempted to do so by not giving them any support at all. In Egypt, children also attend nurseries when they are about 4 years old, whereas in Germany, children attend nurseries earlier and are then trained to attend to their functional needs to help them gaining independence in all aspects of self-care. This might account for the differences observed in Egyptian children as compared to German children. Further research is necessary to investigate the reasons for the poorer performance of Egyptian children on the CDS-P. The present baseline data for Egyptian children may be used as a guideline for a further assessment of children.

Limitations

The present study has, however, certain limitations, which need to be taken into consideration: the data was collected from different medical disciplines of hospital, thus various diagnoses were involved. For this reason the sample size per disease was too small to be able to detect if the children's diagnoses influenced the CDS-P performance in any way (chapter 4). The present study used the Visual Analogue Scale (VAS) to test the criterion-related validity of the CDS-P by investigating the relationship between the CDS-P and VAS scores. Unlike other scales, the VAS does not have set criteria for each of its scale points, as it would be virtually impossible and meaningless to establish criteria for each of the 100 points on the scale. The absence of criteria can initially be mistaken as a limitation of the scale owing to the impression that written criteria improve validity and reliability. However, Vieira et al. (15) emphasized that the simplicity, precision and usefulness of the VAS overcome these initial concerns. Another limitation is that the comparison between children in Germany and Egypt was restricted to normal children, although data was also collected and used from disabled children in Egypt before, but due to difficulties in German clinical settings, there were no data available from disabled children.

Implications for Practice

An appropriate assessment of children's care dependency can help nurses in clinical practice to conduct a nursing care plan in accordance with the children's needs. Practical nursing implications of the findings emphasize the importance of an appropriate assessment tool for children, which is aimed at maximizing their ability to take over the responsibility of their self-care.

In Egypt, the findings result in important clinical implications; they describe the extent to which disabled and also non-disabled school-age children are care dependent. Taking into consideration that Egypt suffers from a severe shortage in the number of nurses at hospitals and public clinics (16), which possibly increases the burden of care on nurses, the CDS-P offers clinicians in Egypt as well as in Germany a valid and reliable assessment instrument of care dependency. With the correct assessment it is possible to offer the appropriate care. Nurses then have an instrument, which is easy to handle and not as time-consuming and it may be helpful in maximizing children's care independency. There was no general valid standard instrument for measuring care dependency in the Arabic world. With the Arabic version of the CDS-P, it may become feasible to measure the same phenomenon in various Arabic speaking countries with the same assessment instrument.

Recommendations for future research

According to the results of the literature review on factors relating to children's care dependency, further research is necessary to confirm or refute these findings on examined children, such as self-concept and other psychosocial factors, and to investigate potentially influential variables such as gender, age, race and health status. It is ideal if a cross-cultural CDS-P assessment can be performed so we can have a better understanding of the actual intercultural differences.

One recommendation for further research regarding the influence of factors is the examination of the cultural background, which may well affect children's CDS-P performance. This requires comparing the present findings with data from other countries to support the cultural differences and to confirm the trans-cultural validity of the CDS-P. In addition, other possible influencing factors, such as family characteristics, should be explored in future studies.

One of the outcomes of the thesis is that Egyptian children participating in this study were somewhat more care dependent than the participating German children. Further research investigating the reasons for the poorer performance of the Egyptian children on the CDS-P is recommended.

The influence of a disability on the care dependency of children with special needs was documented in several studies as well as the present study (chapter 4). Future research needs to pay more attention to the care dependency of children with regard to the type and degree of their disabilities.

References

1. Henderson V. The Nature of Nursing: A definition and its implications for Practice, Research and Education. New York: MacMillan Press1966.

2. Dassen T, Balzer K, Bansemir G, Kühne P, Saborowski R, Dijkstra A. [The Care Dependency Scale, an assessment instrument] Pflege 2001; 14: 123-127.

3. Lohrmann C, Dijkstra A, Dassen T. The Care Dependency Scale: An Assessment instrument for elderly patients in German hospital. Geriatric Nursing 2003; 24: 40-43.

4. Johnston MV, Keith RA. Measurment standards for medical rehabilitation and clinical applications. Phys Med Rehabil Clin North Am 1993; 4: 417-449.

5. Dijkstra A, Buist G, Dassen T. Nursing care dependency: development of an assessment scale for demented and mentally handicapped patients. Scan J Caring Sci 1996; 10: 137-43.

6. Steiner DL, Norman GR. Health Measurement Scales. A practical guide to their development and use, 2nd edn. Oxford University Press, Oxford.1995.

7. Landis J, Koch G. The measurement of observer agreement for categorical data. Biometrics 1977; 33: 159-74.

8. Giovannetti P. Understanding patient classification systems. Journal of Nursing Administration 1979; 9: 4- 9.

9. Gallagher JR. Developing a powerful and acceptable nurse staffÆng system. Nursing Management 1987; 18: 45-49.

10. Hoffman F. Nursing Productivity Assessment and Costing Out Nursing Services. J. B. Lippincott, Philadelphia, 1988.

11. Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T, Heuvel W. An International Psychometric testing of the Care Dependency Scale. Journal of Advanced Nursing 2000; 31 (4): 944-952.

12. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

13. Jongjit J, Komsopapong L, Saikaew T, Wanich U, Chewapanich S, Udomsubpayakul U, Ruangdarganon N. Reliability of the Functional Independence Measure for children in Normal Thai children. Pediatric International 2006; 48: 132-137.

14. Francisco I, Carlson G. Occupational therapy and people with intellectual disability from culturally diverse backgrounds. Australian Occupational therapy Journal 2002; 49: 200-211.

15. Vieira A, Lawrence H, Limeback H, Sampaio F, Grynpas M. A visual analog scale for measuring dental fluorosis severity. Journal of the American Dental Association 2005; 136 (7): 895-901.

16. Centre for Development Services. Egypt Human Development Report. 2005, Available at: http://www.undp.org.eg/publications/NHDR.htm [Accessed 25 Feb. 2007].

SUMMARY

ZUSAMMENFASSUNG

Summary

A higher dependence of children in their daily tasks undoubtedly places a greater burden on their caregivers and all health care providers in clinical settings, especially nurses (1). Therefore, literature describes care dependency as a problem that needs to be addressed (2). In order to estimate the extent of the problem of care dependency, data from different countries are required. Cross-cultural differences in care dependency were documented in literature (3, 4, 5). A comparison between two countries (i.e. Germany and Egypt), with different backgrounds regarding their culture and experiences in dealing with the problem of care dependency, will lead to results that both countries can benefit from.

Aims

The overall aims of the present study were to:

- Develop the paediatric version of the Care Dependency Scale (CDS) and its translation into Arabic so that it can be applied to Egyptian children.
- Evaluate the modified version of the Care Dependency Scale psychometrically in terms of validity and reliability among non disabled children in Germany.
- Test the psychometric properties of the CDS-P for non disabled and disabled children in Egypt.
- Compare the extent of care dependency of non disabled school-age children in Germany and Egypt.

Research questions

To achieve the aforementioned aims, the following main research questions were discussed:

1. Is the modified version of the Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency of hospitalised school-age children in Germany and Egypt?
2. What are the differences between disabled and non-disabled school-age children in Egypt regarding their care dependency?
3. Is the Care Dependency Scale for Paediatrics (CDS-P) a reliable and valid instrument to assess the care dependency of children from different cultures?
4. What are the differences between school-age children in Germany and in Egypt regarding their care dependency?

Method

The present study was conducted in four phases:

I. Modification of the CDS by Delphi technique in order to develop its paediatric version (CDS-P)

II. Study 1: Psychometric testing of the modified Care Dependency Scale among hospitalized school-age children in Germany

III. Study 2: Care dependency of children in Egypt

IV. Study 3: Children's Care dependency: a cross-cultural comparison between Germany and Egypt

I. Modification of the CDS by Delphi technique

The present study started with the modification of the CDS using Delphi technique so that it could be used for children. According to Burns and Grove (6) (P.795) the "Delphi technique is a method of measuring the judgments of a group of experts for assessing priorities or making forecasts". The panel size comprised 12 experts. The experts in this study were graduated nurses with a minimum of three years experience in paediatric care. The Delphi technique was conducted in two rounds and the response rates were 92% for the first round and 85% for the second round, which means there was a good consensus. The Delphi technique resulted in changing the item "Recreational activities" in the original CDS to "Play and hobbies" in the CDS-P. In addition, all item descriptions that could be appropriate for children were modified. Consequently, the modified version, which was named Care Dependency Scale for Paediatrics (CDS-P), was translated into Arabic. Brislin's model, or the back-translation approach (7), was identified as the preferred method of translating instruments (8, 9).

II. Study 1:

Participants and setting: A total of 130 children aged between 6 and 12 years took part in the study. The researcher excluded children with severe medical conditions, which could interfere with the children's independence on their care, and also those who were identified as having cognitive and learning problems. Forty nurses operated as raters for the reliability test and all raters were practicing nurses directly involved in the daily care of the participating children. The study was conducted in four paediatric wards: general paediatrics**,** nephrology**,** cardiology and oncology in Charité University medicine, Berlin.

Instruments: The Care Dependency Scale for Paediatrics (CDS-P) and The Visual Analogue Scale (VAS) were used in data collection. The VAS is one of the most frequently used measurement scales in health care research, it consists of a straight line of 10 cm length with two descriptors. The VAS was employed to verify the criterion related validity of the CDS-P.

Procedure: Practicing nurses, who had already been involved in the care of the children for at least one day, filled in the CDS-P and the VAS. Each child was assessed by two different independent raters to prove the interrater reliability. Prior to rating the raters were verbally informed of the background and purpose of the study and were explained the use of the CDS-P and the VAS. Four hundred questionnaires were distributed to the nurses in the participating wards. A response rate of 88% was obtained and forty-six returned data sets were excluded due to missing data. Consequently, a total of 130 valid data sets were included in the final analysis. The accuracy of the modified versions was established within the following statistical analyses: Cronbach's alpha reliability coefficients, Kappa to determine item-to-item agreement, Pearson's correlation between the modified versions of the CDS-P and VAS to assess the criterion-related validity and factor analysis to determine the construct validity.

III. Study 2:

Participants and setting: A convenient sample of 260 normal and disabled school-age children in Egypt participated in the study (50.8 % of whom were disabled and 49.2 % were non-disabled). Physical (blindness, deafness, speech disorders) and mental disabilities (intellectual disability, slow learning) were included. The extent of the disability ranged from a mild to a moderate disorder. Twenty-nine nurses in Egypt operated as raters for the reliability test. Data of non disabled children were collected from different paediatric wards (general paediatrics**,** nephrology**,** cardiology and oncology) in an Egyptian university hospital. Data of disabled children were collected from three institutionalised schools for children with special needs.

Instruments and procedure: In Egypt, the same instruments and procedure as in Germany were applied for non disabled children. In the case of disabled children, the teachers of the institutionalised schools were responsible for completing the same scales.

IV. Study 3.

In this study the data of both study 1 and 2 were used. For practical reasons, it was difficult to include children with disabilities in the German sample, therefore the comparison between the two countries was restricted to only non-disabled children. Thus, two hundred and fifty eight children (128 from Egypt and 130 from Germany), aged between 6 and 12 years were included in this comparative study.

Results

Study 1: Psychometric testing of the modified Care Dependency Scale among hospitalized school-age children in Germany

Two aspects of reliability were examined: internal consistency and interrater reliability. Cronbach's alpha was high (0.91), which indicates high internal consistency. Cohen's Kappa ranged from 0.57 to 0.80 indicating moderate to substantial interrater reliability. Factor analysis was used to investigate construct validity and resulted in a one-factor solution. A high correlation was detected between the CDS-P sum score and the Visual Analogue Scale (VAS), which means the criterion-related validity. Therefore, it can be concluded that the CDS-P is a valid and reliable instrument for the assessment of care dependency of school-age children.

Study 2: Care dependency of children in Egypt

Reliability was examined in terms of internal consistency using Cronbach's alpha (0.91). Cohen's Kappa was used to calculate the interrater reliability and it ranged from 0.57 to 0.89. The Kappa statistics were interpreted as recommended by Landis & Koch (10), which indicated a moderate to excellent interrater reliability. The indication for the criterion validity was found by comparing the sum scores of the CDS-P and the VAS; the Pearson correlation was significant ($r = 0.67$, $p<0.001$). Concerning the usefulness of the CDS-P in practice, this study provides an Arabic version of the CDS-P that is easy to administer and may be useful to measure the care dependency in various Arabic countries. Statistical significant differences regarding care dependency were found between disabled and non-disabled children as well as among disabled children in the different types of disabilities regarding the CDS-P items. Disabled children were described as more dependent than non-disabled children regarding the all aspects of the CDS-P.

Study 3: Children's Care dependency: a cross-cultural comparison between Germany and Egypt

The first results indicated that both the German and Arabic versions of the CDS-P have satisfactory psychometric properties (internal consistency, interrater reliability, criterion-related validity and construct validity) across German and Egyptian school-age children. A significant correlation was found between the mean score of the CDS-P and the child's age, the mean scale scores increased progressively with the age in Germany as well as in Egypt. An interesting finding was that in both countries, there was no significant difference between boys and girls regarding the mean CDS-P sum scores. Concerning the comparison of care dependency the

participating Egyptian children may be described as more care dependent than the participating German children.

Discussion

The results of the psychometric tests confirmed the assumption that the Care Dependency Scale for Paediatrics (CDS-P) is equivalent to the original CDS. Consistent with previous findings provide further evidence of the reliability and validity of the modified scale (11).

According to the present results, the participating German children had higher mean sum scores in the CDS-P than Egyptian children. Thus, the Egyptian children may be described as more care dependent than German children. One possible explanation could be that in Egypt, children also attend nurseries when they are about 4 years old, whereas in Germany, children attend nurseries earlier and are then trained to attend to their needs to help themselves to gain independence in all aspects of self-care. Another explanation may be provided by the findings of the study of Francisco & Carlson (12) which was conducted in different cultures and reported that the care independency of children in certain aspects, such as eating, drinking and dressing etc., is not appreciated as much in some cultures. Some parents viewed themselves as always being there for their children and therefore performed many daily tasks for them.

Conclusion

In conclusion, the Care Dependency Scale for paediatrics (CDS-P) can be recommended as a valid and reliable instrument to assess the care dependency of children. It seems important in nursing practice to assess the degree of care dependency of children in respect to their developmental stage in order to maximize their self-care abilities.It is ideal if a cross-cultural CDS-P assessment can be performed so we can get a better understanding of the actual intercultural differences.

Zusammenfassung

Eine höhere Pflegeabhängigkeit von Kindern bei ihren täglichen Aufgaben bedeutet eine größere Belastung sowohl ihrer häuslichen Pflegepersonen als auch der Betreuenden in klinischen Settings, vor allem Krankenschwestern oder -pflegern (1). Daher wird Pflegeabhängigkeit als Problem betrachtet, dem man Beachtung schenken sollte (2) und dessen Ausmaß durch Daten aus verschiedenen Ländern näher bestimmt werden sollte. Kulturabhängige Unterschiede sind in der Literatur zu finden (3, 4, 5). Ein Vergleich zwischen Deutschland und Ägypten, zwei Ländern mit unterschiedlichen kulturellen Hintergründen und Ansätzen in der Bewältigung von Pflegeabhängigkeit soll zu Ergebnissen führen, von denen beide Länder profitieren können.

Ziele

Die übergreifenden Ziele der vorliegenden Studie waren:

Die Entwicklung einer pädiatrischen Version der Pflegeabhängigkeitssskala (PAS) sowie ihre Übersetzung in die arabische Sprache

Die psychometrische Evaluation der pädiatrischen Pflegeabhängigkeitsskala (PAS-P) im Hinblick auf Validität und Reliabilität bei nicht behinderten Kindern in Deutschland

Die Evaluation der psychometrischen Eigenschaften der PAS-P bei behinderten und nicht behinderten Kindern in Ägypten

Der Vergleich des Ausmaßes an Pflegeabhängigkeit von nicht behinderten Kindern im Schulalter in Deutschland und Ägypten

Forschungsfragen

Im Hinblick auf die oben genannten Ziele wurden folgende Forschungsfragen formuliert:

Ist die modifizierte, pädiatrische Version der Pflegeabhängigkeitsskala (PAS-P) ein reliables und valides Instrument zur Erfassung der Pflegeabhängigkeit von hospitalisierten Kindern im Schulalter in Deutschland und Ägypten?

Welche Unterschiede sind hinsichtlich der Pflegeabhängigkeit zwischen ägyptischen behinderten und nicht behinderten Kindern im Schulalter zu erkennen?

Ist die pädiatrische Pflegeabhängigkeitsskala (PAS-P) ein reliables und valides Instrument zur Einschätzung der Pflegeabhängigkeit von Kindern verschiedener Kulturen?

Welche Unterschiede liegen hinsichtlich der Pflegeabhängigkeit zwischen ägyptischen und deutschen Kindern im Schulalter vor?

Methode

Die vorliegend Studie erfolgte in vier Phasen:

I. Die Modifikation der Pflegeabhängigkeitsskala mit Hilfe der Delphi-Technik zur pädiatrischen Version (PAS-P).
II. Studie 1: Psychometrische Testung der modifizierten Pflegeabhängigkeitsskala bei hospitalisierten Kindern im Schulalter in Deutschland
III. Studie 2: Pflegeabhängigkeit von Kindern in Ägypten
IV. Studie 3: Pflegeabhängigkeit bei Kindern: Ein interkultureller Vergleich zwischen Deutschland und Ägypten

I. Modifizierung der PAS durch Delphi-Technik

Die vorliegende Studie begann mit der Modifizierung der PAS in eine Version, die bei Kindern anwendbar ist. Dazu wurde die Delphi-Technik eingesetzt, nach Burns und Grove (6, S.795) „eine Methode zur Messung der Beurteilungen einer Gruppe von Experten um Prioritäten einzuschätzen und Prognosen zu treffen“ [1]. Das Expertenteam umfasste zwölf staatlich anerkannte Kinderkrankenschwestern mit mindestens drei Jahren Erfahrung in pädiatrischer Pflege. Die Delphi-Methode wurde in zwei Runden mit einem Rücklauf von 92% im ersten Durchgang und 85% Rücklauf im zweiten Durchgang eingesetzt. Der erzielte Konsens kann als gut eingestuft werden. Aufgrund der Ergebnisse der Expertenbefragung wurde das Item „Aktivitäten zur sinnvollen Beschäftigung“ der ursprünglichen Pflegeab-hängigkeitsskala in das Item „Spielen und Hobbies“ umgewandelt. Außerdem wurden alle für die Anwendung bei Kindern relevanten Beschreibungen der einzelnen Items umgestaltet. Die derart modifizierte Form wurde als pädiatrische Pflegeabhängigkeitsskala (PAS-P) bezeichnet und in die arabische Sprache übersetzt. Es wurde das Übersetzungs-Modell von Brislin (7) eingesetzt. Dieser Rückübersetzungs- Ansatz wird als bevorzugte Methode der Übersetzung von Instrumenten betrachtet (8, 9).

II. Studie 1

Teilnehmer und Setting:

Die Stichprobe bestand aus 130 Kindern im Alter von sechs bis zwölf Jahren. Kinder mit schwerwiegenden Erkrankungen, mit kognitiven Einschränkungen und mit Lernbehinderung wurden von der Studie ausgeschlossen. Als Beobachterinnen kamen vierzig

[1] Übersetzung durch die Autorin

Kinderkrankenschwestern zum Einsatz, die direkt an der täglichen pflegerischen Betreuung der teilnehmenden Kinder beteiligt waren. Die Studie wurde auf vier pädiatrischen Stationen der Charité, Universitätsmedizin Berlin, mit den Schwerpunkten allgemeine Pädiatrie, Nephrologie, Kardiologie und Onkologie durchgeführt.

Instrumente:

Die pädiatrische Pflegeabhängigkeitsskala (PAS-P) und die Visuelle Analog-Skala (VAS) wurden für die Datensammlung eingesetzt. Die VAS ist eine der meistgebräuchlichsten Skalen in der Gesundheitsforschung und besteht aus einer 10 cm langen Linie mit jeweils einem Deskriptor an den beiden Endpunkten. Die VAS wurde zur Überprüfung der Kriteriumsvalidität eingesetzt.

Prozedur:

Kinderkrankenschwestern, die für mindestens einen Tag bevor in die Pflege der beteiligten Kinder involviert waren, nahmen eine Einschätzung der Pflegeabhängigkeit mit Hilfe der PAS-P und der VAS vor. Zur Überprüfung der Beobachterübereinstimmung wurde jedes Kind von zwei verschiedenen, unabhängigen Beobachterinnen eingeschätzt. Zuvor wurden die Beobachterinnen mündlich zu Hintergrund und Ziel der Studie sowie über den Umgang mit der PAS-P und VAS instruiert. Insgesamt 400 Fragebögen wurden an die beteiligten Stationen verteilt. Der Rücklauf betrug 88%. Davon mussten 46 Datensets aufgrund fehlender Daten ausgeschlossen werden. Damit verblieben 130 Datensets für die endgültige Daten-analyse. Die Güte der modifizierten Versionen der Skala wurde mit folgenden statistischen Berechnungen nachgewiesen: Cronbachs Alpha-Koeffizient zur Ermittlung der Internen Konsistenz, Cohens Kappa zur Festlegung der Item-Übereinstimmung, Pearson's Korre-lationskoeffizient zur Bestimmung der Kriteriumsvalidität sowie Faktoranalyse zur Bestim-mung der Konstruktvalidität.

III. Studie 2:

Teilnehmer und Setting:

Eine Gelegenheitsstichprobe von insgesamt 260 ägyptischen Kindern im Schulalter nahm an der Studie teil. Der Anteil an nicht behinderten Kindern betrug 49,2%, der Anteil an behinderten Kindern 50,8%. Es wurden sowohl Kinder mit körperlicher Behinderung (Blindheit, Taubheit, Sprachstörungen) als auch geistiger Behinderungen (intellektuelle Beeinträchtigung, Lernbehinderung) eingeschlossen. Das Ausmaß der Behinderung reichte von leicht bis mittel. Die Daten der nicht behinderten Kinder wurden auf verschiedenen pädiatrischen Stationen (allgemeine Pädiatrie, Nephrologie, Kardiologie und Onkologie) eines ägyptischen Universitätskrankenhauses erhoben. Neunundzwanzig Kinderkrankenschwestern aus Ägypten

übernahmen die Rolle der Beobachterinnen. Die Daten der behinderten Kinder wurden in drei ägyptischen Sonderschulen gesammelt.

Instrumente und Prozedur:

Die Untersuchung wurde bei den nicht behinderten Kindern mit den gleichen Instrumenten und gleicher Vorgehensweise wie in Studie 1 in Deutschland durchgeführt. Bei den behinderten Kindern übernahmen die Lehrer die Rolle der Beobachter.

IV. Studie 3:

Für diese Studie wurden die Daten aus den Studien 1 und 2 verwandt. Aus organisatorischen Gründen war es nicht möglich behinderte Kinder aus Deutschland in die Stichprobe von Studie 1 aufzunehmen. Daher beschränkt sich der vorliegende Vergleich zwischen Ägypten und Deutschland auf die nicht behinderten Kinder. Dadurch konnten insgesamt 258 Kinder, 128 aus Ägypten und 130 aus Deutschland, im Alter von sechs bis zwölf Jahren, in die Untersuchung aufgenommen werden.

Ergebnisse

Studie 1: Psychometrische Testung der modifizierten Pflegeabhängig-keitsskala bei hospitalisierten Kindern im Schulalter in Deutschland

Zwei Dimensionen der Reliabilität, die Interne Konsistenz und die Beobachterüberein-stimmung, wurden untersucht. Der Cronbachs Alpha-Koeffizient wies mit 0.91 auf eine hohe interne Konsistenz der PAS-P hin. Der Cohens Kappa zeigte mit einer Bandbreite von 0.57 – 0.80 eine moderate bis beträchtliche Beobachterübereinstimmung zweier Beobachter. Die Faktorenanalyse wurde eingesetzt, um die Konstruktvalidität zu untersuchen und bestätigte das Ein-Faktor-Modell der PAS-P. Weiter wurde eine hohe Korrelation zwischen dem Gesamtskalenwert der PAS-P und der VAS festgestellt und damit die Kriteriumsvalidität bestätigt. Die psychometrische Überprüfung ergab, dass die PAS-P ein valides und reliables Instrument für die Einschätzung der Pflegeabhängigkeit von Kindern im Schulalter darstellt.

Studie 2: Pflegeabhängigkeit von Kindern in Ägypten

Die Überprüfung der Reliabilität ergab einen Cronbachs Alpha Wert von 0.91 und damit einen hohen Grad an interner Konsistenz. Zur Einschätzung der Beobachterübereinstimmung wurde der Cohens Kappa bestimmt. In Anlehnung an Landis und Koch (10) können die erzielten Kappa-Werte von 0.57 – 0.89 als moderat bis exzellent interpretiert werden. Der Vergleich der

Gesamtskalenwerte der PAS-P und der VAS ergab eine signifikante Korrelation (Pearsons Korrelationskoeffizient $r = 0.67$, $p<0.001$). Die Kriteriumsvalidität wurde damit nachgewiesen. Im Hinblick auf die Verwendbarkeit der PAS-P in der Praxis hat die vorliegende Studie zudem gezeigt, dass die arabische Version der PAS-P einfach anzuwenden ist und zur Einschätzung von Pflegeabhängigkeit in verschiedenen arabischen Ländern eingesetzt werden könnte. Es wurden statistisch signifikante Unterschiede in der Pflegeabhängigkeit nachgewiesen, sowohl zwischen behinderten und nicht behinderten Kindern als auch bezüglich der unterschiedlichen Formen der Behinderung unter den behinderten Kindern selbst. Insgesamt wurden die behinderten Kinder als pflegeabhängiger in allen Items der PAS-P eingestuft als die nicht behinderten Kinder.

Studie 3: Pflegeabhängigkeit bei Kindern: Ein interkultureller Vergleich zwischen Deutschland und Ägypten

Die ersten Ergebnisse zeigten zufrieden stellende psychometrische Eigenschaften (Kriteriums- und Konstruktvalidität, Interne Konsistenz, Beobachterübereinstimmung) sowohl der deutschen als auch der arabischen Version der PAS-P im Hinblick auf Kinder im Schulalter. Beim Vergleich der deutschen mit den ägyptischen Kindern wurde ein signifikanter Zusammenhang zwischen den PAS-P-Mittelwerten und dem Alter der Kinder festgestellt, mit zunehmendem Alter stiegen auch die Skalenmittelwerte fortschreitend an, was bedeutet, dass die Pflegeabhängigkeit sank. Ein signifikanter Unterschied der Skalenmittelwerte zwischen Mädchen und Jungen konnte in keinem der beiden Länder festgestellt werden. Insgesamt kann die Pflegeabhängigkeit der untersuchten ägyptischen Kinder als höher beschrieben werden als die der untersuchten deutschen Kinder.

Diskussion

Die Ergebnisse der psychometrischen Tests unterstützen die Äquivalenz der pädiatrischen Pflegeabhängigkeitsskala (PAS-P) zur originalen PAS. In Übereinstimmung mit vorherigen Forschungsergebnissen (11) wurden die Reliabilität und Validität der modifizierten PAS-P bestätigt. In der vorliegenden Studie wiesen die deutschen Kinder höhere Mittelwerte bezüglich der Pflegeabhängigkeit auf als die ägyptischen Kinder. Das bedeutet, letztere können als pflegeabhängiger beschrieben werden. Eine mögliche Erklärung kann darin liegen, dass ägyptische Kinder mit über vier Jahren in Kindergärten aufgenommen werden. Deutsche Kinder besuchen Kindergärten bereits in jüngerem Alter und werden eher zur Selbsthilfe und zum Erwerb von Unabhängigkeit bezüglich der Selbstpflege angeleitet. Eine andere Erklärung wird

durch die Befunde von Francisco & Carlson (12) bezüglich von Unterschieden zwischen verschiedenen Kulturen geboten. Sie berichten, dass in einigen der untersuchten Kulturen die Unabhängigkeit von Kindern in Bereichen wie Essen, Trinken, Ankleiden, etc. nicht so sehr geschätzt wird wie in anderen. Manche der Eltern sehen sich als Personen, die immer für ihre Kinder da sind und übernehmen von daher viele derer täglichen Aufgaben.

Schlussfolgerung

Die pädiatrische Pflegeabhängigkeitsskala (PAS-P) kann als reliables und valides Instrument zur Einschätzung der Pflegeabhängigkeit von Kindern empfohlen werden. Die Einschätzung der Pflegeabhängigkeit von Kindern in Relation zu ihrem Entwicklungsstadium ist für die Pflegepraxis von Bedeutung, da sie eine Vorraussetzung für die Entwicklung von Selbstpflegefähigkeiten bei Kindern darstellt. Eine kulturübergreifende Einschätzung mittels der PAS-P ermöglicht zudem ein besseres Verständnis von vorhandenen interkulturellen Unterschieden.

References

1. Limperopoulos, C. Majnemer, A. Michael, S. Rosenblatt, B. Rohlicek, C. Tchervenkov C, Darwish H. Functional Limitation in Young Children with congenital heart defects after cardiac surgery. Pediatrics 2001; 108 (6): 1325-1331.

2. Strandberg G, Jansson L. Meaning of dependency on care as narrated by nurses. Scand J Caring Sci 2003; 17: 84–91.

3. Dijkstra A, Coleman M, Tomas C, Välimäki M, Dassen T. Cross-cultural psychometric testing of the Care Dependency Scale with data. Journal of Advanced Nursing 2003; 43 (2): 181-187.

4. Dijkstra A, Brown L, Havens B, Romeren T, Zanotti R, Dassen T, Heuvel W. An International Psychometric testing of the Care Dependency Scale. Journal of Advanced Nursing 2000; 31 (4): 944-952.

5. Wong V, Wong S, Chan K, Wong W. Functional independence measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics; 2002; 109 (2) E36 Available at: http://www.pediatrics.org/cgi/content/full/109/2/e36 [Accessed 15 October 2005].

6. Burns N, Grove S. The Practice of Nursing Research: Conduct, Critique, & Utilization, 4th ed. Philadelphia, PA: W.B. Saunders Co; 2001.

7. Brislin RW. Back translation for cross-cultural research. J. Cross-Cult. Psych. 1970; 1: 187–216.

8. Chang AM, Chau JPC, Holroyd E. Translation of questionnaires and issues of equivalence. J. Adv. Nurs 1999; 29: 316–322.

9. Jones PS, Lee JW, Phillips LR, Zhang XE, Jaceldo KB. An adaptation of Brislin's translation model for cross-cultural research. Nurs. Res. 2001; 50: 300–304.

10. Landis J, Koch G. The measurement of observer agreement for categorical data. Biometrics 1977; 33: 159-74.

11. Bonner A, Wellard S, Kenrick M. Development and validation of the Human Activity Profile into Chinese language: Lessons in determining equivalence. Nursing and Health Sciences 2006; 8: 36–43

12. Francisco I, Carlson G. Occupational therapy and people with intellectual disability from culturally diverse backgrounds. Australian Occupational therapy Journal 2002; 49: 200-211.

Acknowledgements

I would like to express my thanks to everyone participating in some way or another in the conduction of this study.

I am deeply indebted to *Prof. Dr. Theo Dassen* for his constant support, constructive criticism and valuable guidance during the completion and perfection of this thesis.

Words can never express my deep thanks to *Prof. Dr. Christa Lohrmann*, who always devoted to me so much of her time and unlimited assistance; indeed, she taught me many issues that I will treasure for the rest of my life.

My deepest gratitude to the Educational Mission of the Arab Republic of Egypt for giving me the chance to get this Scholarship. Furthermore, my special thanks to all participating children, their families and nurses who gave me time, assistance and cooperation to perform this work.

Deep thanks and best wishes to all my colleagues at the Institut für Medizin-/Pflegepädagogik und Pflegewissenschaft, Charité-Universitätsmedizin Berlin, as they were always there when I needed them.

Finally, I would like to thank Frau Susanne Dolenz, who always provided valuable linguistic guidance. I will forever be indebted to my parents and I would not have been able to complete this dissertation without the strength of my husband. I also owe my friend Gudrun Muna a debt of gratitude for her encouragement and support during all stages of this work.

Hanan Tork
Berlin, May 2007

Appendices

- **German, English (translated) and Arabic Versions of the Care Dependency Scale for Paediatrics (CDS-P)**

- **German, English (translated) and Arabic modified versions of the Visual Analogue Scale (VAS)**

German version of the PAS-P, used in this study

CHARITÉ CAMPUS MITTE

Institut für Medizin-/Pflegepädagogik und Pflegewissenschaft

PAS-P

Einschätzungsinstrument zur Beurteilung der Pflegeabhängigkeit
von Kindern im Schulalter

(6-12 Jahre)

Klinikbereich

Institut für Medizin-/Pflegepädagogik und Pflegewissenschaft
Schumannstr. 20-21
10117 Berlin
Tel.: 030 450 529 043 oder 030 450 529 092 (Sekretariat)
Fax: 030 450 529 900
Email: hannan.tork@charite.de (Ansprechpartner)
http://www.charite.de/ch/pflege

Berlin, August, 2004

Liebe Kolleginnen und Kollegen**,**

vor Ihnen liegt die ***Pflegeabhängigkeitsskala für Pädiatrie (PAS-P).*** Sie umfasst 15 Fragen, basierend auf den Grundbedürfnissen nach Virginia Henderson. Mittels einer 5-stufigen Skala von „völlig abhängig bis völlig unabhängig“ können Sie Ihre Kinder aus der pflegerischen Perspektive einschätzen, was die zu beurteilenden Kinder können bzw. (momentan) nicht können.

Vielen Dank

Prof. Dr. Theo Dassen
Doktorandin: Hanan Tork

Anleitung

Dies ist ein Einschätzungsinstrument, mit dem man beurteilen kann, wie pflegeabhängig Kinder in folgenden Bereichen sind:
Essen/Trinken, Kontinenz, Körperhaltung, Mobilität, Tag-/Nachtrhthymus, An- und Auskleiden, Körpertemperatur, Körperpflege, Vermeiden von Gefahren, Kommunikation, Kontakte mit anderen, Sinn für Regeln (Normen) und Werte, Alltagsaktivitäten, Spiel und Hobbys, Lernfähigkeit.

Bitte lesen Sie jede Frage sorgfältig. Anschließend kreuzen Sie bitte das Kästchen an, das Ihrer Meinung nach den Zustand des Patienten am besten entspricht. Sie haben fünf Möglichkeiten, zwischen denen Sie sich bei jeder Frage entscheiden sollen.

Bitte beurteilen Sie die Kinder, was diese wirklich können. Machen Sie bitte nur ein Kreuz pro Frage.

Beispiel: ein Kind mit eines Thalaseämie ist nicht in der Lage, allein zu essen; es kann aber seine Nahrung in den Mund nehmen. Sie kreuzen demnach die zweite Möglichkeit an:

Beispiel: *Essen und Trinken*

Ausmaß, in dem der Patient in der Lage ist, allein zu essen und zu trinken

☐ Das Kind ist nicht in der Lage, allein zu essen und zu trinken (= völlig abhängig)

☐ Das Kind ist nicht in der Lage, allein seine Mahlzeiten zuzubereiten (z.B. Es kann nicht die Butter auf das Brot schmieren); es kann aber seine Nahrung in den Mund nehmen.
(= überwiegend abhängig)

☐ Das Kind ist in der Lage, allein seine Mahlzeiten zuzubereiten und seine Nahrung in den Mund zu nehmen; es hat aber Schwierigkeiten, die Menge zu bestimmen “pro Löffel”
(= teilweise abhängig)

☐ Das Kind ist in der Lage, allein zu essen und zu trinken; es braucht aber einige Unterstützung (= überwiegend unabhängig)

☐ Das Kind ist in der Lage, allein seine Mahlzeiten zuzubereiten und ohne Hilfe anderer zu essen und zu trinken. (= völlig unabhängig)

Bitte ausfüllen

1. Datum der Beurteilung	☐☐ ☐☐ ☐☐ **Tag Monat Jahr**
2. Beurteilernummer	☐☐☐☐ (bitte weisen Sie jedem Beurteiler eine eigene Nummer zu, beginnend mit 1)
3. Kindnummer	☐☐☐☐ (bitte weisen Sie jedem Kind eine eigene Nummer zu, beginnend mit 1)
4. Dauer	☐☐ ☐☐ ☐☐ **Tag Monat Jahr**
5. Station	☐ ..... (bitte tragen Sie ein, um welche Station es sich handelt z.b. Kardiologie oder Hämatologie)
6. Art der Erkrankung (Diagnose bei der Aufnahme)	**ICD-Codes, falls bekannt** ☐☐☐☐☐☐☐
7. Geschlecht	☐**weiblich** ☐**männlich**
8. Alter	☐☐ **Jahr**

1. Essen und Trinken

Ausmaß, in dem das Kind in der Lage ist, allein zu essen und zu trinken [1]

☐ Das Kind ist nicht in der Lage, allein zu essen und zu trinken

☐ Das Kind ist nicht in der Lage, allein seine Mahlzeiten zuzubereiten (z.B. Es kann nicht die Butter auf das Brot schmieren); es kann aber seine Nahrung in den Mund nehmen

☐ Das Kind ist in der Lage, allein seine Mahlzeiten zuzubereiten und seine Nahrung in den Mund zu nehmen; es hat aber Schwierigkeiten, die Menge zu bestimmen " pro Löffel"

☐ Das Kind ist in der Lage, allein zu essen und zu trinken; es braucht aber einige Unterstützung

☐ Das Kind ist in der Lage, allein seine Mahlzeiten zuzubereiten und ohne Hilfe anderer zu essen und zu trinken[2]

1. Die Diagnose erfolgt ohne Beziehung zum Essen und Trinken (Kinder haben Probleme mit dem Essen und Trinken werden ausgeschlossen)
2. Eventuell unter Aufsicht

2. Kontinenz

Ausmaß, in dem das Kind in der Lage ist, Urin- und/oder Stuhlausscheidungen willkürlich zu kontrollieren

☐ Das Kind ist nicht in der Lage, Urin- und/oder Stuhlausscheidungen zu kontrollieren; es ist vollständig urin- und/oder stuhlinkontinent

☐ Das Kind ist nicht in der Lage, Urin- und/oder Stuhlausscheidungen zu kontrollieren; Ausscheidungen sind ohne Hilfe nicht möglich

☐ Das Kind ist meistens in der Lage, Kontinent am Tag zu sein, es näßt in der Nacht ein

☐ Das Kind ist meistens in der Lage, Ausscheidungen selbständig zu kontrollieren

☐ Das Kind ist in der Lage, Ausscheidungen selbständig zu kontrollieren

3. Körperhaltung

Ausmaß, in dem das Kind in der Lage ist, seine Körperhaltung zu kontrollieren, beziehungsweise eine empfohlene Körperposition einzunehmen *(z.B. orthopädische Fälle)*

☐ Das Kind ist nicht in der Lage, seine Körperhaltung selbständig zu ändern

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, bei bestimmten Aktivitäten eine andere Körperhaltung einzunehmen

☐ Das Kind ist in der Lage, bei bestimmten Aktivitäten die entsprechende Körperhaltung einzunehmen, dies geschieht aber nur in geringem Maße aus eigener Initiative

☐ Das Kind hat einige Schwierigkeiten, eine angemessene Körperhaltung einzunehmen

☐ Das Kind hat keine Schwierigkeiten, eine angemessene Körperhaltung einzunehmen

4. Mobilität

Ausmaß, in dem das Kind in der Lage ist, sich allein fortzubewegen

☐ Das Kind ist immobil: Es ist nicht in der Lage, sich allein fortzubewegen

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, sich allein fortzubewegen; es benutzt oft mechanische Hilfsmittel (Rollstuhl/ Gehhilfe) oder braucht Hilfe der Pflegenden [1]

☐ Das Kind ist ziemlich mobil, manchmal benutzt es mechanische Hilfsmittel oder braucht Hilfe der Pflegenden

☐ Das Kind ist meistens in der Lage, sich selbständig fortzubewegen

☐ Das Kind ist in der Lage, sich selbständig fortzubewegen

---

[1] *Pflegende sind Krankenschwester, Pfleger, Eltern, Familienmitglieder*

5. Tag-/Nachtrhythmus

Ausmaß, in dem das Kind einen angemessenen Tag-/Nachtrhythmus aufrechterhalten kann

☐ Das Kind hat kein Empfinden für den Tag-/Nachtrhythmus

☐ Das Kind hat nur zu einem gewissen Grade ein Empfinden für den Tag-/Nachtrhythmus

☐ Das Kind empfindet den Tag-/Nachtrhythmus, es braucht aber viel Hilfe/ Unterstützung

☐ Das Kind empfindet den Tag-/Nachtrhythmus, es braucht wenig Hilfe/ Unterstützung

☐ Das Kind kennt den normalen Tag-/Nachtrhythmus; es sorgt für ausreichend Erholung (Ruhe und Schlaf)

---

6. An-und Auskleiden

Ausmaß, in dem das Kind in der Lage ist, sich allein an- und auszukleiden

☐ Das Kind ist nicht in der Lage, sich selbständig an- und auszukleiden

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, sich selbständig an- und auszukleiden; es benötigt aber viel Hilfe

☐ Das Kind ist teilweise in der Lage, sich selbständig an- und auszukleiden, Beobachtungen und/oder kleinere Hilfestellungen sind erforderlich

☐ Das Kind ist in der Lage, sich weitgehend selbständig an- und auszukleiden, es braucht aber Hilfe bei der Bewältigung feinmotorischer Aufgaben

☐ Das Kind ist in der Lage, sich ohne Hilfe an- und auszukleiden; es hat Kontrolle über seine Feinmotorik

---

7. Körpertemperatur

Ausmaß, in dem das Kind in der Lage ist, seine Körpertemperatur gegen äußere Einflüsse zu schützen

☐ Das Kind ist nicht in der Lage, zwischen kalten und warmen Temperaturen zu unterscheiden

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, zwischen kalten und warmen Temperaturen zu unterscheiden; es ist aber nicht in der Lage, sich entsprechend zu verhalten

☐ Das Kind ist in der Lage, zwischen kalten und warmen Temperaturen zu unterscheiden; es ist bis zu einem gewissen Grade in der Lage, sich entsprechend zu verhalten

☐ Das Kind ist in der Lage, Wärme- und Kälteempfinden zu zeigen; und es ist in hohem Maße in der Lage, entsprechend zu handeln

☐ Das Kind ist in der Lage, ohne Hilfe seine Körpertemperatur gegen äußere Einflüsse zu schützen

---

8. Körperpflege

Ausmaß, in dem das Kind in der Lage ist, sich selbständig zu pflegen

☐ Das Kind ist nicht in der Lage, sich selbständig zu pflegen, d.h. zu baden, die Zähne zu putzen, Haare zu kämmen etc

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, sich zu pflegen; es ist aber nicht in der Lage, dies aus eigener Initiative zu tun

☐ Das Kind ist in der Lage, verschiedene Pflegeverrichtungen durchzuführen, es braucht aber Anleitung und/oder Hilfen

☐ Das Kind ist in der Lage, verschiedene Pflegeverrichtungen durchzuführen, Aufforderungen Beobachtungen und/oder kleine Hilfestellungen sind erforderlich

☐ Das Kind ist in der Lage, sich selbständig zu pflegen*

---

* *Eventuell unter Aufsicht*

9. Vermeiden von Gefahren

Ausmaß, in dem das Kind in der Lage ist, selbständig für seine Sicherheit zu sorgen.

☐ Das Kind ist nicht in der Lage, selbständig Gefahren zu erkennen und zu vermeiden

☐ Das Kind ist ein wenig in der Lage, gefährliche Situationen in seiner Umgebung zu erkennen, es braucht aber für seinen Schutz viel Hilfe

☐ Das Kind ist teilweise in der Lage, gefährliche Situationen in seiner Umgebung zu erkennen, es braucht für seinen Schutz Anleitung und Hilfestellung

☐ Das Kind ist in der Lage, gefährliche Situationen in der eigenen Umgebung zu erkennen und sich meistens selbst zu schützen

☐ Das Kind ist in der Lage, selbständig für seine Sicherheit zu sorgen

---

10. Kommunikation

Ausmaß, in dem das Kind in der Lage ist zu kommunizieren

☐ Das Kind ist nicht in der Lage, sich verbal mitzuteilen, ggf. ist es aber in der Lage, nonverbal zu kommunizieren

☐ Das Kind ist bis zu einem gewissen Grade in der Lage, verbal und nonverbal zu kommunizieren; es benutzt u.U. Laute oder Gesten, um sich mitzuteilen

☐ Das Kind ist in der Lage, sich durch einfache Worte und/oder bestimmte Gesten auszudrücken; es versteht einfache kurze Worte

☐ Das Kind ist in der Lage, sich durch Worte und Sätze und/oder entsprechende Gesten mitzuteilen; es versteht einfache Sätze und Gesten

☐ Das Kind ist in der Lage, sich verbal und nonverbal mitzuteilen und kann mit anderen kommunizieren

---

11. Kontakte mit Anderen

Ausmaß, in dem das Kind in der Lage ist, soziale Kontakte aufzunehmen, aufrechtzuerhalten und zu beenden.

☐ Das Kind ist nicht in der Lage, Kontakte zu anderen herzustellen; es reagiert ggf. positiv auf angenehme und/oder negative Erfahrungen

☐ Das Kind ist ein wenig in der Lage, allein Kontakt zu anderen herzustellen; es reagiert auf andere Personen

☐ Das Kind ist in der Lage, eine begrenzte Anzahl von Kontakten zu anderen Personen aufzunehmen, aufrechtzuerhalten und zu beenden. Es braucht aber Unterstützung und Aufforderung

☐ Das Kind ist meistens in der Lage, Kontakte zu anderen herzustellen, aufrechtzuerhalten sowie zu beenden

☐ Das Kind ist in der Lage, allein Kontakte zu anderen herzustellen, aufrechtzuerhalten sowie zu beenden

---

12. Sinn für Regeln und Werte

Ausmaß, in dem das Kind in der Lage ist, Regeln einzuhalten und Werte (z.B. Ehrlichkeit, Liebe, Kooperation,...) anzuerkennen

☐ Das Kind ist nicht in der Lage, Regeln einzuhalten und Werte anzuerkennen

☐ Das Kind ist in der Lage, eine begrenzte Anzahl von Regeln in der Einrichtung einzuhalten und Werte anzuerkennen

☐ Das Kind ist in der Lage, die in der Einrichtung geltenden Regeln einzuhalten, ein Sinn für die eigene Privatsphäre und die anderer Personen fehlt

☐ Das Kind ist sich der Regeln bewusst, die innerhalb und außerhalb der Einrichtung gelten; es verhält sich aber nicht immer entsprechend; es legt meistens Wert auf die eigene Privatsphäre und die anderer Personen

☐ Das Kind ist sich der Regeln und Werte bewusst, die innerhalb und außerhalb der Einrichtung gelten; er verhält sich entsprechend; er legt Wert auf seine Privatsphäre und die anderer Personen

---

13. Alltagsaktivitäten

Ausmaß, in dem das Kind in der Lage ist, tägliche Aktivitäten innerhalb der Einrichtung zu bewältigen (z.B. aufräumen, Müll zu entsorgen)

☐ Das Kind ist nicht in der Lage, ohne Hilfe tägliche Aktivitäten zu bewältigen

☐ Das Kind ist in der Lage, einfache tägliche Aktivitäten innerhalb der Einrichtung mit Hilfe anderer zu bewältigen

☐ Das Kind ist in der Lage, verschiedene tägliche Aktivitäten innerhalb der Einrichtung zu bewältigen, aber nur durch Anregung oder nach Aufforderung

☐ Das Kind ist in der Lage, die meisten tägliche Aktivitäten selbständig zu bewältigen

☐ Das Kind ist in der Lage, alle tägliche Aktivitäten selbständig zu bewältigen

---

14. Spiel und Hobbys

Ausmaß, in dem das Kind in der Lage ist, durch Beschäftigung (Lesen, Malen, Basteln) seine Zeit während des Klinikaufenthaltes zu gestalten

☐ Das Kind ist nicht in der Lage, sich selbständig mit einem Hobby zu beschäftigen und/oder mit anderen Kindern zu spielen

☐ Das Kind ist bis zu einem gewissen Grad in der Lage, sich selbständig zu sich zu beteiligen

☐ Das Kind ist in der Lage, sich zu beschäftigen, jedoch nicht aus eigenem Antrieb heraus. Es muß aufgefordert werden

☐ Das Kind ist in der Lage, weitgehend selbständig seine Zeit zu gestalten. Es benötigt jedoch etwas Anleitung

☐ Das Kind ist in der Lage, sich selbständig zu beschäftigen

---

15. Lernfähigkeit

Ausmaß, in dem das Kind in der Lage ist, sich Kenntnisse und/oder Fähigkeiten/ Fertigkeiten zu erwerben und beizubehalten

☐ Das Kind ist nicht in der Lage, Kenntnisse, Fähigkeiten/Fertigkeiten zu erlernen

☐ Das Kind ist in der Lage, durch häufige Wiederholungen, vorhandene Kenntnisse, Fähigkeiten/Fertigkeiten beizubehalten

☐ Das Kind ist in der Lage, neue Kenntnisse und/oder Fähigkeiten/Fertigkeiten zu erlernen und beizubehalten mit Unterstützung und durch Wiederholungen

☐ Das Kind ist in der Lage, neue Kenntnisse, Fähigkeiten/Fertigkeiten zu erlernen und beizubehalten. es benötigt etwas Unterstützung

☐ Das Kind ist in der Lage, neue Kenntnisse, Fähigkeiten/Fertigkeiten zu erlernen, beizubehalten, es treten keinerlei Verluste von vorhandenen Kenntnissen und Fähigkeiten auf

---

Gesamteinschätzung

Schätzen Sie bitte ein, welche Gesamteinstufung für das Kind zutreffend ist:

☐ Das Kind ist völlig von Pflege abhängig

☐ Das Kind ist überwiegend von Pflege abhängig

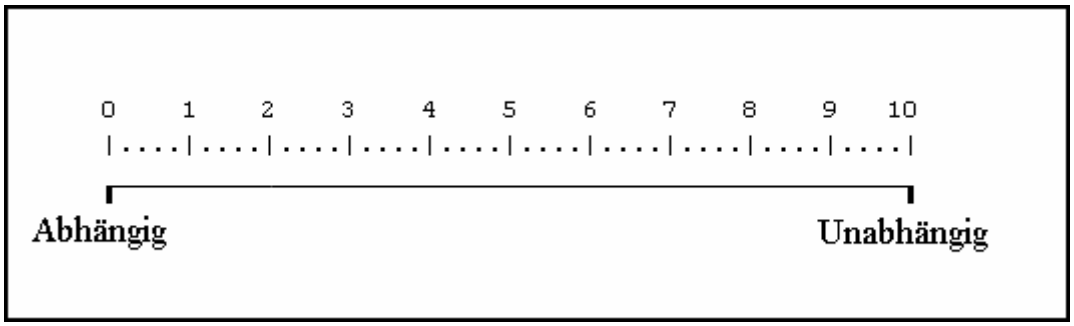
☐ Das Kind ist teilweise von Pflege abhängig

☐ Das Kind ist überwiegend von Pflege unabhängig

☐ Das Kind ist von Pflege unabhängig

Visuelle Analog Skala (VAS)

Bitte zeigen Sie die Abhängigkeitsstufe des Kindes im jeweiligen Gebiet (Essen und Trinken, Mobilität, Kommunikation, usw.) durch Markieren eines X an der passenden Stelle.



Vielen Dank!

English version (translated) of the CDS-P

1. Eating and drinking

The extent to which the child is able to satisfy his/her need for food and drink unaided [1]

☐ The child is unable to take food and drink unaided

☐ The child is unable to prepare food and drink unaided; (e.g He/she can not butter the bread); but the child is able to put food and drink into his/her mouth unaided

☐ The child is able to prepare and put food and drink into his/her mouth unaided; He/she has difficulties to determine the quantity "per spoon"

☐ The child is able to eat and drink most of the time unaided; He/she needs however some support

☐ The child is able to prepare his/her meals and to satisfy his/her need for eating and drinking unaided [2]

---

1. The medical diagnosis does not interfere with eating and drinking (children having problems with eating and drinking will excluded)
2. Ssupervision might be needed

2. Continence

The extent to which the child is able to control the discharge of urine and faeces

☐ The child is unable to prevent the discharge of urine and/or faeces; He/she is completely incontinent

☐ The child is unable to control the discharge of urine and/or faeces; He/she needs assisstence

☐ The child is continent during the day, but he/ she wets the bed during the night

☐ The child is able to control the discharge most of the time unaided

☐ The child is able to control excretions unaided

---

3. Body posture

The extent to which the child is able to change his/ her position, and to take the recommended position (e.g orthopedic cases)

☐ The child is unable to change his/her body posture unaided

☐ The child is to some extent able to adopt to a different position unaided

☐ The child is able to adopt a position appropriate for certain activity, but fails to do so sufficiently on his/her own initiative

☐ The child has some limitations as to adopting the appropriate position

☐ The child has no limitations as to adopting the appropriate position

---

4. Mobility

The extent to which the child is able to move unaided

☐ The child is immobile and unable to move him/herself

☐ The child is to some extent able to move unaided; he/she uses mechanical aids often (e.g. Wheelchair/Walker) or needs assistance from the caregiver

☐ The child is fairly mobile, some times he/she uses mechanical aid or needs help of the caregiver

☐ The child is able to move unaided most of time

☐ The child is able to move unaided all of the time

---

[7] ***Caregiver*** *may be nurse, parent or family member*

5. Day/night pattern

The extent to which the child can maintain an appropriate day/night pattern unaided

☐ The child is insensitive to day/night pattern

☐ The child is somewhat insensitive to the day/night pattern

☐ The child is sensitive to the day/night pattern, but needs much aid/support

☐ The child is sensitive to day/night pattern, and needs little aid/support

☐ The child knows the normal day/night pattern, and secures enough rest for him/herself (rest and sleep)

---

6. Getting dressed and undressed

The extent to which the child is able to get dressed and undressed unaided

☐ The child is unable to get dressed and undressed unaided

☐ The child is to some extent able to get dressed and undressed, but needs much help

☐ The child is partly able to get dressed and undressed, but supervision and/or some assistance are required

☐ The child is able to get dressed and undressed almost unaided, but needs help with fine motor skills

☐ The child is able to get dressed and undressed unaided; he/she has control over fine motor movements

---

7. Body temperature

The extent to which the child is able to protect his/her body temperature against external influences unaided

☐ The child is unable to distinguish between cold and warm temperatures by him/herself

☐ The child is to some extent able to distinguish between cold and warm temperatures by him/herself, but he/she is unable to take appropriate action

☐ The child is able to distinguish between cold and warm temperatures by him/herself, and to some extent able to take appropriate action

☐ The child is able to indicate feelings of cold and warm temperature by him/herself, and to a great extent able to take appropriate action

☐ The child is able to protect his/her body temperature against external influences unaided

---

8. Hygiene

The extent to which the child is able to take care of his/her personal hygiene unaided

☐ The child is unable to care for his/her personal hygiene unaided (e.g. bathing, brushing teeth, combing hair, etc.)

☐ The child is some what able to contribute to his/her personal hygiene, but does not do so on his/her own initiative

☐ The child is able to perform several tasks regarding his/her personal hygiene, but supervision and assistance are required

☐ The child is able to perform most actions regarding his/her personal hygiene, but supervision and/or little ssistance may be required

☐ The child is able to take care of his/her personal hygiene unaided*

**Ssupervision might be needed.*

9. Avoidance of danger

The extent to which the child is able to assure his/her own safety unaided

☐ The child is unable to recognize and avoid dangers by him/herself

☐ The child is somewhat able to recognize and avoid dangers in his/her environment by him/herself, but needs lots of assistance to protect him/herself

☐ The child is partly able to recognize and avoid dangers in his/her environment by him/herself, but needs some help and instructions

☐ The child is able to recognize and avoid dangers in his/her environment, and able to protect him/herself most of the time

☐ The child is able to take care of his/her own safety unaided

---

10. Communication

The extent to which the child is able to communicate

☐ The child is unable to express him/herself verbally, but is able to communicate nonverbally with persons known to him/her

☐ The child is somewhat able to express him/herself verbally and nonverbally; uses sounds or gesture to express his/her experiences

☐ The child is able to express him/herself by means of simple words and/or specific gestures; he/she understands simple and short words

☐ The child is able to express him/herself in words and sentence and/or specific gestures; he/she understands simple sentences and/or gestures from others

☐ The child is able to express him/herself verbally and nonverbally; he/she is able to communicate with others

---

11. Contact with others

The extent to which the child is able to initiate, maintain and end social contacts appropriately

☐ The child is unable to initiate contacts with others by him/herself; reacts positively to pleasant experiences and/or negatively to unpleasant experiences

☐ The child is somewhat able to make contacts with others he/she reacts to persons important to him/her

☐ The child is able to maintain a limited number of contacts with persons, but needs assistance and prompting

☐ The child can initiate, maintain and end contacts independently most of time

☐ The child can initiate, maintain and end contacts independently

---

12. Sense of rules and values

The extent to which the child is able to observe rules and to respect values (e.g. Honesty, love, cooperation)

☐ The child is unable to observe rules or respect values

☐ The child is able to observe a limited number of rules and values

☐ The child is able to follow the rules, of the facility, but a sense of privacy for hem/herself or others is absent

☐ The child is aware of rules, both within and outside of the facility; but he/she does not always behave accordingly; he/she has a limited sense of privacy

☐ The child is aware of rules, both within and outside of the facility; he/she behaves accordingly; and expresses his/her own privacy and that of other persons

---

13. Daily activities

The extent to which the child is able to performe daily activities within the facility unaided (e.g. Clean up, disposal of waste)

☐ The child is unable to carry out daily activities by him/herself

☐ The child is able to carry out simple daily activities within the facility with assistance

☐ The child is able to carry out several daily activities within the facility by him/herself, but does so only when promted

☐ The child is able to carry out most of the daily activities within the facility by him/herself

☐ The child is able to perform all daily activities within the facility by him/herself

---

14. Play and hobbies

The extent to which the child is able to spend his/her time while staing at the facility participating in hobbies (reading, painting, handicrafts)

☐ The child is unable to participate in hobbies and/or play with other children

☐ The child is to some extent able to participate in hobbies and/or play

☐ The child is able to participate in hobbies and/or play, but does so only when prompted

☐ The child is able to participate in hobbies and/or play independently most of the time, but sometimes supervision is required

☐ The child is able to participate in hobbies and/or play independently

---

15. Learning ability

The extent to which the child is able to acquire knowledge and/or skills and/or to retain that which was previously learned unaided

☐ The child is unable to acquire knowledge and/or skills

☐ The child is able to retain existing skills through frequent repetition

☐ The child is able to learn new and simple skills through repetition

☐ The child is able to learn new skills, but needs assistance

☐ The child is able to learn new and complex skills

Summary sheet

Please assess the overall classification appropriate for the child:

☐ The child is completely care dependent

☐ The child is to a great extent care dependent

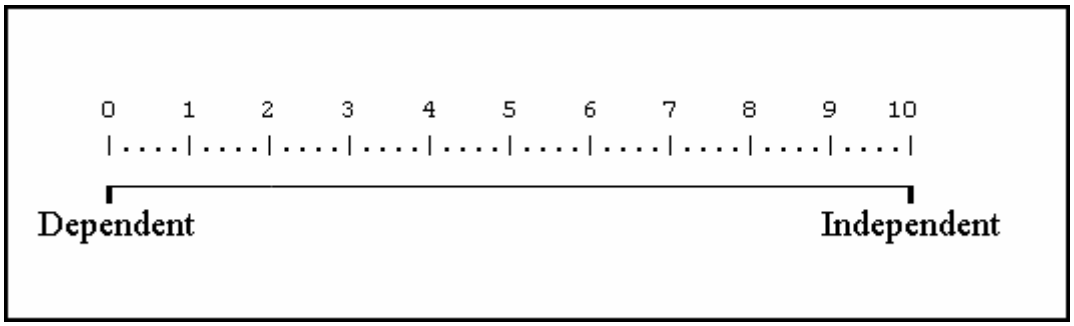
☐ The child is partially care dependent

☐ The child is to a limited extent care dependent

☐ The child is almost care independent

Visual Analogue Scale (VAS)

Please indicate the child's level of independent in the area of (Eating and drinking, Continence, **Body posture, etc…) by marking an X at the appropriate distance.**



Thank you!

Arabic version of the CDS-P, used in this study

١. الطعام و الشراب

مقياس قدرة الطفل على تناول طعامه و شرابه بمفرده 1

- ☐ الطفل غير قادرا تماما على تناول طعامه و شرابه بمفرده
- ☐ الطفل غير قادر على تجهيز وجبته بمفرده (لا يستطيع وضع الزبد على الخبز) ولكنه قادر على وضع الطعام في فمه
- ☐ الطفل قادر على تجهيز وجبته بمفرده ووضع الطعام في فمه ولكنه يعانى صعوبة القدرة على تحديد الكمية(للوجبة/ للمعلقة)
- ☐ الطفل قادر على تناول طعامه و شرابه بمفرده لكنه بحاجة لبعض المساعدة
- ☐ الطفل قادر على تناول طعامه و شرابه بمفرده دون مساعدة من الآخرين٢

---

١ *الأطفال ذوى الحالات التي تعوق الطعام والشراب تستبعد من الاستقصاء (حالات الجراحة)*
٢ *من المحتمل احتياج الطفل إلى المتابعة*

٢. التحكم في الإخراج

مقياس قدرة الطفل على التحكم في التبول والتبرز

- ☐ الطفل غير قادرا تماما على التحكم في التبول والتبرز
- ☐ الطفل غير قادر على التحكم في التبول والتبرز و الإخراج الطبيعي يحتاج لتدخل
- ☐ الطفل قادر على التحكم في التبول والتبرز نهارا و لكنه يتبول في الفراش ليلا
- ☐ الطفل قادر على التحكم في التبول والتبرز معظم الوقت بدون مساعدة
- ☐ الطفل قادر على التحكم تماما في التبول والتبرز بدون مساعدة

---

٣. وضع الجسم

مقياس قدرة الطفل على تغيير وضع الجسم (مثال/ حالات العظام)

- ☐ الطفل غير قادر تماما على تغيير وضع جسمه بدون مساعده
- ☐ الطفل قادر إلى حد ما على أخذ وضع ما بدون مساعده
- ☐ الطفل قادر على تغيير وضع جسمه و لكن فقط عندما يحفز على ذلك
- ☐ الطفل قادر على تغيير وضع جسمه ولكن لديه بعض المعوقات لذلك
- ☐ الطفل قادر على تغيير وضع جسمه وليس لديه أي معوقات لذلك

---

٤. الحركة

مقياس قدرة الطفل على الحركة بدون مساعدة

- ☐ الطفل غير قادر تماما على تغيير وضع جسمه بدون مساعده
- ☐ الطفل قادر إلى حد ما على أخذ وضع ما بدون مساعده
- ☐ الطفل قادر على تغيير وضع جسمه و لكن فقط في حالة وجود دافع ذاتي
- ☐ الطفل قادر على تغيير وضع جسمه ولكن ربما توجد بعض المعوقات
- ☐ الطفل قادر على تغيير وضع جسمه بدون أي معوقات

القائم بالرعاية هنا قد يكون الممرضة/ الوالدين/ أحد أفراد الأسرة

٥ . إيقاع الليل والنهار

مقياس قدرة الطفل على التمييز بين إيقاع الليل والنهار بدون مساعدة

- ☐ الطفل لا يدرك تماما إيقاع الليل والنهار
- ☐ الطفل يدرك إلى حد ما إيقاع الليل والنهار
- ☐ الطفل يدرك إيقاع الليل والنهار ولكن يحتاج الكثير من المساعدة
- ☐ الطفل يدرك إيقاع الليل والنهار ولكن يحتاج بعض المساعدة
- ☐ الطفل يدرك إيقاع الليل والنهار ويتوازن معه (يهدأ و ينام ليلا)

---

٦. القدرة على ارتداء/ خلع الملابس

مقياس قدرة الطفل على ارتداء/ خلع ملابسه بدون مساعدة

- ☐ الطفل غير قادر تماما على ارتداء/ خلع ملابسه
- ☐ الطفل قادر إلى حد ما على ارتداء/ خلع ملابسه و لكن يحتاج الكثير من المساعدة
- ☐ الطفل قادر نسبيا على ارتداء/ خلع ملابسه ولكن يحتاج بعض المساعدة أو المتابعة
- ☐ الطفل قادر غالبا على ارتداء/ خلع ملابسه ولكن يحتاج المساعدة فقط فيما يتطلب مهارات دقيقه
- ☐ الطفل قادر تماما على ارتداء/ خلع ملابسه بدون مساعدة

---

٧. حرارة الجسم

مقياس قدرة الطفل على الحفاظ على حرارة جسمه الطبيعية ضد المؤثرات الخارجية دون مساعدة

- ☐ الطفل غير قادر تماما على إدراك انخفاض/ ارتفاع حرارة جسمه بنفسه
- ☐ الطفل قادر إلى حد ما على إدراك انخفاض/ ارتفاع حرارة جسمه بنفسه ولكنه لا يستطيع عمل اللازم لذلك (مثل إبلاغ القائم على رعايته)
- ☐ الطفل قادر نسبيا على إدراك انخفاض/ ارتفاع حرارة جسمه بنفسه و إلى حد ما يستطيع عمل اللازم لذلك
- ☐ الطفل قادر غالبا على التعرف على دواعي/ مؤشرات انخفاض وارتفاع حرارته بنفسه والى حد كبير يستطيع عمل اللازم
- ☐ الطفل قادر تماما على الحفاظ على حرارة جسمه الطبيعية ضد المؤثرات الخارجية دون مساعدة

---

٨. العناية البدنيه

مقياس قدرة الطفل على القيام بنظافته الشخصية بمفرده/ معتمدا على ذاته

- ☐ الطفل غير قادر تماما على القيام بنظافته الشخصية من استحمام، غسيل أسنان، تمشيط الشعر.... بمفرده
- ☐ الطفل قادر إلى حد ما على القيام بنظافته الشخصية ولكن فقط عندما يحفز على ذلك
- ☐ الطفل قادر نسبيا على القيام بالعديد من نواحي النظافة الشخصية ولكن يحتاج إلى المتابعة أو المساعدة
- ☐ الطفل قادر على القيام بمعظم نواحي النظافة الشخصية ولكن قد يحتاج إلى بعض المتابعة أو المساعدة
- ☐ الطفل قادر تماما على القيام بنظافته الشخصية دون مساعدة

---

٩. تجنب الخطر

مقياس قدرة الطفل على حماية نفسه بمفرده/ معتمدا على ذاته

- ☐ الطفل غير قادر تماما على إدراك وتجنب الأخطار بنفسه
- ☐ الطفل قادر إلى حد ما على إدراك الأخطار في البيئة المحيطة به بنفسه ولكن يحتاج الكثير من مساعدة الآخرين لحماية نفسه
- ☐ الطفل قادر نسبيا على إدراك و تجنب الأخطار في البيئة المحيطة به ولكن يحتاج بعض المساعدة لحماية نفسه من الآخرين
- ☐ الطفل قادر على إدراك و تجنب الأخطار في البيئة المحيطة به وحماية نفسه في كثير من الأحيان
- ☐ الطفل قادر تماما على حماية نفسه بمفرده/ معتمدا على ذاته

---

١٠. التواصل

مقياس قدرة الطفل على التواصل مع الآخرين

- ☐ الطفل غير قادر تماما على التعبير لفظيا ولكن يتواصل مع من يعرفهم غير لفظي
- ☐ الطفل قادر إلى حد ما على التواصل لفظيا وغير لفظيا مستخدما الصوت و الإشارة للتعبير عما يريد
- ☐ الطفل قادر نسبيا على التعبير عن نفسه بكلمات بسيطة أو ببعض الإشارات ويفهم الكلمات البسيطة من الآخرين
- ☐ الطفل قادر على التعبير عن نفسه بالكلمات والعبارات أ وبعض الإشارات وكذلك يستطيع استيعابها من الآخرين
- ☐ الطفل قادر تماما على التعبير لفظيا وغير لفظي ويستطيع التواصل مع الآخرين

---

١١. الاحتكاك مع الآخرين

مقياس قدرة الطفل على الاحتكاك مع الآخرين

- ☐ الطفل غير قادر تماما على الحوار مع الآخرين بمفرده حيث أنه لا يستطيع التجاوب سلبا أو إيجابا تبعا للموقف
- ☐ الطفل قادر إلى حد ما على الاحتكاك والحوار لكنه لا يستطيع ذلك إلا مع المقربين له
- ☐ الطفل قادر نسبيا على الحوار مع الآخرين و لكنه يحتاج مساعدة أولمن يحثه على ذلك
- ☐ الطفل قادر في معظم الأحيان على بدء ومواصلة وختام الحوار مع الآخرين بمفرده
- ☐ الطفل قادر تماما على بدء ومواصلة وختام الحوار مع الآخرين بمفرده

---

١٢. إدراك القواعد والقيم

مقياس قدرة الطفل على إدراك القواعد و القيم

- ☐ الطفل غير قادر تماما على إدراك القواعد
- ☐ الطفل قادر على إدراك بعض القواعد المنوط به استيعابها، الملائمة لمرحلته العمريه
- ☐ الطفل قادر على إتباع القواعد المنوط به استيعابها، الملائمة لمرحلته العمر يه و لكنه لا يدرك مفهوم الخصوصية
- ☐ الطفل يعي القواعد المنوط به استيعابها، الملائمة لمرحلته العمريه ولكنه لا يستطيع إتباعها في كثير من الأحيان
- ☐ الطفل يعي القواعد المنوط به استيعابها، الملائمة لمرحلته العمريه ويتبعها في سلوكياته ويدرك مفهوم الخصوصية

---

١٣. الأنشطة اليومية

مقياس قدرة الطفل على القيام بالأنشطة اليومية المنوطة به/ الملائمة له

- ☐ الطفل غير قادر تماما على القيام بأنشطته اليومية بدون مساعدة
- ☐ الطفل قادر على القيام ببعض الأنشطة اليومية المنوطة به، الملائمة له ولكن بمساعدة الآخرين
- ☐ الطفل قادر على القيام بالعديد من الأنشطة اليومية الملائمة له بمفرده
- ☐ الطفل قادر على القيام بمعظم الأنشطة اليومية الملائمة له بمفرده
- ☐ الطفل قادر على القيام بالأنشطة اليومية المنوطة به بمفرده

---

١٤. اللعب و الهوايات

مقياس قدرة الطفل على شغل وقته بالهوايات أثناء الإقامة بالمستشفى (القراءة، الرسم، المهارات اليدوية)

- ☐ الطفل غير قادر على المشاركة في الهوايات أو اللعب مع الأطفال
- ☐ الطفل قادر إلى حد ما على المشاركة في الهوايات أو اللعب مع الأطفال
- ☐ الطفل قادر على المشاركة في الهوايات أو اللعب ولكن عندما يحفز فقط
- ☐ الطفل قادر على المشاركة في الهوايات أو اللعب مع الأطفال بمفرده ولكنه أحيانا يحتاج إلى متابعة
- ☐ الطفل قادر على المشاركة في الهوايات أو اللعب تماما بمفرده

---

١٥. القدرة على التعلم

مقياس قدرة الطفل على اكتساب معلومات و مهارات جديدة

- ☐ الطفل غير قادر تماما على اكتساب المعلومات والمهارات
- ☐ الطفل قادر على اكتساب المعلومات والمهارات بكثرة تكرارها
- ☐ الطفل قادر على اكتساب المعلومات والمهارات البسيطة بتكرارها
- ☐ الطفل قادر على اكتساب المعلومات والمهارات الجديدة ولكنه يحتاج إلى مساعدة
- ☐ الطفل قادر على اكتساب المعلومات والمهارات الجديدة

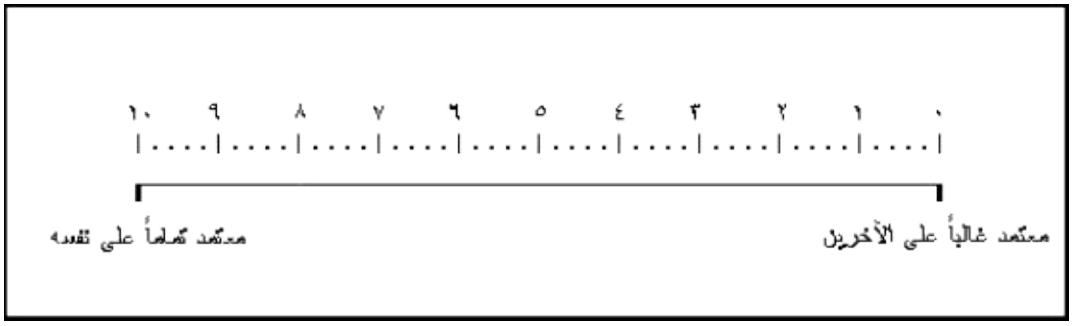
ملخص الاستمارة

حدد آي التصنيفات الآتية تلائم الطفل محل التقييم:

- ☐ الطفل معتمد تماما على الآخرين
- ☐ الطفل معتمد إلى حد كبير على الآخرين
- ☐ الطفل معتمد إلى حد ما على الآخرين
- ☐ الطفل معتمد نسبيا على الآخرين
- ☐ الطفل معتمد غالبا على نفسه

المقيـــــاس التمثيلـــــي البصـــــري

من فضلك حدد مستوى اعتماد الطفل على ذاته فى كل من النواحى التالية (الطعام و الشراب، التحكم في الإخراج، وضع الجسم، الخ.....) بوضع علامة فى المسافة المناسبة لذلك



شكراً

CURRICULUM VITAE

Personal Data

Name	Hanan Mohamed Mohamed Tork
Date of Birth	01.08.1970
Place of Birth	Alexandria, Egypt
Nationality	Egyptian
Martial status	Married
E-Mail	hannan.tork@charite.de hatork@yahoo.com
Business address	Faculty of Nursing, El-Zagazig University, El-Zagazig, El-Sharkia Governorate, Egypt.
Telephone No.	(2055) 2318833
Current Position	Assistant Lecturer, Dept. of Paediatric Nursing, Faculty of Nursing, El-Zagazig University, Egypt.

Education

1976 – 1988	Primary, Preparatory and Secondary Schools, Alexandria, Egypt.
1988 – 1993	**B.Sc.** degree in Nursing Science, The degree awarded by El-Zagazig University with Grade of "very good".
1997 – 2001	**M.Sc.** degree in Paediatric Nursing, degree awarded by Faculty of nursing, El-Zagazig University, Egypt. with Grade of "Excellent" Title of thesis: *Comparative study of Physical care of Mentally and physically disabled and Normal school-age children in Zagazig city.*
2003 – 2007	**PhD,** in nursing care of children degree awarded by

Charité-Universitätsmedizin, Berlin, Germany

Title of thesis: "*Care Dependency of Children in Germany and in Egypt-a Comparative Study"*. The Study in Germany was supported financially by fellowship from the Egyptian Mission.

Professional Experience

1992 – 1993	Clinical training in different departments in" Nasr city Hospital", Cairo, Egypt.
1993 – 1995	Head nurse in the coronary care unit of Nasr cityHospital for Health Insurance, Cairo, Egypt.
1995 – 2001	**Demonstrator**, Dept. of Paediatric Nursing, Faculty of Nursing, El-Zagazig University, Egypt.
2001 – 2002	**Assistant Lecturer**, Dept. of Paediatric Nursing, Faculty of Nursing, El-Zagazig University, Egypt.

Training Courses

Mai – July 2000	**Lecturer preparation,** El-Zagazig University, Egypt.
October 2001	**Staff development,** Faculty of Nursing, Cairo University, Egypt

Languages

English, German

Computer Information

MS-Office (word, Excel, Power point), Internet Explorer, Acrobat, SPSS

Publications and Presentations

Scientific articles

Tork H, Dassen T, & Lohrmann C. (2007): Care Dependency among School-Age Children: Literature review. *Nursing and Health Sciences*. 9, 142 - 49.

Tork H, Lohrmann C, & Dassen T. (2007): Care Dependency of Children in Egypt. In print,

Journal of clinical Nursing.

Tork H, Dassen T, & Lohrmann C. (2007): Psychometric testing of the modified Care Dependency Scale among hospitalised school-age children in Germany. In print, *Nursing and Health Sciences*

Presentations

Tork H. *Physical care of disabled school-age children.* 4th Egyptian Paediatric & Child Health Nursing Conference, 4-6 March 2002, Faculty of nursing, Cairo University, Egypt.

Tork H. *Comparative Study of Care Dependency among Children in Germany and in Egypt*

European Doctoral Conference in Nursing Science (4th EDCNS) 3-4 October 2003, Maastricht-Universiteit, Maastricht, Niederland.

Tork H. *A Delphi Study for Modifying the Care dependency Scale*. Promotionsbetreuungs-Programm (Doktor der Pflegewissenschaft) Institut für Medizin-/Pflegepädagogik und Pflegewissenschaft, 18-20 February 2004, Charité–Universitätsmedizin, Berlin, Germany.

Tork H. *Care Dependency among School-Age Children: Literature review*. European Doctoral Conference in Nursing Science (5th EDCNS) 1-2 October 2004 Berlin, Germany.

Tork H. *Care Dependency of German Children*. Institut für Medizin-/Pflegepädagogik und Pflegewissenschaft, 23-24 June 2005 Berlin, Germany.

Tork H. *Care dependency of disabled and non-disabled children in Egypt.* European Doctoral Conference in Nursing Science (7 th EDCNS), 29-30 September 2006, Charité–Universitätsmedizin Berlin.

Tork H. *Care Dependency of Children in Egypt and Germany- a Comparative Study.* PhD Programme Nursing Science, 22-24 January 2007, Maastricht-Universiteit, Maastricht, Niederland.

Tork H. A cross-cultural comparison: testing the Care Dependency Scale for Paediatrics (CDS-P) among school-age children. PhD Programme Nursing Science, 14-16 May 2007, Charité-Universitätsmedizin Berlin.

Erklärung

„Ich, Hanan Tork, erkläre, dass ich die vorgelegte Dissertationsschrift mit dem Thema: „Pflegeabhängigkeit bei Kindern in Deutschland und Ägypten- eine vergleichende Studie“ selbst verfasst und keine anderen als die angegebenen Quellen und Hilfsmittel benutzt, ohne die (unzulässige) Hilfe Dritter verfasst und auch in Teilen keine Kopien anderer Arbeiten dargestellt habe.“

Unterschrift

Datum

10.05.07