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HEALTH-RELATED QUALITY OF LIFE IN SCHOOL CHILDREN

-Validation of Instrument, Child Self Assessment, Parent-Proxy Assessment and School Nursing Documentation of Health Check-ups

by

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HEALTH-RELATED QUALITY OF LIFE IN SCHOOL CHILDREN -validation of instrument, child self assessment, parent-proxy assessment and school nursing documentation of health check-ups

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ABSTRACT

The aims of this study were to validate an international Health-Related Quality of Life (HRQL) instrument, to describe child self and parent-proxy assessed HRQL at child age 10 to 12 and to compare child self assessments with parent-proxy assessments and school nursing documentation. The study is part of the Schools on the Move – research project. In phase one, a cross-cultural translation and validation process was performed to develop a Finnish version of Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0). The process included a two-way translation, cognitive interviews (children n=7, parents n=5) and a survey (children n=1097, parents n=999). In phase two, baseline and follow-up surveys (children n=986, parents n=710) were conducted to describe and compare the child self and parent-proxy assessed HRQL in school children between the ages 10 and 12. Phase three included two separate data, school nurse documented patient records (children n=270) and a survey (children n=986). The relation between child self assessed HRQL and school nursing documentation was evaluated.

Validity and reliability of the Finnish version of PedsQL™ 4.0 was good (Child Self Report α=0.91, Parent-Proxy Report α=0.88). Children reported lower HRQL scores at the emotional (mean 76/80) than the physical (mean 85/89) health domains and significantly lower scores at the age of 10 than 12 (dMean=4, p=<0.001). Agreement between child self and parent-proxy assessment was fragile (r=0,4, p=<0.001) but increased as the child grew from age 10 to 12 years. At health check-ups, school nurses documented frequently children's physical health, such as growth (97%) and posture (98/99%) but seldom emotional issues, such as mood (2/7%).

The PedsQLTM 4.0 is a valid instrument to assess HRQL in Finnish school children although future research is recommended. Children's emotional wellbeing needs future attention. HRQL scores increase during ages between childhood and adolescence. Concordance between child self and parent-proxy assessed HRQL is low. School nursing documentation, related to child health check-ups, is not in line with child self assessed HRQL and emotional issues need more attention.

Keywords: school child, Health-Related Quality of Life, school nurse, nursing documentation

Camilla Laaksonen
KOULULAISTEN TERVEYTEEN LIITTYVÄ ELÄMÄNLAATU -mittarin validointi, lasten itsearvio, vanhempien rinnakkaisarvio ja kouluterveydenhoitajien terveystarkastuksiin liittyvät kirjaukset
Hoitotieteen laitos, lääketieteellinen tiedekunta, Turun yliopisto, Suomi

TIIVISTELMÄ

Tutkimuksen tarkoituksena oli validoida kansainvälinen Terveyteen Liittyvä Elämänlaatu (TLEL) - mittari, kuvata 10-12 vuotiaiden koululaisten itsensä ja vanhempien rinnakkais arvioimaa TLEL:a, sekä vertailla lasten itsearviointia vanhempien rinnakkaisarvioon sekä kouluterveydenhoitajien terveystarkastuksiin liittyviin kirjauksiin. Tutkimus on osa Koulut Liikkeelle –tutkimushanketta. Tutkimuksen ensimmäisessä vaiheessa toteutettiin The Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0) suomenkielisen version käännös ja kulttuurinen validointiprosessi. Prosessi sisälsi kaksivaiheisen käännöksen, kognitiivisia haastatteluja (lapsia n=7, vanhempia n=5), sekä kyselyn (lapsi n=1097, vanhempia n=999). Toisessa vaiheessa toteutettiin alku- ja seurantakysely (lapsia n=986, vanhempia n=710). Vaiheessa kuvattiin ja verrattiin lasten itse- ja vanhempien rinnakkaisarvioimaa TLEL:a 10 ja 12 ikävuoden välillä. Kolmas vaihe sisälsi kaksi erillistä aineistoa, potilasasiakirja- (lapsia n=270) ja kyselyaineiston (lapsia n=986). Vaiheessa vertailtiin lasten itse arvoimaa TLEL:a kouluterveydenhoitajien terveystarkastuksiin liittyviin kirjauksiin.

PedsQL TM 4.0 suomenkielisen version validiteetti ja reliabiliteetti oli hyvä (Lapsen itsearvio $\alpha = 0{,}91$, vanhempien rinnakkaisarvio $\alpha = 0{,}88$). Lapset ilmoittivat heikompia TLEL arvoja henkisen (ka = 76/80) kuin fyysisen (ka = 85/89) terveyden osa-alueilla. Lasten TLEL arviot paranivat merkittävästi 10 ja 12 ikävuoden välillä (ka ero = 4, $p = <0.001$). Lasten itse- ja vanhempien rinnakkaisrvioiden välinen korrelaatio oli heikko ($r = 0{,}4$, $p = <0.001$). Kouluterveydenhoitajat kirjasivat terveystarkastuksissa yleisesti fyysistä terveyttä, kuten kasvua (97%/97%) ja ryhtiä (98/99%), mutta harvoin henkiseen hyvinvointin liittyviä tekijöitä, kuten mielialaa (2/7%).

PedsQL TM 4.0 on luotettava mittari arvioitaessa suomalaisten koululaisten TLEL:a, mutta lisätutkimusta suositellaan. Lasten henkiseen hyvinvointiin tulee kiinnittää erityistä huomiota. Lasten TLEL paranee siirryttäessä lapsuudesta varhaisnuoruuteen. Lasten itse- ja vanhempien rinnakkaisrvioiden välinen yhteys on heikko. Kouluterveydenhoitajien terveystarkastuksiin liittyvät kirjaukset eivät ole linjassa lasten itsearvioimaan TLEL:tuun.

Avainsanat: koululainen, Terveyteen-Liittyvä-Elämänlaatu, TLEL, kouluterveydenhoitaja, hoitotyön kirjaaminen

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ABBREVATIONS

α	Cronbach' s alpha
dMean	Difference in Mean
HRQL	Health-Related Quality of Life
N	Total population
n	Sample
p	p-value
PedsQL™ 4.0	The Pediatric Quality of Life Inventory™ 4.0
r	Pearson correlation coefficient
SD	Standard deviation
t	Paired t-test

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications, which are referred to in the text with Roman numbers I-IV.

I. Laaksonen, C., Aromaa, M., Heinonen, O.J., Suominen, S. & Salanterä, S. 2007. Paediatric health-related quality of life instrument for primary school children: cross-cultural validation. Journal of Advanced Nursing 59(5), 542-550.

II. Laaksonen, C., Aromaa, M., Heinonen, O.J., Koivusilta, L., Koski, P., Suominen, S., Vahlberg, T. & Salanterä, S. 2008. Health related quality of life in 10-year-old schoolchildren. Quality of Life Research 17, 1049-1054.

III. Laaksonen, C., Aromaa, M., Asanti, R., Heinonen, O.J., Koivusilta, L., Koski, P., Suominen, S., Vahlberg, T. & Salanterä, S. 2010. The change in child self-assessed and parent proxy –assessed Health Related Quality of Life (HRQL) in early adolescence (age 10-12). Scandinavian Journal of Public Health 38, 9-16.

IV. Laaksonen, C., Aromaa, M., Suominen, S., Asanti, R., Heinonen, O.J., Koivusilta, L., Koski, P., Liuksila, P-R., Vahlberg, T. & Salanterä, S. The relation between child self reported health and school nursing documentation: descriptive correlational follow-up study. Submitted 15.12.2012

1. INTRODUCTION

Finnish school children are generally in good health though they report suffering from different psychosomatic symptoms quite frequently (School Health Promotion (SHP) Study 2010). Finnish school children also quite frequently use medicines, have diagnosed long term illnesses and are overweight or obese (Hämeen-Anttila et al. 2010, School Health Promotion (SHP) Study 2010). Moreover alarming results concerning the emotional wellbeing among Finnish children and their families have been published (Holmila et al. 2009, Sourander et.al. 2008).

Health-Related Quality of Life (HRQL) has been suggested to be a valid measure in evaluating, predicting and catching health risks in early stage (Eiser & Morse 2001a, Matza et al. 2004). HRQL is based on the WHO definition of multidimensional health (Constitution of the World Health Organization Basic Document) and rely on the supposition that the primary judge of HRQL is the individual whose health is assessed. There are well validated paediatric HRQL assessment tools available internationally but only few available in Finnish. The Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0) has been suggested to be one of the most validated paediatric HRQL tools available internationally (Rajmil et al. 2004, Solans et al. 2008). The tool is valid in assessing HRQL in children from age 5 to 18 (PedsQL™ 4.0).

School health care is responsible for primary health care of school aged children in Finland and aim at supporting the health of the children and their families as well as the health of the whole school as a community. Yearly health check-ups of the school children are provided by the school health care professionals, most of them by the school nurses. According to national regulations, school child health check-ups should take multidimensional health issues, such as physical, social and emotional health into account. The individual needs of the child as well as the family situation should be addressed at the health check-ups according to national regulations. (Government Decree 380/2009, Health care act 1326/2010.)

Knowledge about the realization of school health check-ups is limited and mostly relies on national surveys examining the area from the management point of view (Kivimäki et al. 2007a, 2007 b, Wiss et al. 2007). In the past few years new knowledge about school nursing documentation related to child check-ups has been published (Mäki et al. 2008, 2010). Knowledge is lacking on how children's own assessment of their health associate to the services provided by the school health care.

Knowledge about health in child populations is needed for developing and producing sufficient, high quality health care services for children (Health care act 1326/2010). School aged children are in general capable to give their own assessments of their health and children are to be considered as main informants in questions concerning their health (Varni et al. 2007, Convention of the rights of the child 1990, Act on the Status and

Rights of patients 785/1992). Child age-appropriate, well validated measurement tools are needed to enable high quality research and international comparison. Knowledge about the relation between child self assessed health and school nursing documentation is needed for evaluating and developing the quality of care.

This study was needed as previous knowledge about health and Health-Related Quality of Life in school children between childhood and adolescence was lacking. There was lack of well validated, international measurement tools that would be suitable for epidemiological research in assessing multidimensional health in Finnish school child populations. Knowledge about the relation between child self and parent-proxy assessed health and school nursing documentation was also lacking. In the present study Health-Related Quality of Life (HRQL) was used as the measure to describe health. Child self assessed HRQL was described and followed from ages 10 to 12 and compared to parent-proxy assessments and to school nursing documentation related to child health check-ups. HRQL was assessed utilizing The Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0).

2. LITERATURE SEARCH

Literature search was performed to define main concepts, search for previous knowledge and identify gaps in the existing knowledge. An information specialist was consulted when the first (search 1.) and second (search 2.) search were performed in spring 2010.

Search 1. was performed to identify previous research on 1) the HRQL in general population of school aged children, 2) concordance between child and parent-proxy assessed HRQL in general population of school aged children, 3) age specific change in HRQL in general population of school aged children. PubMed (MEDLINE) was searched using search terms "generic health", "Quality of Life"[Mesh] AND "Health"[Mesh] and generic, "health related quality of life" AND generic (limiters: only items with abstracts, English, Child: 6-12 years, Adolescent: 13-18 years, published in the last 10 years). Cinahl was searched using search terms: generic health, health related quality of life AND generic (limiters: Abstract Available; Publication Year from: 2000-2010; English Language; Exclude MEDLINE records; Age Groups: Child, 6-12 years, Adolescence, 13-18 years) and (MH "Adolescent Health" or MH "Child Health") and MH "Quality of Life" (limiters: Abstract Available; English Language; Age Groups: Child, 6-12 years, Adolescence, 13-18 years).

Search 2. was performed to identify previous research on 1) school nursing documentation and 2) relation between school nursing documentation and school child self assessed health. PubMed (MEDLINE) was searched using terms: "Medical Records"[Mesh] AND "School Nursing"[Mesh] (limiters: **P**ublished in the last 10 years, Abstract available). Cinahl was searched using terms: MH "School Health Records" or ((MH "Documentation" or MH "Medical Records" or MH "Nursing Records") and MH "Schools, Nursing") (limiters: Abstract Available Publication Year from: 2000-2010)

In addition literature was searched to gain knowledge about the main concepts: school child, Health-Related Quality of Life (HRQL), school health care, school nurse and nursing documentation. Search was performed utilizing the Medic, Cinahl and PubMed(MEDLINE) data bases, scanning national legislation, national and international documents, guidelines and other similar references relevant to the concepts. Also the University of Turku library collections as well as reference lists of identified references were scanned. Additionally references found in various stages of the doctoral research process and theoretical studies were exploited.

3. LITERATURE REVIEW

3.1. School child

3.1.1. Definition of school child and rights of the child

The Convention of the Rights of the Child defines a child as a human being below the age of eighteen (Convention of the rights of the child 1990). The school child is defined in this study as a person who attends compulsory education (Basic education act 628/1998) at comprehensive schools (grades 1-9). The compulsory education is described in the section 3.1.2.

Children have specially protected rights (Convention of the rights of the child 1990) in addition to the general human rights (United Nations 1948). All children have the right for healthy living and growing conditions, the best health care possible and to primary education. Parents and guardians are mainly responsible for the well being of their child, but service providers, such as schools and health care services, are also responsible for the well being of the children. Service providers are in addition responsible for promoting parents' abilities to take care of their child. (Convention of the rights of the child 1990, Act on the Status and Rights of patients 785/1992, Child welfare act 417/2007.)

School aged children have the right to participate in the decision making concerning themselves as well as the right to knowledge and information (Convention of the rights of the child 1990, The Act on the Status and Rights of patients 785/1992, The Constitution of Finland 731/1999). Health care services need to develop child centred care, including assessment tools, that generate the active involvement of the child as a client and patient (Varni et al. 2007, Government Decree 380/2009, Coyne 2008, Pelander et al. 2009, Salmela et al. 2009).

3.1.2. Compulsory education

Compulsory education in Finland starts the year the child turns seven and lasts for nine years. The compulsory education covers all children living permanently in Finland. The aims of the education are to promote the children's growth to humanity and ethically responsible members of the society, promoting their general learning skills as well as giving them knowledge and skills necessary in life. The compulsory education strives to promote civilization, equality, children's conditions to participate in education and develop themselves in life. The education has to be provided in collaboration to the parents or guardians of the children. (Basic education act 628/1998.)

Municipalities are responsible for organizing the compulsory education (Basic education act 628/1998) and most Finnish children attend public funded schools although private schools also exist (Statistics Finland 2011). In 2010 there were 546 400 children attending

comprehensive schools in Finland and the amount of schools was 3000 (Statistics Finland 2011). The general content of the basic education is defined in the Finnish National Core Curricula for Basic Education but the more specific content is set on the local level (The Finnish National Board for Basic Education).

3.1.3. Child normal development at ages 10 to 12

There are several theories and perspectives to the development in children and different disciplines emphasize different aspects. In this section description of child development is limited to 10-12 year old children being on the border of middle childhood (6-11 years) (Feigelman 2007) and early adolescence (10-13) (Marcell 2007). Physical, cognitive, emotional and social developments are described on a very general level to gain some understanding about the developmental state (Table 1.). According to the bio psychosocial theory physical, emotional, social and cognitive development is closely interlinked with each other (Laine 2002).

Physical development in school age includes the physical growth, that is slow and steady between ages 6 and 10. The weight increases 3-3,5 kilograms and the length 6-7 centimetre per year (Feigelman 2007). In early adolescence, age between 10 and 13, rapid growth starts (Marcell 2007). The on average two year lasting rapid growth period appears in Finnish girls approximately at the age of 12 and boys at the age of 14.The muscular strength and fat tissue grow rapidly and the gross motor skills are well developed. By the age of twelve also fine motor skills are close to the adult level. Puberty starts to occur slowly between ages 10 and 12. (Feigelman 2007, Marcell 2007).

Cognitive development is fast in the school age and logical thinking on an abstract level is usually possible by the age of 12. The child is interested in learning and cognitive learning processes start to develop rapidly from the first school years. By the age of 10 children should read fluently and be able to understand what they read. The child gets interested in knowing things beyond the closest living environment and starts to understand the value and use of money. The level of cognitive development also enables the child to think about consequences and understand quite abstract constructs resulting in a high ability to make conscious decisions even in fairly complicated situations. (Feigelman 2007.) In early adolescence moral thinking develop to include the consequential aspect (Marcell 2007) in addition to the previous normative aspect. The age between middle childhood and early adolescence is seen as a very important stage in the development of values (Laine 2002). Cognitive development in the school age also provides the ability for self-evaluation and making perceptions about how others see one self. (Feigelman 2007, Marcell 2007).

Social and emotional development is strongly connected to the occurrence of the child starting to move towards friends and grow more independent from the family (Feigelman 2007). School is an important growing environment of a school aged child and the school provides opportunities for the child to develop and practice multiple skills, including

social and emotional skills. It is however notable that some children experience school more important than others and that the role of the school in individual children's social development may vary (Kaivosoja 2002). Friends, school and other societies outside the family start to become growingly important and the child seeks acceptance outside the family. The self-consciousness of physical appearance and attractiveness increase, self-esteem becomes a central issue and the child starts to compare herself to others. The self-confidence of the child develops rapidly and the child wants to gain responsibility. Parents are in a central role in setting new limits that promote a healthy and secure start in the child's more independent life. The 10-12 year old child show increased need for privacy (Feigelman 2007, Marcell 2007). The age between middle childhood and early adolescence is seen as a very important stage in the development of values (Laine 2002). The child between the ages 10-12 is typically emotionally balanced, socially active and interested in new things and environments (Laine 2002).

Table 1. Summary of child normal development at ages 10 to 12

Physical development	growth	slow and steady at ages 6 -10, height increases 6-7 cm and weight 3-3,5 kg/year rapid growth period starts at ages 10-13 and lasts about two years
	puberty	starts to occur between ages 10-12
	fine motor	about adult level at age 12
	gross motor	about adult level
Cognitive development	thinking	logical thinking on abstract level by age 12 understanding of value and use of money develops
	learning	great interest in learning cognitive learning processes develop rapidly interested in knowing things beyond the closest living environment
	reading	fluent reading by age 10
	moral thinking	well developed by age 12 important age in the development of internal values
	consciousness	ability to think about consequences and understand abstract constructs enables conscious decisions ability for self-evaluation and making perceptions about how others see one self
Social and emotional development	family	parents role in setting new limits that promote a healthy and secure start in the child's more independent life
	friends	growing influence
	school	important environment for cognitive, social and emotional growth
	physical appearance	self-consciousness of physical appearance and attractiveness increase
	self-esteem and self-confidence	central issues significant comparison of self to others need for increased responses
	emotional state	emotionally balanced, socially active and interested in new things and environments

3.2. Health-Related Quality of Life

3.2.1. Definition of Health-Related Quality of Life

The concept Health-Related Quality of Life originates from the concept Quality of Life. The concept Quality of Life bases on the idea of Aristoteles (384–322 BC.) that ”good life” equals to ”happy life” (Fayers & Machin 2000). According to Aristoteles ”good life” requires misfortune or challenges to some extent. This idea still emerges in some philosophical discussions related to the concept Quality of Life. (Eiser & Morse 2001a.) In the 19th century Quality of Life was increasingly used in several sciences, such social- , medical- (Fayers & Machin 2000.) and nursing science (Meeberg 1993, Rustøen et al. 1999, Anderson & Burckhardt 1999, Haas 1999, Sarvimäki & Stenbock-Hult 2000, Sousa & Williamson 2003, Moons 2004.)

There is no unequivocal definition of Quality of Life and different definitions and operationalizations of the concept exist in different sciences, even within one science. The concept is used eg. in nursing research fairly often, but rarely clearly defined or the definitions significantly differ from each other (Meeberg 1993, Anderson & Burckhardt 1999, Haas 1999, Rustøen et al. 1999). For example Sarvimäki & Stenbock-Hult (2000) define Quality of Life as a subjective experience of wellbeing, meaning fullness, value and self-esteem when Haas (1999) defines the concept as a subjective experience of physical, emotional, social and spiritual wellbeing.

The concept Health-Related Quality of Life was introduced in early 19th century and base on the World Health Organization definition of multidimensional health (Constitution of the World Health Organization Basic Document) including physical, emotional and social dimensions (Felder-Puig et al. 2004, Rajmil et al. 2004). The concept refers particularly to the influence of health and sickness on the general or total life quality (Eiser & Morse 2001a). Assessing HRQL bases on the assumption that the main informant of HRQL is the person her self whose health is assessed. Proxy assessments are used when self assessments are impossible or support is needed eg. due to respondents young age or cognitive or emotional disabilities. (Fayers & Machin 2000.)

Even if the concept HRQL traditionally was introduced within the medical field, it can also be adapted to nursing. The WHO definition of health (that the concept HRQL base on) is considered in nursing and nursing science as one of several acceptable health definitions (Roper et al. 1990). Nursing science stresses on observing the subjective experience of health (Roper et al. 1990, Lauri & Elomaa 1995), that also emerges in the basic assumptions of assessing HRQL (Carr et al. 2001, Carr & Higginson 2001, Moons 2004). As HRQL focuses basically on the health dimension of the total Quality of Life, one may argue that HRQL focus directly on one of the central concepts in the paradigm of nursing and nursing science (Henderson 1966, Rogers 1970, King 1981, Roper et al.1990, Lauri & Elomaa 1995, Sousa & Williamson 2003).

3.2.2. Factors associated with Health-Related Quality of Life

Previous studies, conducted in normal population adult samples, suggest that HRQL is associated with several factors, such as psychiatric diagnoses, different chronic conditions, mortality, body mass index, physical activity and future health care costs and use of services (Alonso et al. 2004, Parkerson et al. 2005, Acree et al. 2006, Kaplan et al. 2007, Salaffi et al. 2009, Serrano-Aguilar et al. 2009, Saharinen et al. 2010, Garner et al. 2011). Previous knowledge about factors associated with HRQL in normal population paediatric samples is however somewhat lacking.

There are controversial results about the gender and age influencing child HRQL. Girls tend to assess lower emotional well being than boys (Reinfjell et al. 2006, Upton et al. 2005, Marklund et al. 2006.) and older children may assess higher, indicating better, HRQL compared to younger children (Reinfjell et al. 2006). Some previous studies however show no significant associations between child gender or age and HRQL (Schwimmer et al. 2003, Russell et al. 2006, Varni et al. 2006, 2007).

Psychological factors, such as optimism and pessimism, have been suggested to be associated with HRQL both in cancer as well as healthy samples of children (Williams et al. 2010). Being bullied as well as having bullied someone else impact negatively on adolescent HRQL (Frisen & Bjarnelind 2010). Overweight and physical inactivity have also been suggested to be associated with low HRQL in adolescents (Swallen et al. 2005) as well as sleepiness, depressed mood and sleep- problem behaviours (Tzischinsky & Shochat 2011). Chronic childhood diseases and symptoms are associated with child HRQL. Beattie & Lewis-Jones (2006) compared HRQL of children with dermatologic disease and other chronic conditions. Children with cerebral palsy were found to have the lowest HRQL, followed by generalized AD, renal disease, cystic fibrosis, urticaria, asthma, psoriasis, epilepsy and diabetes. Children diagnosed with acne, alopecia and localized eczema had the highest HRQL compared to the children with other types of dermatological diseases or other chronic conditions. Marklund et al. (2006) found that the clinical condition itself, food hypersensitivity, did not associate to low HRQL as significantly as did the perceived risk of food reactions and measures to avoid them.

Family economic status and high parental education level seem to be positively associated with child HRQL (von Rueden et al. 2006). Parent-proxy assessed HRQL seem to be strongly associated with child health service use as well as health care costs (Rajmil et al. 2006).

3.2.3. Assessing Health-Related Quality of Life

Health-Related Quality of Life is commonly assessed both in clinical, organizational and political fields. HRQL is most often assessed utilizing standardized assessment tools and there are numerous different tools available (Sousa & Williamson 2003, Moons 2004). For example there are at the Quality of Life Instruments Database almost 700 instruments available for assessing HRQL in different populations (PROQOLID 2011).

Despite the huge amount of HRQL assessment tools, several questions still exist in assessing the concept. One main question relate to the operationalization of the concept. Even if some agreement exists on the concept being based on the WHO definition of health (Constitution of the World Health Organization Basic Document), variables addressing different health dimensions, eg. physical or emotional health have not been commonly identified. The lack of a well developed, common definition of HRQL results in challenges to reliably assess, interpret and exploit the results (Sousa & Williamson 2003).

Health-Related Quality of Life in adult population has commonly been assessed since 1970s and assessment of pediatric HRQL gained interest in 1990s (Felder-Puig et al. 2004). The first studies on pediatric HRQL in 1980s concerned children with cancer and children who had been in intensive care as newborn (Eiser & Morse 2001a). Discussion exists in the literature about the age of children being capable of giving self assessments of HRQL as well as the validity of these assessments and the role of parent-proxy assessments (Eiser & Morse 2001b, Matza et al. 2004, Varni et al. 2007). Previous research has found that even young children, age 5 and above, are capable of giving valid self assessments of their HRQL if the instrument is age appropriate. It has however been recommended that parent-proxy assessments should be used as validation base or additional information for the self assessments of children younger than 9 years. (Varni et al. 2007.)

Paediatric HRQL assessment tools can be classified into two groups; generic and disease specific (Raat et al. 2006) questionnaires. Generic tools intend to assess all dimensions of HRQL and can be applied both in healthy and in clinical populations. Generic tools offer possibilities to assess HRQL in normal child populations, compare clinical groups to normal populations and enables comparison between different clinical groups. (Eiser & Morse 2001a.)

3.2.4. Generic paediatric Health-Related Quality of Life assessment tools

According to a systematic literature review, performed by Solans et al (2008), there has been a considerable growth in the amount of both generic and especially disease specific pediatric HRQL assessment tools during the 21st century. There were 30 generic and 67 disease specific paediatric HRQL assessment tools found in 2005. Most of the tools met acceptable psychometric criteria but only few were tested for test-retest reliability, sensitivity for change, or structural validity (Solans et al. 2008.)

When analyzing the content of the available paediatric HRQL assessment tools, significant differences between tools were found. The only common feature seems to be that most tools include items referring to physical, emotional and social health aspects. The distribution of the items however varies considerably as well as the focus of the assessment. Some paediatric HRQL measurement tools focus on the satisfaction experienced by the individual in relation to her expectations. Others focus on the level of

functioning or abilities to perform certain activities. Considerable differences also exist in the items assigned to the domains, time to complete (vary between 5-30 minutes) as well as the child involvement in the development process of the instruments (Rajmil et al. 2004, Solans et al. 2008). The lowest age group for self assessments is 5 years. Most tools include both child self- and parent-proxy reports (Solans et al. 2008).

Few generic paediatric HRQL assessment tools are available in Finnish. The Health State Descriptive System, 16D for children age 8-11 and 17D for adolescent age 12-15, have been developed in Finland (Apajasalo et al. 1996a, 1996b). The originally Finnish tools have been validated only for content validity (Solans et al. 2008).

The Child Health Questionnaire (CHQ, Pelkonen et al. 2001) and the Nordic Quality of Life Questionnaire for Children (Lindström & Kohler 1999) have been translated into Finnish. The Child Health Questionnaire (CHQ) has been considered as a well validated tool (Solans et al. 2008) but only translated and validated in Finland for the parent-proxy report form (CHQ, Pelkonen et al. 2001). The validity of the Nordic Quality of Life Questionnaire for Children has only been tested for content validity (Solans et al. 2008).

The Pediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) child- and parent- proxy reports were translated into Finnish, validated and used in this study. At present time there also exists an other Finnish version of the PedsQL ™ 4.0 translated and validated by other actors (PedsQL ™ 4.0). The PedsQL™ 4.0 is described in more detail in the next section and the translation and validation process of the Finnish version of the instrument is described in the methods section.

3.2.5. The Paediatric Quality of Life Inventory ™ 4.0

The Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) has originally been developed in the USA and it bases on the World Health Organization definition of health (Constitution of the World Health Organization Basic Document). The instrument has been developed to measure generic HRQL in paediatric (ages 2-18) populations and provides both child self and parent proxy –report forms. (PedsQL ™ 4.0, Varni et al. 1999, 2001.) The instrument has been translated and cross-culturally validated in more than 30 languages (PedsQL ™ 4.0.), including Scandinavian countries, Norway (Reinfjell et al. 2006).

The PedsQL™ 4.0 comprise of five dimensions: physical, psychosocial, emotional, social and school functioning. The instrument consists of 23 items encompassing the total HRQL as well as summary scores (physical and psychosocial) and sub scales scores (physical, emotional, social and school functioning). The respondent is instructed to recall certain problems that might have occurred during the past one month. The responding scale is a 5-point Likert scale rating from “never” (0) to “almost always” (4). (PedsQL ™ 4.0.) The cross-cultural translation and validation process of PedsQL™ 4.0 is described in the section 3.2.7 .

3.2.6. Translating and validating international assessment tools

There are several different types of translation: pragmatic, aesthetic-poetic, ethnographic and linguistic translations. In the pragmatic translations, the main issue is to communicate the content of the original tool into the translated version. This type of translation is suitable for eg. translating written form patient education material. The aesthetic-poetic translations aim at transferring the atmosphere and evoke moods and feelings held in the original version to the translated one. Ethnographic translations aim at maintaining equal cultural content and meaning between the original and translated version. Linguistic translations aim at grammatical equivalence between the original and translated version. (Burns & Grove 2009.) The translation and validation process of the Finnish version of The Paediatric Quality of Life Inventory ™ 4.0 described in the methods section, included both ethnographic and linguistic translation.

Validity of an instrument in general can be determined by the extent to which it captures the abstract construct being assessed. Validity can be considered as a broad concept that can be sliced into three main types: content, criterion-related and construct validity. (Burns & Grove 2009, Parahoo 2006, Polit & Beck 2006.) Validity of an instrument is not an all-or-nothing phenomenon but a matter of estimation and degree (Burns & Grove 2009).

Content validity refers to the extent to which the assessment tool includes relevant elements of the construct being measured. The evidence for content validity is obtained from sources, such as previous literature, content experts and the relevant population. The content validity of an instrument is based on judgement as no objective measures to test content validity exist. Relevant questions for observing content validity of an instrument are: 1. are the items of the instrument relevant and appropriate in terms of the construct, 2. are the items adequately measuring all dimensions of the construct. (Burns & Grove 2009, Polit & Beck 2006.) Readability and comprehensibility may also be identified as parts of content validity (Burns & Grove 2009). Calculating the content Validity Index (CVI) provides a checklist for rating questionnaire items and calculating an index of content validity based on the agreement of a panel of experts (Parahoo 2006). The content validity and readability of the Finnish version of The Paediatric Quality of Life Inventory ™ 4.0 were examined in this study and are described in the methods section.

Criterion-related validity emphases on establishing the relationship between the phenomena assessed by the instrument and some other phenomena. The key issue is whether the instrument predicts subsequent behaviours, experiences or conditions. Criterion-related validity can be sliced into two types: predictive and concurrent validity. Predictive validity refers to the ability of the instrument to differentiate the character, behaviour or performance of an individual on some future criterion. Concurrent validity refers to the ability of an instrument to distinguish individuals who differ in their present character, behaviour or performance on some criterion. (Parahoo 2006, Polit & Beck

2006.) Predictive validity of the Finnish version of The Paediatric Quality of Life Inventory ™ 4.0 was examined in this study and is described in the methods section.

Construct validity is the most sophisticated but at the same most challenging type of validity both to establish and to test. Construct validity is the link between theory and theoretical conceptualization of the instrument and assessment of the existing phenomena. Construct validity can be observed in several different ways such as known-groups technique, factor analysis, convergent validity and divergent validity. (Burns & Grove 2009). The construct validity of the Finnish version of The Paediatric Quality of Life Inventory ™ 4.0 was examined for the convergent validity and is described in the methods section.

Cross-cultural translation and validation process requires time, careful planning and rigorous methodology (Sousa & Rojjanasrirat 2011). The aim for translating and validating an assessment tool to a new language and culture is to assure highest possible equivalence between the original and the translated tool (Beaton et al. 2000, Corless et al. 2001, Bowden & Fox-Rushby 2003, Maneesriwongul & Dixon 2004). A carefully performed translation process alone does not ensure sufficient equivalence between the original and translated tool and validation is an essential part of a sophisticated cross-cultural translation and validation processes (Beaton et al. 2000, Sousa & Rojjanasrirat 2011). Equivalence can be addressed regarding eg. concepts, constructs and cultural equivalence (Beaton et al. 2000).

Several sophisticated guidelines exist for performing the translation and validation process of international instruments (Beaton et al. 2000, Corless et al. 2001, Bowden & Fox-Rushby 2003, Hilton & Skrutkowski 2002, Maneesriwongul & Dixon 2004). Sousa & Rojjanasrirat (2011) for example suggest a seven phase process including a carefully performed translation process, pilot testing, preliminary psychometric testing and full psychometric testing. Despite well established methods for translating and validating instruments, a great variation in the use of these recommended approaches exist. There is also a big variation in the quality of translators as well as reporting the translation and validation process. (Maneersriwongul & Dixon 2004, Sousa & Roijjanasrirat 2011).

3.2.7. Translating and cross-cultural validation of The Paediatric Quality of Life Inventory ™ 4.0

The cross-cultural translation and validation process of The Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) has been standardized by the copyright holder. The process includes three phases: 1. forward translation (from original to "new" language), 2. backward (from "new" back to original language) translation, 3. patient testing (cognitive interviews). The translations are recommended to be performed by qualified translators and the developer of the original instrument should be involved in the translating process. The developer of the original instrument also makes recommendations regarding the patient testing phase and utilization of the cognitive interviews. (The PedsQL Linguistic Validation Protocol.) Cognitive interviewing as a method is described in the section 5.5.1.

3.3. Health-Related Quality of Life in school children (age 6-15)

There is very little previous knowledge about HRQL in general school child populations and no previous research was found describing HRQL in a total cohort of general primary school children age 10-12 years. Previous studies suggest that perceptions of health decrease as the child grows from childhood to adolescence (Berntsson & Köhler 2001, Cavallo et al. 2006) but HRQL self assessments seem not to change significantly (Varni et al. 2006, 2007) or even increase (Reinfjell et al. 2006) as the children grow. The change in HRQL scores may be a result of greater conceptual skills or other cognitive processes involved in assessing as well as responding (Cremeens et al. 2006). Previous studies however show that children as young as five can give a valid self-assessment of their HRQL (Varni et al. 2007).

Child self assessed HRQL scores in general school child populations tend to be higher (indicating better HRQL) in physical and social functioning scales than in the emotional scales (Varni et al. 2006, Upton et al. 2005, Reinfjell et al. 2006). Several studies show no gender specific differences in HRQL assessments (Varni et al. 2006, Russell et al. 2006, Schwimmer et al. 2003) but also controversial suggestions exist (Robitail et al. 2006). In some previous studies girls have reported lower emotional but higher total HRQL scores compared to boys (Reinfjell et al. 2006, Upton et al. 2005, Marklund et al. 2006.). Some results also show girls reporting lower total HRQL scores than boys (Simeoni et al. 2001.)

The role of the parent-proxy assessments as well as the meaning of child-parent agreement has been widely discussed in the literature (Cremeens et al. 2006, Upton et al. 2008). Previous studies show diverging results on how parents assess the HRQL of their child. It has been suggested that parent-proxy assessments of HRQL are higher than child self assessments in normal population samples (Reinfjell et al. 2006, Varni et al. 2006) but lower if the child suffers from some chronic condition (Eiser & Morse 2001a). However controversial findings exist that suggest parent-proxy assessments being higher than the child self assessments even if the child suffers from a chronic condition such as food-allergy (van der Velde et al. 2011).

There are diverging results on the concordance between child self and parent-proxy assessments. Concordance between child self and parent-proxy assessments seem generally to be fragile (Upton et al. 2008) but also controversial findings exist suggesting fairly high equivalence between child self and parent-proxy assessments (Matza et al. 2004). It has been suggested that the concordance would be higher in the observable, physical domains as well as in cases where the child suffers from a chronic condition than in healthy child populations (Eiser & Morse 2001b, Robitail et al 2006). Child-parent concordance seems to increase as the age of the child increases (Creemens et al. 2006, Robitail et al. 2006, Varni et al. 2006, 2007). Agreement between child self and parent-proxy assessments has been suggested to depend on the country (Robitail et al. 2007).

It is commonly recommended that the children are to be the first and most important informants about their HRQL. Parent-proxy reports are however recommended as

validation bases or background information especially regarding young (age under 9) children's assessments. (Creemens et al. 2006, Varni et al. 2007, Upton et al. 2008.)

3.4. School health care

Municipalities are responsible for providing school health care services for children attending primary school. The services include promotion and evaluation of a healthy and safe school environment, providing yearly child health check-ups, promoting parents, oral health services and early detection and early intervention of special needs. (Health care act 1326/2010.)

School health care services are publicly funded services that are intended for school children and their families. School health care services are basically located at the schools and provided during school hours. The services include actions related to primary prevention of health risks, health promotion, preventive and curative health care services, including dental care, multi professional collaboration as well as services related to the school as a community and learning environment. (Terho 2002a, Government Decree 380/2009, Health care act 1326/2010). School child health check-ups are common preventive health care services provided by the school health care (Government Decree 380/2009, Health care act 1326/2010, Mäki et al. 2011) and are more precisely described in section 3.4.1. as they are in the focus of this study.

Previous research has been exploring school health services from aspects such as management (Kivimäki et al. 2007a, Rimpelä et al. 2008), amount of personnel (Wiss et al. 2007, Rimpelä et al. 2008) and amount of visits to school health care professionals (Kivimäki et al. 2007b, Rimpelä et al. 2008). Only little is known about the clinical quality or content of the school health care services (Mäki et al. 2008, 2010).

3.4.1. School child health check-ups

School child health check-ups have been central activities since the early years of the school health care services. At the beginning of the 20th century health check-ups were performed to screen infectious diseases such as tuberculosis and physical health. In the 1970's attention toward health education and health promotion increased in preventive child health care services, including school health care (Terho 2002b). In the late 20th and early 21st century attention was expanded to a more holistic approach to health including the growing attention for emotional health issues, environmental health, patient and family centred care (Government Decree 380/2009, Health care act 1326/2010, Mäki et al. 2011).

According to national legislation school child check-ups are performed yearly and the 1st, 5th and 8th grade health check-ups are extended. Health check-ups shall contain an age and individual specific, holistic evaluation of the health, development and wellbeing of the child, a care need assessment and a further care plan. The evaluation, assessment

and further planning shall be performed in close collaboration with the child and if needed also with the family. Bullying and child abuse issues shall be observed at health check-ups and methods to capture the children's self assessments of their health shall be systematically developed. (Government Decree 380/2009, Mäki et al. 2011.)

Health check-ups are commonly performed by school nurses and the extended health check-ups are performed in collaboration with the school physician. According to a previous study there is wide variety between municipalities in the specific content of school child health check-ups. Need for congruent content, measurement instruments as well as documentation regarding school health check-ups have been expressed (LATE –project, Mäki et al. 2008, 2010.) A handbook for performing school child health check-ups has been published in 2011 (Mäki et al. 2011).

3.4.2. Role of the school nurse

Internationally school nurses hold different roles and provide different types of services (Ruski 2002, Croghan et al. 2004, Council of school health 2008). In Finland school nurses are public health nurses that provide preventive and curative health care services to school children. In some municipalities, school nurses work entirely in school nursing practice, in others school nurses may partly work in school nursing and partly at well-baby clinics or within home health care services (Ruski 2002). No national registry exists on the amount of school nurses in Finland.

School nurses are responsible for the school nursing. The school nursing can be described as a process including the client (school children and their families), collaborative partners (school physician, teachers, other school personnel etc.), organizational aspects (environment, recourses, collaboration, equipment), helping process and outcomes (well-being, health and learning outcomes). School physicians are responsible for the medical aspect of school health care and close collaboration between the school nurse and school physician is essential for high quality school health care (Ruski 2002).

3.4.3. School nursing documentation

Nursing has been identified since late 1970s by nursing theories as a profession that lay on planned, effective problem solving and information and nursing documentation has been regarded as a precondition for high quality nursing (Moen 2003, Lindström et al. 2006). At present time there is a growing interest in developing electronic nursing documentation (Moen 2003). According to a Cochrane review on effective nursing record systems, it seems that record systems may help solving specific problems related to documentation, such as lack of documentation of pain but the knowledge on how nursing documentation systems actually effect on the nursing care or the wellbeing of patients is lacking (Urcuhart et al. 2009). Häyrinen et al. (2008) suggest that studies evaluating electronic health records stress on evaluating the completeness or accuracy

of different types of information systems and future studies are suggested on evaluating the content of these systems.

Although the well accepted argument of nursing documentation being an essential part of high quality nursing care, the quality of nursing documentation has been suggested to be somewhat fragile. Electronic health records have been found to present mostly physical needs or medical issues and lacking a more holistic, patient centred content and issues relevant for nursing (Kärkkäinen & Erkisson 2003, Törnvall et al. 2004, Voutilainen et al. 2004, Kärkkäinen et al. 2005). Laitinen et al. (2010) concluded that electronic patient records only partly reflect patient centeredness and patient-focused care.

Structured nursing terminology has been suggested to effect positively on the quality of documentation as well as use of nursing process and nursing terminology (Saranto & Kinnunen 2009). There may however bee insufficient documentation also in the structured documentation system, such as stressing on physical and medical aspects and not supporting the nursing process and patient centred care (Törnvall et al. 2004).

According to the Finnish legislation health care professionals are obligated to document relevant information about providing care, such as health check-ups, in the patient record system. The patient records shall contain all relevant information about planning, providing and monitoring the care or treatment of the client. Documentation in the patient records shall be done without delay and errors. (Act on Status and Rights of patients 785/1992, Personal data act 523/1999.)

Little previous research has been published related to school nursing documentation. School nursing documentation has been evaluated eg. as means for monitoring child and adolescent growth and evaluating asthma prevalence and asthma care interventions (Knorr et al. 2004, Logue et al. 2007, Werner et al. 2007, Werner & Bodil 2007).

The effects of implementing diagnoses from North American Nursing Diagnosis Association International, interventions from the Nursing Interventions Classification, and outcomes from the Nursing Outcomes Classification (referred to as NNN) have been evaluated in school health care settings. According to the study school nurses' focused on health promotion and management of health risks. Health problems were identified and treated. The study suggests that using NNN help nurses to identify diagnoses, interventions, and outcomes relevant for school health care settings. (Lunney 2006). The feasibility of the effects of using terms from NANDA, NIC, and NOC was tested in a pilot study. The study suggests that using NANDA; NIC and NOC terms improved the nurses' ability to provide care for school children. (Lunney et al. 2004). A study has also been conducted to determine school nurses' perceptions of the relevance of outcomes developed by the Nursing Outcomes Classification (NOC) research team to school nursing practice (Cavendish et al. 2001).

School nursing documentation has also been studied by evaluating school child absence and nurses' interventions to prevent the absences. The study suggests that nurses were

involved with most of high-absence students but according to the documentation, no referrals to the school nurse for absenteeism or school nurse intervening in high school absences of the school child, were found. The school nurse documentation was sparse and mostly task related. Few documents contained information about nursing diagnoses, interventions, or outcomes of the care. There was not enough documentation to evaluate effectiveness of the care nor did the record system support the nursing care process. (Weismuller et al. 2007.)

Previous research on school nurses' views of the health of school children and attitudes towards documenting, suggest nurses to view children being physically healthy but increasingly suffering from psychosocial and mental problems (Clausson et al. 2003, Clausson et al. 2008a). School nurses however perceive ethical challenges in documenting psychosocial health as well as family situations, mental problems, behavioral problems and school situations. (Clausson et al. 2003, Clausson et al. 2008b). No previous research on the relation between school nursing documentation and child self assessed health was identified.

A national study suggests that nurses at well-baby clinics and school health care settings systematically document physical issues, such as length and weight of children. Puberty and posture is not assessed as systematically. The contents of the check-ups differ significantly even inside one municipality. Several different electronic patient record systems are used in documentation. According to the study, nurses have got education on documentation in electronic patient record systems. (Mäki et al. 2008, 2010.)

3.5. Summary of the literature review

Children aged 10 to 12 years are at the border between childhood and early adolescence (Feigelman 2007, Marcell 2007). They have the right to be seen as active members of the society and consumers of health care services (Act on the Status and Rights of patients 785/1992, Convention of the rights of the child 1999, Child welfare act 417/2007). Assessing HRQL in school children may generate patient centered care, promote early detection of health problems and early intervention as well as help focusing health care services and prediction of future health care needs (Eiser & Morse 2001a, Moons 2004).

Children aged 10 to 12 are able to give valid self assessments of their HRQL (Varni et al. 2007). Concordance between child self and parent-proxy assessed HRQL vary but seem to be fragile and it is commonly recommended that the children are to be the first and most important informants about their HRQL. Parent-proxy assessments are recommended as validation bases or background information especially regarding young children's self assessments. (Creemens et al. 2006, Varni et al. 2007, Upton et al. 2008.) No previous studies following the development of HRQL in total cohorts of primary school child populations were identified.

Internationally validated measurement tools enable international comparison as well as utilization of international research. Pediatric Quality of Life Inventory TM 4.0 (PedsQL™ 4.0) is a sophisticated, well validated, cross-culturally utilized measurement tool for assessing HRQL in 8-12 year old children (Varni et al. 1999, 2001, 2006). No previous Finnish version of Pediatric Quality of Life Inventory TM 4.0 existed at the beginning of this research.

School health care services are regulated to provide health check-ups that include a holistic evaluation of the health and well-being of the individual child and her family (Government Decree 380/2009, THL 2011). Documentation is a central feature of high quality nursing and all relevant information concerning provision of care has to be documented (Act on Status and Rights of patients 785/1992, Personal data act 523/1999). Documentation is centrally related to the decision making process of nursing (Lindsrtöm et al. 2007). Previous research about school nursing documentation suggests problems in documenting emotional and family-related matters (Clausson et al. 2003, 2008b). No previous research was identified describing the association between school nursing documentation and child self assessed health. Summary of the literature review is presented in Tables 2. and 3.

Table 2. Summary of what is already known

Children aged 10-12 in general	- have the right to be seen as active members of the society and consumers of health care services - are able to give valid self assessments of their HRQL - concordance between child self and parent-proxy assessed HRQL vary but seem to be fragile - are to be considered as the first and most important informants about their HRQL
Assessing HRQL in school children	- may generate patient centered care, promote early detection of health problems and early intervention, help focusing health care services and predict future health care needs
Pediatric Quality of Life Inventory TM 4.0 (PedsQL™ 4.0)	- PedsQL™ 4.0 is a well validated, cross-culturally utilized measurement tool for assessing HRQL in 8-12 year old children
School health care	- school health care services are regulated to provide health check-ups that include a holistic evaluation of the health and well-being of the individual child and her family - nursing documentation in the school health care may be fragile
Nursing documentation	- documentation is a central feature of high quality nursing and all relevant information concerning provision of care has to be documented - documentation is centrally related to the decision making process of nursing

Table 3. Summary of what is not yet known

Development of Health-Related Quality of Life (HRQL)	- no previous reports on the development of HRQL in total cohorts of primary school children between ages 10 and 12 was identified - no previous research describing the development of HRQL in total cohorts of Finnish school children was identified
Translating and validating the Finnish version of the Pediatric Quality of Life Inventory TM 4.0 (PedsQL™ 4.0)	- no previous reports of translating and validating the PedsQL™ 4.0 was identified - no previous research utilizing the PedsQL™ 4.0 in Finnish school child populations was identified
Association between nursing documentation and child self assessed health	- no previous research was identified describing the association between school nursing documentation and child self assessed health

4. AIMS OF THE STUDY AND STUDY HYPOTHESES

The aims were to validate an international Health-Related Quality of Life (HRQL) instrument, to describe child self-assessed HRQL at the age of 10 and 12 and to compare child self assessment to parent-proxy assessments and school nursing documentation. The purpose was to support child centred care by increasing knowledge about child's self-assessed health.

The study phase specific sub aims and research questions were:

1) To describe the validity and reliability of the Finnish version of Pediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) (Phase 1.)

   a) What is the content and construct validity of the translated Finnish version of the PedsQL™ 4.0 Child –Self (ages 8-12) and Parent-Proxy (ages 8-12) Reports.
   b) What is the reliability of the translated Finnish version of the PedsQL™ 4.0 Child –Self (ages 8-12) and Parent-Proxy (ages 8-12) Reports.

2) To describe and compare child self- and parent-proxy assessed Health-Related Quality of Life (HRQL) in 4th (mean age 10) and 6th (mean age 12) grade school children (Phase 2.)

   a) What is the child self and parent-proxy assessed HRQL in 10 and 12 year old school children?
   b) How do child self and parent-proxy assessed HRQL develop when children grow from age 10 to 12?
   c) What is the concordance between child self and parent-proxy assessed HRQL?

3) To compare the relation between child self assessed HRQL and school nursing documentation of health check-ups (Phase 3.)

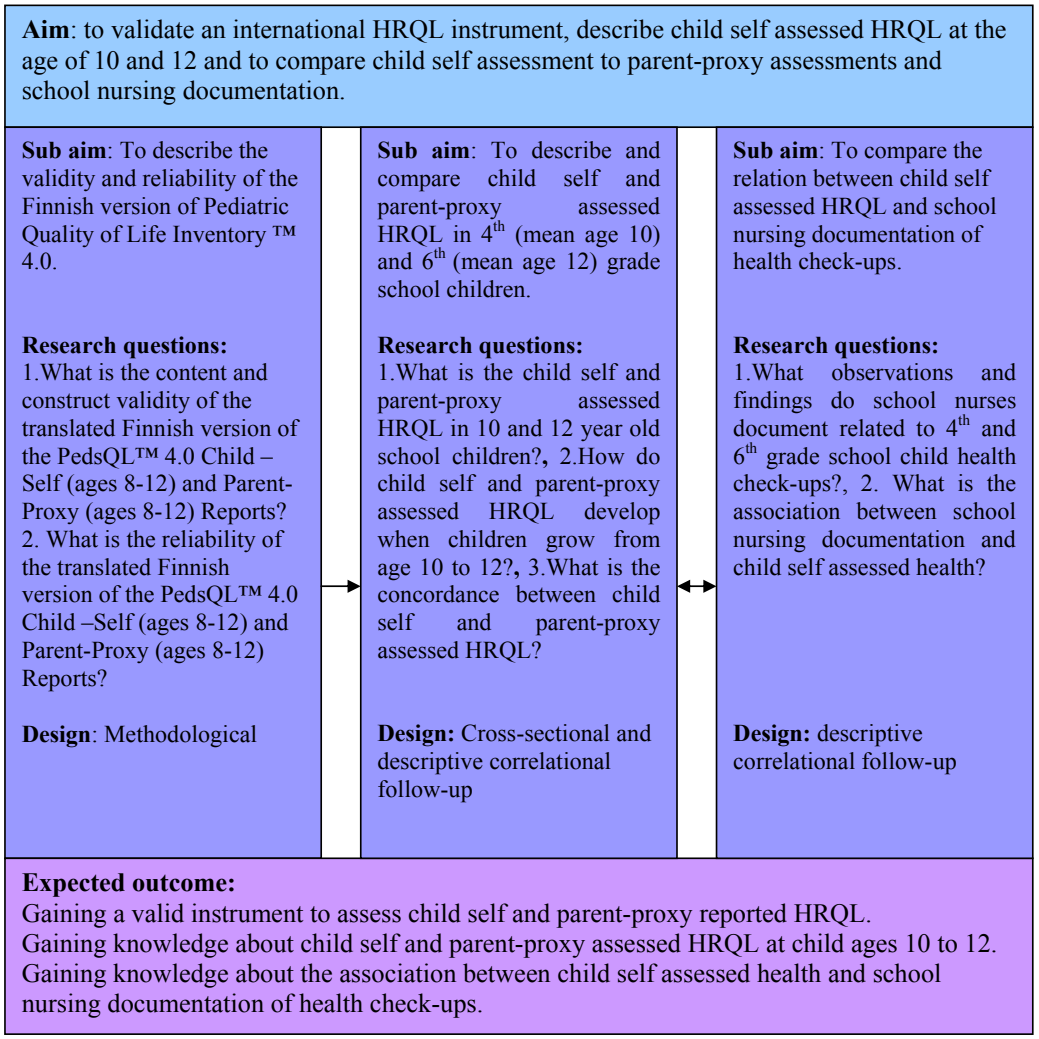
   a) What observations and findings do school nurses document related to 4th and 6th grade school child health check-ups?
   b) What is the association between school nursing documentation and child self assessed health?

The hypothesis of the study was that the Finnish version of the PedsQL ™ 4.0 is a valid tool for assessing HRQL in a general school child population, child self assessments of HRQL change as the children grow and concordance between child self and parent-proxy assessments is fragile. Moreover the hypothesis was that school nurses document multidimensional health issues related to child health check-ups and that nursing documentation is in line with child self assessed health.

5. MATERIAL AND METHODS

5.1. Study design

The study included methodological, cross-sectional and descriptive correlational study designs (Picture 1.). The study comprises of three phases (Picture 2.).



Picture 1. Study aim, sub aims, research questions, designs and expected outcome

Phase 1	**Validity and reliability of the Finnish version of the PedsQL™ 4.0.** Method: Translation process and cognitive interviews 2004 (data A) Baseline 2004 survey as part of the Turku Schools on the Move –project (data B) Population: Children aged 8-12 and their parents (data A.) Children starting 4th grade (child mean age10) in Finnish primary schools in a city of 175 000 inhabitants (n= 1346) and their parents (data B.) Sample: Purposive sampling; children (n=7) and their parents (n=5) (data A.) Total sampling; children (n=1097) and their parents (n=999) (data B.) Measure: Qualitative interview (data A.) Pediatric Quality of Life Inventory (PedsQL ™4.0) (data A. and B.) Analysis: Deductive content analysis (data A.) Statistical analysis (data B.) Report: Paper I
Phase 2	**Health-Related Quality of Life in 4th (mean age 10) and 6th (mean age 12) grade school children** Method: Baseline 2004 and follow-up 2006 surveys as part of Turku Schools on the Move – project (data C.) Population: Children starting 4th grade (child mean age10) in Finnish primary schools in a city of 175 000 inhabitants (n= 1346) and their parents (data C.) Sample: Total sampling of children (n=986) and their parents (n=710) participating at baseline and follow up (data C.) Measure: Pediatric Quality of Life Inventory (PedsQL ™4.0) Analysis: Statistical analysis Report: Papers II-IV
Phase 3	**Association between child self assessed HRQL and school nursing documentation** Method: Baseline 2004 and follow-up 2006 surveys as part of Turku Schools on the Move – project (data C.) Registry data collected from patient records documented by school nurses (data D.) Population: Children starting 4th grade (child mean age10) in Finnish primary schools in a city of 175 000 inhabitants (n= 1346) Sample: Total sampling of children (n=986) participating at baseline and follow up (data C.) Random sample of child (n=270) patient records (school nurse documented health check up summaries) (data D.) Measure: Pediatric Quality of Life Inventory (PedsQL ™4.0) (data C.) Structured data extraction (data D.) Analysis: Statistical (data C.) Data extraction (data D.) Report: Paper IV

Picture 2. The study phases

5.2. Population and sample

The population for the cognitive interviews in phase 1. (data A.) was Finnish speaking school aged children and their parents. The population for the survey in phase 1-3 (data B. and C.) was children who started 4th grade (mean age 10) in autumn 2004 in

Finnish primary schools in a city of 175 000 inhabitants (N=1346) and their parents. The population for the patient record data in phase 3 (data D.) was the same children as for the surveys (data B. and C.).

In phase 1. non-probability, convenience sampling was utilized for cognitive interviews (data A.). The sample comprised of children, aged 8-12 (n=7) and their parents (n=5). The participants were recruited by sending a general information letter about the study to all students of the University of Turku, department of nursing science in autumn 2004. Students who had children aged between 7-12 years and who were willing to participate and who thought their child/children would like to participate contacted the researcher. The potential parent participants were given oral and written form information to enable informed consent both for their child as well as themselves to participate. The children were also given age specific information and their written consent to participate.

In phase 1. total sampling of the children who started 4th grade (mean age 10) in autumn 2004 in Finnish primary schools in a city of 175 000 inhabitants (N=1346) and their parents was utilized for baseline survey data (data B.). The baseline sample in 2004 consisted of children (n=1097, girls n=566, boys n=525; 81% of the study population) who had given their written-form consent and whose guardian, in addition, had given their written-form consent for the child to participate. The sample for parents (n=999) consisted of a parent or guardian who filled out the study questionnaire and whose child belonged to the study population.

In phases 2. and 3. the baseline-follow up sample (data C.) consisted of all children (n=986, girls n=506, boys n=480; 73% of study population) and their parents (n= 710) who participated both at baseline and follow up.

In phase 3. random sampling was utilized for the patient records (data D). The sampling was performed within the study population for data B. The original sample consisted of 300 children's health records. Due to lacking documents, the final sample consisted of 270 children's (20% of the total population) 4th and 6th grade health check-up summaries documented by the school nurse.

5.3. Study setting and data collection

In phase 1. the study setting for cognitive interviews (data A.) varied according to participants. The qualitative interviews were performed according to wishes of the participants either at the participants home or the facilities of the University of Turku, Department of Nusring Science. Children and parents were interviewed separately and the interviews were performed by the researcher herself. The interviews started by the researcher telling the respondent to fill out the PedsQL TM 4.0 and advising the respondent to ask if there are questions or uncertainty while responding. The researcher coded the responding time. The semi-structured cognitive interview started after the respondent had completed the questionnaire. Respondents' observations, remarks, comments and

answers to the semi-structured questions were written down by the interviewer partly during and partly after the interview. The plan including the semi-structured questions for the cognitive interviews presented in appendix 1. and the interviewing technique was pre tested by the researcher prior to data collection. The pilot testing included one interview of a child and one of a parent.

In phase 1.to 3.the study settings for the baseline (data B) and follow-up surveys (data C.) were kept as similar as possible. Children participating in the surveys filled out questionnaires during school hours in the presence of a teacher. Most children filled out electronic form questionnaires at the school computer class. In some schools children filled out the questionnaires in paper form version due to lack of computers available at the school at the time. The electronic and paper form questionnaires were identical by content. The outer appearance of the different form questionnaires were also tried to make as identical as possible. Both electronic and paper form questionnaires had been pre tested. The cognitive interviews described previously can be considered as part of the pre testing process as for pre testing the study instrument. Additionally pre testing was performed with children attending 4th grade in a school outside the city where the survey was conducted. The researcher conducted the pre testing process and evaluated child behaviour at the cognitive interviews as well as the school class room situation and children's capability to use the computers in answering. No problems were identified and the pre testing process did not make any changes to the study instrument or the protocol of the survey.

Parents' questionnaire was in paper form and the parents filled out their questionnaires at home. The questionnaires were coded to match child-parent pairs. Data security and privacy of the respondents was considered very carefully during the data collection. No data was stored on the school data system. The paper form questionnaires were returned in sealed envelopes via the teacher to the Schools on the Move –research assistant. Pre-testing of the parents' study instrument was performed during the cognitive interviews described previously.

In phase 3. the patient records, health check-up summaries, (data D) were collected by the researcher. The health check-up summaries were collected from the electronic, Pegasos ®, patient record system at the facilities of the health care organization responsible for the patient records. The permission to use the patient records data for research purposes was granted by the organization responsible for the patient records and the data was collected and managed according to national legislation and ethical guidelines (Act on the Status and Rights of patients 785/1992, Medical Research Act 488/1999, Personal data act 523/1999). Special consideration was paid to privacy protection. The patient records of the participants were only opened as for the 4th and 6th grade health check-up summary leafs. All personal data, as well as names of relatives, teachers, schools, nurses, friends etc. were removed before storing. The data was stored on a memory stick. Data D. was not coded in any way eg. to enable matching the patient record data (data D.) with

the survey data (data B. and C.) due to national regulations (Act on the Status and Rights of patients 785/1992, Personal data act 523/1999).

5.4. Measurements

5.4.1. Translation process of the Finnish version of Paediatric Quality of Life Inventory ™ 4.0 (paper I)

In 2004, a two-way translation process, aiming at producing high semantic and conceptual equivalence between the original and the translated, Finnish version of The Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) was conducted. Two qualified English-Finnish translators translated the original version of PedsQL™ 4.0 into Finnish. The two separate translations were evaluated by the researcher and her supervisors. This process produced the first Finnish version of PedsQL™ 4.0. The first verion was back translated by a qualified Finnish-English translator into English. The back-translated version was evaluated by the copyright holder of the instrument (PedsQL™ 4.0). According to the copyright holder and the developer of the original instrument, some modifications were made and the second Finnish version of PedsQL™ 4.0. was produced and further tested utilizing cognitive interviews and surveys.

5.4.2. Cognitive interviews (paper I)

Cognitive interviewing aims at understanding a questionnaire from the respondents' perspective (Collins 2003, Drennan 2003). Cognitive interviewing is especially recommended for pre testing of questionnaires involving complex or sensitive questions or for special groups (eg. children) having potential problems in the completion of questionnaires (Drennan 2003).

The cognitive interviewing process involves analysis of respondents' verbal data prior to distribution of the questionnaire in the main data collection (Collins 2003). The interviewer may use three types of methods: think-aloud, probing questions and/or observation (Collins 2003, Drennan 2003). The think-aloud method is respondent-driven as the probing method being more interviewer-driven. Probes are often semi-structured and focus on the respondent to paraphrase questions, define meanings of word, explain responses and identify areas being difficult to understand, interpret or complete in the questionnaire. (Collins 2003.)

In this study cognitive interviews aimed at testing content validity of the Finnish version of Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0). The interviews were performed using the probing method and utilizing a semi-structured format. The semi-structured format followed the recommendations of the developer of the original Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0). The probes were set to gain understanding about the respondents' thinking related to the instructions, concepts,

questions and response alternatives of the instrument. Data collection is described in the data collection section.

5.4.3. Child Health-Related Quality of Life (paper I-IV)

Child Health-Related Quality of Life (HRQL) was measured using the Finnish version of Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0) Child-Self Report (ages 8-12) and Parent-Proxy Report (ages 8-12). The PedsQL™ 4.0 comprise of five dimensions: physical, psychosocial, emotional, social and school functioning. The instrument consists of 23 items encompassing the total HRQL as well as summary scores (physical and psychosocial) and sub scales scores (physical, emotional, social and school functioning). The respondent is instructed to recall certain problems that might have occurred during the past one month. The responding scale is a 5-point Likert scale rating from "never" (0) to "almost always" (4). (PedsQL ™ 4.0.)

The content validity of the Finnish version of PedsQL™ 4.0 was established and evaluated during the two-way translation process and further tested qualitatively by conducting cognitive interviews described in the previous section. Construct validity and reliability were tested statistically.

5.4.4. School nursing documentation (paper IV)

School nursing documentation was evaluated using a structured format that included physical, emotional, social and school related dimensions. The format was built according to the multidimensional health definition of WHO (Constitution of the World Health Organization Basic Document) and conceptualization of Health-Related Quality of Life (Felder-Puig et al. 2004, Rajmil et al. 2004).

5.5. Data analysis

5.5.1. Analysis of cognitive interviews, data A. (paper I)

The cognitive interviews were analyzed to examine content validity, readability and comprehensibility of the Finnish version of Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0). The interviews started by the researcher telling the respondent to fill out the PedsQL TM 4.0 and advising the respondent to ask if there are questions or uncertainty while responding. The researcher coded the responding time. The semi-structured cognitive interview started after the respondent had completed the questionnaire. Respondents' observations, remarks, comments and answers to the semi-structured questions were written down by the interviewer partly during and partly after the interview.

The cognitive interviews were analyzed according to purpose. The minimum, maximum and the mean time spent to respond was calculated. The questions addressed at the interviews by the respondents were analyzed and classified by content. The responses to the questions addressed by the researcher were mainly analyzed by extracting phrases that indicated categories such as no difficulties/difficulties or understood/not understood according to purpose. Responses indicating some difficulties or miss understanding were analyzed by content and classified inductively.

5.5.2. Analysis of surveys, data B. and C. (paper I-IV)

Data B. was collected utilizing The PedsQL 4.0 and managed preparatory to the statistical analyses according to the instrument scoring instructions (PedsQL™ 4.0). The items were reversely scored and transformed to a linear scale (0-100), with 100 indicating highest and 0 lowest possible HRQL. Scale scores were created by dividing the sum of the responses by the number of items answered. The scale scores were not calculated if more than 50% of items in the scale were missing. The questionnaires were coded in order to match parent-child pairs and baseline-follow up results.

The program used for statistical analysis was SAS ® System for Windows, version 9.1 (SAS). Frequency, mean, standard deviation (SD), 25^{th} and 75^{th} percentiles and minimum and maximum values were calculated to describe the data. Reliability was estimated by the internal consistency using Cronbach's alpha (Cronbach 1951). HRQL scores were approximately normally distributed. Parametric statistical tests were applied on the basis of high number of observations and the similar results between nonparametric and parametric tests. The described tests were also performed to examine convergent validity of the Finnish version of Paediatric Quality of Life Inventory ™ 4.0 (PedsQL™ 4.0).

Two-sample t-test was used for analyzing the mean differences in the HRQL scores between girls and boys. Paired t-test was used for analyzing differences in the HRQL scores between the children at age 10 and 12 as well as the differences between child self and parent-proxy assessments. Pearson correlation coefficient was used for calculating the correlation between child self assessments at age 10 and 12 as well correlation between child self and parent-proxy assessments. P-values lower than 0.05 were considered statistically significant.

5.5.3. Analysis of health check-up summaries, data D. (paper IV)

School nurses documented health check-ups as summaries in free text under the headings: growth, posture, skin and allergies, special diet, puberty, school, hobbies, substances, social data, other, actions and patient education. An example of an authentic text (in original language and translated into English) is presented in pictures 3.and 4.

Table 4. Authentic (Finnish) example of school nursing documentation

Kasvu:norm. Ryhti:norm. Iho ja allergiat:hyvä iho, ei allergioita Erikoisruokavalio:- Puberteetti :M1 Koulunkäynti:sanoo että mukavasti menee, tukiopetustaa ei ole tarvinnut. On kaveri, ei ole kiusattu tai haukuttu. Harrastukset:kitaransoitto, tanssi Päihteet:vanhemmat tupakoivat Sos.tiedot:ydinperheen ainokainen Muuta:murheena vanhempien tupakointi.... Toimenpiteet:- Neuvonta:terveet elämäntavat, henk. koht. hygienia 4. lk jakomateriaali

Table 5. Translation (English) of authentic example of school nursing documentation

Growth: normal Posture: normal Skin and allergies: good skin, no allergies. Special diet: - Puberty: M1 School: tells that goes well, has not needed remedial education. Has a friend, not been bullied or ticked off. Hobbies: plays the guitar, dance Substances: parents smoke Social issues: single child of a nuclear family Other: concerned about parents' smoking… Actions: - Education: healthy living habits, personal hygiene, 4th grade material

The health check-up summaries, data D., was analysed utilizing quantitative content analysis that is referred in this study as data extraction (Polit & Beck 2009). Information from the health check-up summaries was extracted and entered onto categories that had been established according to the WHO heath definition of health (Constitution of the World Health Organization Basic Document) and categories included in the PedsQL™ 4.0 (PedsQL™ 4.0). The categories and extracted phrases are presented in Table 6.

The extracted and classified data was transformed to a quantitative format. The transformation was performed by using the following codes: code 1=the issue exist in the text and is positive, code 2= the issue exist in the text and is neutral, code 3= the issue exist in the text and is negative, code 0= the matter does not exist in the record.

In some cases short lines were documented after a main heading (eg. Special diet: -). In such cases, the issue was interpreted as a documented observation and coded 1-3. The data comprised of school nurse documented health check-up summaries of (n=270; girls n=136, boys n=104, gender unidentified n=30) children.

Table 6. Extracted phrases and categories

Extracted phrases	**Categories (established according to WHO definition of health and the PedsQL™ 4.0)**
Growth, Posture, Skin/Allergies, Special diet, Pubertial status, Sleep, Nutrition/Eating	Physical issues
Friends, Bullying, Family relations, Family structure, Parents' health custom, Housing, Hobbies, Substance use	Social issues
Mood, Distress, Character	Emotional issues
School grade, Subject at school, Liking school, Managing school, Teacher's comment	School issues

6. RESULTS

6.1. Summary of main results

Validity and reliability of the Finnish version of PedsQL™ 4.0 was good (Table 7.). Children reported lower emotional than physical health (Table 8.) and child self and parent-proxy agreement was frail (Table 7.). Both child self and parent-proxy assessed HRQL scores increased as the child grew older from age 10 to 12 (Table 8. and 9.). School nursing documentation related to child health check-ups and child self assessed HRQL were not in line with each other (Table 10.). School nurses tend to report physical but fail to report emotional issues at child health check-ups (Table 10.).

6.2. Phase specific results

6.2.1. Validity and reliability of assessing Health-Related Quality of Life in Finnish school children (paper I-III)

Content validity of the Finnish version of PedsQL™ 4.0 was good regarding the ease of understanding. Most respondents reported instructions, concepts, questions, and response alternatives to be easily understood. The youngest participants in the cognitive interviews however reported some uncertainty about how to mark their response. Some of the youngest children also reported difficulties in judging the degree of a problem if they were judged never or almost always a problem. Most respondents filled out the instrument within five minutes.

Construct validity of the Finnish version of PedsQL™ 4.0 was good in terms of fairly high equivalence in comparing scale statistics between phase 1. survey and a previous study (Varni et al. 2006). The previous study (Varni et al. 2006) was conducted with school age normal population sample children (5-18 years) utilizing the original PedsQL™ 4.0 instrument. Comparision of scale statistics showed similarities in mean values and the behaviour of the scale statistics (Table 7.).

The reliability of the Finnish version of PedsQL™ 4.0 was excellent in terms of internal consistency (Cronbachs's alpha). The Finnish version of PedsQL™ 4.0 child self report total scale score exceed α 0.90 and all sub scales exceed α 0.70. The Finnish version of PedsQL™ 4.0 parent- proxy report also showed satisfactory internal consistency, the total score being α 0.88 and sub scales ranging between α 0.69-0.86 (Table 7.).

Table 7. Comparison of scale statistics for the original Pediatric Quality of Life Inventory™ 4.0 (Varni et al. 2006) and the translated Finnish version

	Original version of PedsQL™ 4.0 (Varni et al. 2006)		**Finnish version of PedsQL™ 4.0 (Paper I)**		
	Mean	SD	Mean	SD	α
Child self assessed HRQL*					
Total score	81	13	82	11	0.91
Psychosocial	79	15	80	13	0.89
Physical health	86	13	85	11	0.75
Emotional health	75	18	75	16	0.77
Social functioning	83	18	85	14	0.78
School functioning	78	16	79	15	0.73
Parent-proxy assessed HRQL*					
Total score	78	17	81	10	0.88
Psychosocial	77	16	80	11	0.86
Physical health	79	22	83	13	0.81
Emotional health	78	17	72	14	0.78
Social functioning	80	21	86	13	0.81
School functioning	73	20	81	13	0.69

* HRQL scale 0-100; 0 indicating lowest and 100 highest possible HRQL

6.2.2. Health-Related Quality of Life in 10 to 12 year old school children (paper I-IV)

Health-Related Quality of Life (HRQL) assessed by the children at 4th (mean age 10) and 6th (mean age 12) grades are presented in Table 8. In 4th grade, the mean value for the total HRQL was 80.96 (SD=11.76) and the mean values for the sub scales ranged between 85.00 (physical sub scale) and 75.43 (emotional sub scale). The mean scores of HRQL in the follow up ranged between 89.48 (social scale) and 79.6 (emotional sub scale).

Girls reported moderately higher HRQL scores than boys in most scales both at 4th and 6th grade. The difference between the genders was most significant in the emotional functioning sub scale, girls reporting considerably lower emotional functioning than boys.

Child self assessed HRQL scores increased significantly both in total as well as sub scales between 4th and 6th grade (age 10 to 12). The difference between 4th and 6th grade scores varied between t=10.16 (total HRQL) and t=5.96 (school functioning). The change between child self assessed HRQL at 4th and 6th grade are presented in Table 8.

Table 8. Health-Related Quality of Life in 4th (mean age 10) and 6th (mean age 12) grade and change between baseline and follow-up

	Child self assessed HRQL* (Paper III)			Parent-proxy assessed HRQL* (Paper III)		
	4th grade n, Mean	6th grade n, Mean	Change in scores n, dMean, t p-value	4th grade n, Mean	6th grade n, Mean	Change in scores n, dMean, t p-value
Total	910 81	904 85	835 4 <0.001	859 81	791 83	709 2 <0.001
Physical	933 85	926 89	877 4	859 83	791 85	709 2 <0.001
Emotional	913 76	924 80	856 4 <0.001	860 72	791 76	709 3 <0.001
Social	927 85	913 89	860 4 <0.001	861 87	791 89	710 2 <0.001
School	931 79	924 82	873 3 <0.001	861 82	791 82	710 1 0.006

* HRQL scale 0-100; 0 indicating lowest and 100 highest possible HRQL

There was correlation between child self assessed 4th (baseline) and 6th (follow-up) grade scores but the correlation was negative. The correlation in change between baseline and follow-up is presented in Table 9.

Parent-proxy assessed HRQL is presented in Table 8. The child self assessments show higher HRQL scores in most scales compared to their parent-proxy assessments. The differences were significant in the physical ($p<0.001$) summary score and in the emotional ($p<0.001$), school ($p=0.006$) and social ($p=0.01$) functioning sub scales. The child self assessments show higher physical and emotional functioning but lower social and school functioning than their parents' proxy assessments.

The correlation between parent-proxy assessments at 4th (baseline) and 6th (follow up) grade and baseline and change are presented in Table 9. There was correlation between baseline and follow up as well as baseline and change. The correlations were however negative between baseline and change similarly to the child self-reported assessments.

The child–parent agreement is presented in Table 9. The agreement increased as the child grew from age 10 to 12. The highest child– parent correlation at the baseline was found in the psychosocial ($r=0.39$, $p<0.001$) scale score and the lowest in the physical ($r=0.2$, $p<0.001$) scale score. The highest child–parent correlation at the follow up was found in the social ($r=0.42$, $p<0.001$) scale score and the lowest in the physical ($r=0.3$, $p<0.001$) scale score.

Table 9. Correlation in Health-Related Quality of Life scores between 4th (baseline) and 6th (follow up) grade, baseline and change and child-parent agreement

	Child self assessed HRQL (Paper III)		**Parent-proxy assessed HRQL (Paper III)**		**Child-parent agreement (Paper III)**	
	4th vs 6th grade n, r, p-value	4th grade vs change n, r, p-value	4th vs 6th grade n, r, p-value	4th grade vs change n, r, p-value	4th grade child-parent pair n, r, p-value	6th grade child-parent pair n, r, p-value
Total	835 0.5 <0.001	835 -0.6 <0.001	709 0.6 <0.001	709 -0.5 <0.001	801 0.4 <0.001	725 0.4 <0.001
Physical	877 0.4 <0.001	877 -0.7 <0.001	709 0.5 <0.001	709 -0.6 <0.001	819 0.2 <0.001	741 0.3 <0.001
Psychosocial	836 0.5 <0.001	836 -0.6 <0.001	709 0.6 <0.001	709 -0.5 <0.001	802 0.4 <0.001	726 0.4 <0.001
Emotional	856 0.4 <0.001	856 -0.6 <0.001	709 0.5 <0.001	709 -0.5 <0.001	805 0.3 <0.001	740 0.4 <0.001
Social	860 0.4 <0.001	860 -0.6 <0.001	710 0.5 <0.001	710 -0.6 <0.001	815 0.4 <0.001	732 0.4 <0.001
School	873 0.5 <0.001	873 -0.6 <0.001	710 0.6 <0.001	710 -0.5 <0.001	819 0.4 <0.001	741 0.4 <0.001

6.2.3. Association between child self assessed health and school nursing documentation (paper IV)

School nursing documentation regarding health check-ups is presented in Table 10. Observations and findings related to physical health were commonly documented. According to the documentation, most children grew normally (4th grade 90%/ 6th grade 93%) and have normal posture (83%/78%). Nurses documented findings related to eating or sleeping habits occasionally and according to documentation very few children had unhealthy sleeping (1%/6%) or eating (2%/5%) customs.

Social wellbeing, such as hobbies were documented in most cases but friendship or bullying issues more rarely. According to nurses' documentation, most children participated in health promoting hobbies (77%/ 81%), such as sports, musical hobbies or scouting. According to documentation, children had not problems in friendships (0%/0%) and only few had been bullied (4%/3%). Family structure was occasionally documented at 4th grade check-ups (62%) but more commonly at 6th grade check-ups (91%). Health customs of parents, commonly related to smoking, were documented occasionally (29% /44%). Family relations (8%/ 11%) were seldom documented. According to documentation, substance use was observed occasionally at 4th grade

check-ups (22%) but more frequently at 6th grade health check-ups (89%). According to the 4th grade health check-up documentation, no child (0%) had tried substances, but some children (2%) had tried substances according to the 6th grade documentation.

School related well being, such as managing school was documented frequently but issues related to emotional feelings toward school, such as liking or disliking school, were only occasionally documented. According to documentation most children managed school well (76%/80%) and only some disliked school (1%/3%). Teachers' comments about the child were rarely documented (2%/7%) and according to documentation, only very few children (1%/1%) were documented to have problems according to the teacher.

Observations related to emotional wellbeing, were seldom documented. Adjectives related to the character of the child, such as quiet, silent, phlegmatic, talkative, nice, were the most frequently documented emotional issues (29%/ 30%) but issues related to distress (13%/ 17%) or mood (2%/7%) were rarely documented. According to the documented findings, only few children had emotional problems (1%/2%).

Child self assessed HRQL scores and nursing documentation is presented in Table 10. Children reported highest, indicating good, HRQL scores in the physical and social domains of health both at 4th and 6th grade. Nursing documentation related to health check-ups are in concordance to the child self assessments on the physical domain. Children assessed lowest HRQL scores in the emotional domain of HRQL but school nursing documentation related to emotional health is frail. According to the documentation, only few abnormal findings related to emotional health was found.

Table 10. Observations and findings documented by school nurses and child self assessed health

	Child self assessed HRQL * Mean		Child 4th and 6th grade health check-up summaries	Documented %		Normal finding %		Abnormal finding %	
	4th grade	6th grade	Children n= 270	4th grade	6th grade	4th grade	6th grade	4th grade	6th grade
Physical issues	85	89	Growth	97%	97%	90%	93%	2%	2%
			Posture	98%	99%	83%	78%	6%	10%
			Skin/allergies	94%	90%	26%	23%	7%	7%
			Special diet	79%	87%	-	-	-	-
			Puberty	53%	94%	-	-	-	-
			Sleep	16%	20%	14%	10%	1%	6%
			Eating/ nutrition	16%	27%	5%	12%	2%	5%
Emotional issues	76	80	Mood	2%	7%	1%	4%	1%	2%
			Disterss	13%	17%	13%	14%	0%	2%
			Character	64%	30%	24%	45 %	2%	2%
Social issues	85	90	Friends	64%	62%	63%	61%	0%	0%
			Bullying	48%	47%	43%	43%	4%	3%
			Family relations	8%	10%	6%	8%	1%	1%
			Family structure	62%	91%	-	-	-	-
			Parents' health custom	29%	33%	19%	19%	9%	14%
			Housing	3%	4%	-	-	-	-
			Hobbies	95%	100%	77%	81%	10%	10%
			Substance use	22%	89%	11%	83%	0	2%
School related issues	79	82	School grade	24%	29%	23%	23%	0%	2%
			Subject at school	45%	38%	-	-	-	-
			Liking school	31%	29%	29%	23%	1%	3%
			Managing school	83%	89%	76%	80%	1%	3%
			Teachers' comment	2%	7%	-%	5%	1%	1%

* HRQL scale 0-100; 0 indicating lowest and 100 highest possible HRQL

7. DISCUSSION

7.1. Discussion of results

The hypothesis that the Finnish version of the PedsQL ™ 4.0 is a valid tool for assessing HRQL in a general school child population, child self assessments of HRQL change as the children grow and concordance between child self and parent-proxy assessments is fragile was supported by the results of this study. The hypothesis that school nurses document multidimensional health issues related to child health check-ups and that nursing documentation is in line with child self assessed health was not supported by the results of this study.

The main results of this study were that PedsQL ™ 4.0 is a valid instrument for assessing HRQL in Finnish school children. Children assess their emotional wellbeing to be lower than their physical, social or school related wellbeing. The concordance between child self assessed health and parent-proxy assessments or school nursing documentation regarding health check-ups is frail. School nurses tend to document physical but fail to document emotional issues regarding child health check-ups. The main results will be discussed in the following sections.

7.1.1. Validity and reliability of assessing Health-Related Quality of Life in Finnish school children

The PedsQL ™ 4.0 had not previously been translated into Finnish and validated in any Finnish child population. This study shows promising results of The PedsQL ™ 4.0 being a valid, reliable instrument for assessing HRQL in Finnish school children. The two-way translation process was utilized carefully following recommendations (The PedsQL Linguistic Validation Protocol) and content validity was tested utilizing cognitive interviews (Collins 2003, Drennan 2003).

The cognitive interviews confirmed that the translation process had succeeded in keeping close equivalence between the original and the translated instrument. The cognitive interviews confirmed that the instructions, concepts, questions and response alternatives were mostly understood as the developer of the original instrument intended. The cognitive interviews gave good insight and advanced understanding to the researcher especially about the way children think and respond to the questionnaire. These experiences are in line with previous suggestions of cognitive interviews being especially recommended for pre testing instruments for special groups, such as small children (Collins 2003, Drennan 2003).

Construct validity of the Finnish version of PedsQL™ was tested for convergent validity by comparing results between this (utilizing the Finnish version) and a previous study

(utilizing the original instrument) by Varni et al. (2006). The construct validity of the Finnish version of The PedsQL ™ 4.0 gave promising results but needs further testing. Construct validity of The PedsQL ™ 4.0 has been tested in previous studies by comparing contrasting groups, mainly healthy and chronically ill samples (Felder-Puig et al. 2004, Upton et al. 2005).

Reliability of The Finnish version of PedsQL 4.0 was tested by internal homogenity assessed by Cronbachs alpha (Cronbach 1951, Burns & Grove 2001). The Cronbachs alpha values were good both for the child self and parent-proxy assessment summary scales as well as most of the sub scales. Only the school functioning scale of parent-proxy report form, show slightly weak internal homogeneity and need further clarification. Reliability of The PedsQL ™ 4.0 has been tested also in previous studies by calculating Cronbahcs alpha and the results of this study are in line with previous studies. (Reinfjell et al. 2006, Varni et al. 1999, 2001, 2006).

7.1.2. Health-Related Quality of Life in 10 to 12 year old school children

The children assessed their emotional wellbeing to be lower than their school, social or physical well being. Generally parents assessed their childs' emotional well being even lower than the child herself. The tendency for children and parent-proxies to assess the child emotional well being lower than the other dimensions of health is also found in previous studies and the phenomena does not seem to be nation specific (Reinfjell et al. 2006, Varni et al. 2006). The state of school aged children's emotional well being however needs future attention as also previous studies rise concern about the children's emotional well being (Sourander et al. 2008, Gyllenberg et al. 2011, Lehti et al. 2009).

Previous research suggests that about 10% of Finnish children suffer from some psychiatric symptom or emotional problems (Sourander et al. 2008, School Health Promotion Study 2010). No significant changes in the prevalence of psychiatric symptoms among children or adolescents have been found but use of antidepressant medication and psychiatric services have increased significantly in about 15 years (Sourander et al. 2008, Gyllenberg et al. 2011). Only a minority of children with psychiatric symptoms however are referred to services (Sourander et al. 2008) and school services play a central role in early support and detection of children who need special emotional support or psychiatric services (Sourander et al. 2008, Counsil of State decree on school health care 280/2009, Health care act 1326/2010).

When comparing child HRQL scores to previous, international studies, it seems that Finnish school children tend to report somewhat lower HRQL scores than samples eg. in USA (Varni et al. 2006) but similar to school children in Norway (Reinfjell et al. 2006). International comparison of HRQL scores in Finnish school children however needs future examination.

Both child self and parent-proxy assessed HRQL increased, indicating improved HRQL at the transformation stage between childhood and adolescence. Previous research shows diverging results about the development of HRQL as the age of the child increase. Some studies have not found significant changes in HRQL scores between 10 and 12 year old children (Varni et al. 2006, 2007) while other studies have found significant increase in HRQL scores between 10 and 12 year old children (Svavarvsdottir & Orlygsdottir 2006).

One may argue that the significant increase in the child self assessed HRQL scores may be simply due to cognitive development effecting responding to the questionnaire. This may however be answered by previous studies indicating children as young as 5 years of age being able to give valid and reliable assessments of their HRQL when using age appropriate instruments. Moreover, the parent-proxy assessed child HRQL scores also increased significantly as the child grew from age 10 to 12 and verifies the child self assessments.

7.1.3. Association between child self assessed HRQL and school nursing documentation

There was no logical association between school nursing documentation related to child health check-ups and child self assessed HRQL. Nurses tended to document physical but failed to document emotional issues as children themselves assessed lower emotional than physical health.

Reasons for the incongruence between nursing documentation and child self assessed health may only be speculated on. The assessment of child's emotional state and family situation require skills as well as time and unbroken attention (Gleason et al. 2007) and one may speculate that there may be limited recourses for the school nurses to evaluate emotional issues at health check-ups. Moreover, previous studies suggest that school nurses feel unease as well as ethical problems in reporting sensitive issues (Clausson et al. 2003, 2008a) as well as lack of time for documentation (Maki et al. 2008, 2010).

Previous studies show that school nurses document systematically issues when they have been given specific regulations (Mäki et al. 2008, 2010) and since new and more precise regulations and recommendations related to school child health check-ups have recently been published (Mäki et al. 2011), the documentation of health check-ups may have improved since 2004-2006 when this study was conducted.

7.2. Study limitations

The trustworthiness of the cognitive interviews was carefully considered during the whole study process. The interviews were carefully planned, the interviewer had pre tested the interviewing protocol, analyzed possible problems that may occur during the interviews and thought of solutions to potential problems in advance. Also the interviewer had collected theoretical knowledge about cognitive interviewing as well

as interviewing children in general. Despite the previous actions, some limitations need to be addressed. The researcher had no previous experience in interviewing children and some of the youngest children seemed to "look for the right answer". In such cases the interviewer reminded the children to give their self assessments and stated that no "right answers existed". Moreover, the purposive sample of the cognitive interviews was quite homogenous in that the participants were recruited among students taking the masters' degree in nursing science, no single parent families or low income families were involved. Also the sample for the interviews, especially regarding the youngest children, could have been somewhat bigger since some uncertainty about the data saturation regarding the interviews of the youngest children exists.

The Finnish version of PedsQL 4.0 was carefully translated and tested for its content validity. There are however limitations regarding the testing of the construct validity of the instrument. Construct validity of The Finnish version of PedsQL 4.0 was only estimated by comparing results of this study to a previous study using the original instrument. Comparing the results between the two separate studies is however challenging since there were significant differences between the study samples. There was however no better solution for examining the construct validity of The Finnish version of PedsQL 4.0 available at the time and similarity between the results and trends of the scale statistics is however notable. Moreover, the discussion between the present and previous studies on validity of The Finnish version of PedsQL 4.0 is limited by there being no previous studies utilizing the PedsQL 4.0 in Finnish child populations.

Construct validity of The PedsQL ™ 4.0 has been tested in previous studies by comparing contrasting groups, mainly healthy and chronically ill samples (Felder-Puig et al. 2004, Upton et al. 2005). This comparison was not performed in this study and is recommended in future testing of construct validity of the Finnish version. Also examining convergence (Burns & Grove 2001) to other paediatric HRQL instruments is recommended.

The surveys were carefully planned and conducted according to the study protocol. Some limitations however need to be addressed. The children responded the surveys during class and even if the teacher was present at the data collection, there may have been some disturbance at the time of responding. There is also the possibility that some children under- or over estimated their assessments eg. due to inappropriate attitudes to the research or concern about data protection. Also the effect of the differences of the administration formats between child self assessments (mainly electronic form questionnaire and responding at school during school hours) and parent-proxy assessments (paper form questionnaire and responding at home) have to be addressed. According to Puhan et al. (2011), however, administration formats have no significant effect on HRQL outcomes on repeated measurements of HRQL and Rew et al. (2004) suggest that electronic responding improves validity of surveys.

Comparison between child self assessed HRQL and school nursing documentation at child health check-ups has limitations. One may argue that there is not reasonable cause for

comparing two totally separate and different types of data. The argument can however be answered invoking to recommendations (published at the time of this study) regarding school child health check-ups (Ministry of Social Affair and Health & Stakes 2002, Ministry of Social Affair and Health 2004) as well as nursing documentation (Act on the Status and Rights of Patients 785/1992, Personal data act 523/1999). School child health check-ups shall include observation of multidimensional health (including physical, emotional and social dimensions) and focus on the individual child (Ministry of Social Affair and Health & Stakes 2002, Ministry of Social Affair and Health 2004, Government Decree 380/2009). All relevant information regarding care shall be documented (Act on the Status and Rights of Patients 785/1992, Personal data act 523/1999). Realization of these recommendations and regulations could be tested by comparing the two totally separate and different data.

Limitations exist in generalizing the results of this study. The study was conducted in a city in South-Western Finland. Children and parents may assess HRQL differently in different parts of the country and HRQL may vary eg. between urban and rural populations. There are also significant differences between different municipalities in the content of school child health check-ups as well as nursing documentation systems (Mäki et al. 2008, 2010). The findings of this study can however be generalized as preliminary knowledge of The PedsQL™ 4.0 being a valid tool for assessing HRQL in Finnish school children and preliminary reference scores of HRQL in 10 to 12 year old Finnish school children have been reported. The findings can also be generalized as knowledge to motivate discussion and further research needs regarding the emotional well being of urban Finnish school children as well as the relation between child assessed health care needs, nursing interventions, such as health check-ups and school nursing documentation in general.

7.3. Ethical consideration

National legislation and ethical guidelines regarding research have been carefully executed through out the study process (Medical research act 488/1999, National Advisory Board on Research Ethics. 2002, Academy of Finland Guidelines on Research Ethics. 2003, Act on changing the medical research act 794/2010).

The subject and aim of this study are justifiable. Knowledge of HRQL in Finnish school children as well as generally knowledge about the development of HRQL in school children as children grow from childhood to pre adolescence was lacking although being significant for clinical, organizational and political decision making as well as research. Moreover, no previous knowledge existed about the relation between child self assessed health, school health check-ups or school nursing documentation. The knowledge although being important both for clinical, organizational and political reasons.

Research on children is only approved in cases the knowledge is not reachable by studying adults (Medical Research Act 488/1999). This research would not have been possible to conduct without children because children have the right to be heard (Convention of

the Rights of the child 1990, The Constitution of Finland 731/1999, Child welfare act 417/2007), they are to be held as main informants of their HRQL and general school aged children are able to give valid self assessments of their HRQL (Eiser & Morse 2001a, Creemens et al. 2006, Varni et al. 2007, Upton et al. 2008). There was unlikely no potential benefit of this research to the individual children who participated, but much potential benefit for the future school child populations. Moreover, there was unlikely any potential harm of participating to this study to any participant.

Research has to be well prepared, carefully planned and carried out systematically (National Advisory Board on Research Ethics 2002). The research plan of this study was approved by the University of Turku, medical faculty and the researcher worked in close collaboration to the research supervisors, the University of Turku, Department of Nursing Science and the Schools on the Move –study group through out the study process. The researcher gained theoretical knowledge regarding research methodology, research on children and health in general school child populations along with the research process both to develop competence as well as ensure the quality of the study.

The permission to conduct the research was received from organizations involved in the different study phases. The Schools on the Move –research had also been approved by the Ethics Committee of the Hospital District of Southwest Finland (VSSHP 2011). Permission to translate, validate and utilize the Finnish version of PedsQL™ 4.0 had been granted by the copyright holder of the original instrument (PedsQL™ 4.0).

All child participants of this study had given their written form consent (Medical research act 488/1999) to participate. There are ethical questions about how well children manage to understand information regarding the study or their rights as potential participants in research. There is uncertainty about how well all the children participating in the surveys understood the written form study information leaflet or considered their participation. This is a common ethical question in large surveys where the researcher is hindered from informing all potential participants personally. The information leaflet had been pre tested both by the children participating in the pre-test as well as their teacher. Additionally the information leaflet had been proved by the Hospital District of Southwest Finland (VSSHP 2011) .There is less uncertainty about the consent given for participating in the cognitive interviews as the researcher was able to confirm the understanding and volunteer participation from the children individually prior to starting and during the interviews.

There are ethical questions regarding methods utilized in this study. The questions regarding the two-way translation process relate to the competence of performing the translation, such as the competence of the translators and the decisions made to ensure equivalence between the original and the translated instrument. In this study the translation process was carefully performed according to international translation guidelines and recommendations of the developer of the instrument. There are ethical questions about how much the developer should participate in further development of the instruments. Close collaboration to the developer of the original instrument can

however be justified by the long experience and wide knowledge about the strengths and weaknesses of the instrument as well as previous experiences in translation and cross-cultural validation processes of the instrument.

Ethical discussion regarding the cognitive interviews as a method relate to the respondents behaviour, the relationship between the participant and the researcher and the validity of the data. The participants of the interviews were able to decide where the interviews were performed. The sets were mostly quiet and there were no disturbing factors at the interviews at most occasions. There where however some disturbing factors, such as parents interrupting the interviews momentarily. The effect of these disturbances can however be considered small in this study as no deep interviewing techniques or sensitive issues were discussed. Some of the youngest children may have been a bit nervous in the beginning of the interviews but they seemed to get fast comfortable with the situation and seemed excited about participating.

Survey as a research method carries several ethical questions such as how well the participants are informed, validity of the measurement tool, respondent behaviour and validity of the results. The participant information and conscious consent was discussed previously. There is no knowledge about where the parents responded their questionnaire, at home, work or somewhere else. Children responded their questionnaires during school hours in the presence of the teacher and some estimation about the responding environment can be made. Uncertainty however exists on responding behaviour and possible disturbances during responding. Not knowing the exact responding environments and situations limit the estimation of the validity of the results.

Using registry data for research purposes has been motivated by several factors. Using patient records for research purposes can be justified as not requiring additional efforts of the informants, data being as correct as possible and developed close to the event. Ethical questions regarding utilizing registry data, such as patient records, relate mainly to personal data security. In this research, the researcher collected the patient record data her self and paid special consideration on the personal data security. All person identification data was removed from the records and the data was not coded in any way. The patient record data was collected and managed according to national legislation and ethical guidelines (Act on the Status and Rights of patients 785/1992, Medical Research Act 488/1999, Personal data act 523/1999).

All data collected in this study has been stored and will be destroyed according to regulations. The survey data (data B. and C.) have been coded to enable comparison between child and parent assessments as well as change between the baseline and follow up. The code key is however kept separate from the data. The cognitive interview and patient record data (data A. and D.) have not been coded and contain no knowledge to enable person identification. Interview and patient record data (data A. and D.) will be disposed as this research close and the survey data (data B. and C.) as the Schools on the Move –research project close.

This study has been reported according to good scientific practice and the results of this research are presented truthfully (National Advisory Board on Research Ethics. 2002).

7.4. Suggestions for further research

Validity and reliability of The Finnish version of PedsQL 4.0 need further examination particularly regarding construct validity. Future validity testing is recommended utilizing divergent validity testing as well as confirmatory factory analysis. Future research is also recommended to test the development of child self assessed HRQL from young childhood to late adolescence and to test the validity of PedsQL 4.0 as a screening instrument in school health care settings.

The emotional state of the school children requires future attention. Future research is needed to gain understanding about reasons for children as well as parent-proxies assessing lower emotional than school, social or physical well being. Interventions, developed and tested utilizing scientific research methods, to promote the emotional well being of school aged children are recommended.

School nursing documentation in general needs future examination as well as documentation of present time school health check-ups across different municipalities. Reasons for incongruence between child self assessment and school nursing documentation needs future clarification. Further research utilizing different research methods are recommended to evaluate the quality of health check-ups from child, family, nurse and organizational perspectives.

7.5. Relevance and implementation of the results

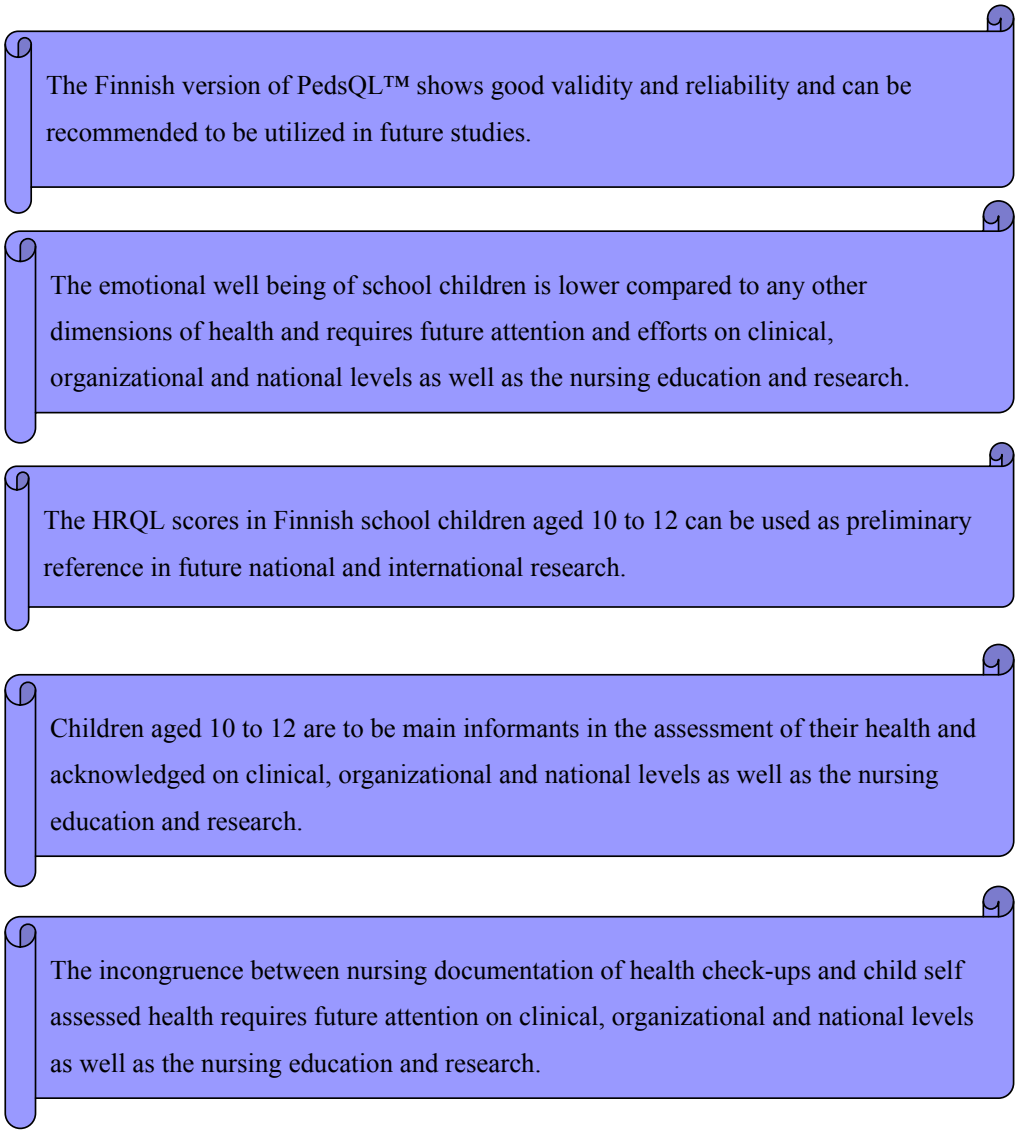
The results of this study have both clinical as well as theoretical relevance on national and international levels.

The Pediatric Quality of Life Inventory (PedsQL) has internationally been recognized as one of the most sophisticated paediatric HRQL assessment tools (Solans et al. 2008). This study is the first testing validity and reliability of the Finnish version of PedsQL™ and to produce preliminary national results and reference scores.

The findings of children as well as parent-proxies assessing lowest scores in the emotional than in any other dimension of health is highly relevant. The emotional state of the school children needs future efforts at individual and family as well as school and national levels. The school health care system plays a central role in planning, organizing, carrying out and evaluating these efforts. This study also produces relevant knowledge about the development of child self and parent-proxy assessed HRQL in the same children growing from childhood (age 10) to pre adolescence (age 12). in general.

Incongruence between child self assessed health and school nursing documentation relating health check-ups motivates discussion about nursing documentation as well as child centred care in general. Findings of school nurses documenting different health problems than children themselves require future evaluation regarding both the reasons and the content and quality of care.

The findings of this study can be implemented as presented in picture 3.



Picture 3. Suggestions for implementations of the findings of this study.

8. CONCLUSIONS

The PedsQLTM 4.0 is a valid instrument to assess HRQL in Finnish school children although future research is recommended. The HRQL scores reported in this study can be used as preliminary reference in future national and international research. Children's emotional wellbeing needs future attention. HRQL scores increase during ages between childhood and adolescence but concordance between child self and parent-proxy assessed HRQL is low. School nursing documentation, related to child health check-ups, is not in line with child self assessed HRQL. Children aged 10 to 12 are to be considered as main informants in assessment of their health.

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APPENDIX 1.

Kognitiivisen haastattelun suunnitelma ja haastattelukysymykset

1. Kerrataan tutkimuksen tarkoitus, eteneminen ja vapaaehtoisuus (info -kirjeessä mainitun kertaus).

2. Pyydetään kirjallinen suostumus lapselta ja nuorelta, sekä lapsen vanhemmalta

3. Haastateltava täyttää kyselyn ja voi täyttövaiheessa esittää kysymyksiä tarpeen mukaan. Kyselyihin ei merkitä henkilöllisyystietoja. Kyselyt jäävät haastattelijalle ”arkistoitaviksi” ja tarkoituksenmukaisesti hävitettäviksi.

4. Haastattelija mittaa kyselyn vastaamiseen kuluvan ajan ja merkitsee muistiin mahdolliset haastateltavan vastaamisen aikana esittämät kysymykset.

5. Kun kysely on täytetty, esitetään seuraavat kysymykset:

   Miltä kyselyn vastaaminen tuntui, oliko helppo vai vaikea täyttää?
   Oliko ohjeet helppo vai vaikea ymmärtää ?
   Millaiselta alkukysymys tuntui, oliko helppo vai vaikea ymmärtää ?
   Miten ymmärrät kuluneen kuukauden aikana ja millaisia asioita esimerkiksi koulussa ovat tapahtuneet viimeksi kuluneen kuukauden aikana ?
   Miten pitkäksi matkaksi kuvailisit 100 metriä ? Mahdollinen lisä kysymys, jolla pyritään selvittämään lapsen /nuoren mielikuvaa 100 m. pitkästä matkasta
   Mikä esine on mielestäsi raskas nostaa ?
   Mitä asioita mielestäsi kuuluu kotiaskareisiin ?
   Mitä mielestäsi tarkoittaa käsite/sana ”vetämätön olo”?
   Mitä mielestäsi tarkoittaa käsite/sana ”väsynyt olo”?
   Mitä tarkoitetaan sillä, että on vaikea nukkua? Mitä asioita kuuluu nukkumisongelmiin ?
   Millaisia asioita ajattelet liittyvän siihen jos on huolissaan siitä, mitä tulee tapahtumaan ? Millaisista asioista itse/lapsesi voisi olla huolissaan?
   Mitä tarkoittaa että ”ei pysy toisten lasten/nuorten tasalla”?
   Mitä asioita liittyy tunnilla keskittymiseen ? Mistä tietää että jaksaa tai ei jaksa keskittyä tunnilla?
   Mitä tarkoittaa ” vaikea pysyä koulussa muiden tahdissa” ? Osaatko kertoa esimerkin siitä, mistä osaisi arvioida onko vaikea vai helppo pysyä koulussa muiden tahdissa ?
   Mitä tarkoitetaan sillä, että jokin asia ei ole ollut ongelma kuluneen kuukauden aikana, entä mitä tarkoittaa tuskin koskaan, entä kuinka usein mielestäsi on joskus tai usein?

6. Haastattelussa edetään haastateltavan ”ehdoilla” mutta pyritään selvittämään miten ohjeet/ kysymykset ja käsitteet /vastausvaihtoehdot ymmärretään ? Erityisesti kiinnostuksen kohteena on selvittää lasten (8-12 –vuotiaat) ajattelua.

7. Lopuksi kysytään onko haastateltava jotain kysyttävää tai kommenttia ja oliko haastattelu ollut helppo vai vaikea. Mainitaan vielä luottamuksellisuus ja tietosuoja, sekä pyritään varmistetaan että haastateltavalle jää haastattelusta positiivinen kokemus.

8. Lapsi/nuori saa ottaa vanhemman mukaan haastattelutilanteeseen, jos niin ehdottomasti haluaa. Ensisijaisesti hän osallistuu haastatteluun yksin.