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A review of children's decision-making competence in health care

Eva K Mårtenson¹ and Astrid M Fägerskiöld²

ABSTRACT

Aims and objectives. The purpose of this literature review was to search for and review, systematically, children's decision-making competence in health care in the scientific literature. Findings of both quantitative and qualitative studies were analysed thematically.

Background. Most previous research in children's decision-making competence in health care concerns adults' care in the best interests of the child. It is important to consider decision-making competence from the child's perspective because of children's own human rights.

Methods. Systematic review including database search, manual selection, supplementary searching, management and acquisition of relevant literature, quality appraisal, literature review saturation and thematic review.

Results. Six themes emerged: measurable issues, values and beliefs, power, parent-related communication, trust and self-determination. Measurable issues were age, reading ability and memory. Values and beliefs as well as power and parent-related communication were associated with healthcare professionals. Children showed trust and expressed a wish to use self-determination.

Conclusions. Age appropriate information and participation were prerequisites for allowing children to have possibilities of making competent decisions about their own care. Children's decision-making competence is dependent on others, such as parents and healthcare professionals, attitudes and not only on their own capacity. Lack of competence, however, does not exclude children from the human right to have a say. It should be noted that it is a decision to leave the determination to a parent or healthcare professional.

Relevance to clinical practice. Future research from the viewpoint of children is important to reach optimal levels of participation, through respecting their integrity and to develop them into potential competent decision makers.

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Introduction

The Convention on the Rights of the Child (UNCRC) is considered to be an important guarantee of full human rights for every child, which means every person up to 18 years old (United Nations 1989). Children in Sweden believe that they are only, to a limited extent, allowed to participate in decisions concerning themselves; they are allowed to talk but it does not matter what they say, nobody listens to them (The Children's Ombudsman 2005). Children wish to be consulted on issues related to their health as these affect them directly (Stafford *et al.* 2003). This makes it important to focus on the possibility of children participating in decisions related to health care, as these are fundamental to them.

The UNCRC permeates all decision making concerning children in government authorities, county councils and local authorities (The Children's Ombudsman 2005). Although Swedish legislation agrees with fundamental features of the UNCRC, there are differences. Swedish acts emphasize the duty of parents and society instead of the rights of the child. The Act on The Children and Parents Code regulates rights and obligations of the person in custody of a child (Swedish Statute Book 1949: 381). In contrast to countries such as the UK and USA, Swedish courts of law are not allowed to pass judgement concerning medical treatment in an individual case (Rynning 1994).

Children are in a state of integrity, with expectations of having their human dignity respected, just as if they were an adult. Integrity can be invaded or respected but never replaced by someone else (Bischofberger *et al.* 1991). Integrity stands for an unreduced wholeness and the right to speak and to have an opinion and that it matters what is said. Children are particularly vulnerable in hospital concerning violation of integrity, due to their development (Price 1994). Autonomy means having the power to make free choices, unconstrained by external agencies (Beauchamp & Childress 2001). Fundamental demands of consent in healthcare and medical service and the content of the Children and Parents Code (Swedish Statute Book 1949: 381) should mean that even minors, persons not of legal age, can be considered competent to make decisions about themselves in nursing care and treatment (Rynning 1994).

Decision-making competence means having capacity to make a decision and competence is described as 'the ability to perform a task' (Beauchamp & Childress 2001, p. 70). Competence is relative to decision, but is not a matter of degree; it is about reaching a level of understanding to make a decision (Buchanan & Brock 1998). Weithorn and Campbell (1982) studied developmental differences regarding competence in making informed treatment decisions. One result was that children at the age of nine were able to participate in decision making concerning healthcare. The study used adults as the gold standard for competent decision making since adults are considered competent because of age. Alderson (1992) argues that the social context will contribute to children's ability to consent. Informed consent includes competence, voluntariness, information, recommendation, understanding, decision and authorization (Beauchamp & Childress 2001). Children have to have relevant information and subsequently have the right to participate in decision making, as well as assent to or dissent from treatment, assuming they are competent (Alderson & Montgomery 2001). Children are presumed competent from the age of five and their incompetence has to be proved rather than the child having to demonstrate competence (Alderson & Montgomery 2001). Halpern-Felsher and Cauffman (2001) studied differences between decision-making competence in adolescents and in adults and the results showed that adolescents did not consider risks and benefits associated with the decision as much as the adults did. However,

Pretzlaff (2005) implies that, for example, motivation and the will to do good are other characteristics for determining decision-making competence; age is not a sufficient parameter.

Lögstrup (1997) developed an ethical theory of interdependence, which means mutual dependency, as human beings are always in relationships with each other. This provides conditions for exertion of power, individuals become vulnerable. Possibilities of abuse of power are an ethical challenge for individual and must be taken in account when encountering children. This is supported by Brook (2000): working with children and youth is based on mutual respect and trust. Children dare to express what they are thinking and feeling in a trustful relationship. Ambitions for paediatric nursing are to adjust to assuming equality of children and building a supportive relationship with parents is a prerequisite. Otherwise, it is easy for a state of conflict to occur, between children's right to know and parents instinct to protect (Fulton 1996).

Because of all these observations, it is important to investigate children's possibilities of decision making about their own nursing care. Just as with adults, it is a question of decision making in collaboration with healthcare professionals and family (McPherson & Thorne 2000).

Aims

The purpose of this literature review was to search for and review, systematically, children's decision-making competence in health care in the scientific literature. Specific questions were: are there any instruments for assessment of decision-making competence in children? How do healthcare professionals perceive decision-making competence in children? What are the findings when children use decision-making competence in nursing?

Objectives and methods

This systematic literature review followed seven steps described by Hek *et al.* (2000): (i) main computerized database search; (ii) narrow and more focused manual selection by two reviewers; (iii) supplementary searching; (iv) management and acquisition of relevant literature; (v) quality appraisal of literature; (vi) literature review saturation and (vii) thematic review of literature.

Databases used were CINAHL (Table 1), Medline/PubMed (Table 2) and PsycINFO (Table 3) to include nursing care, medical care and psychological research. The Cochrane Library was used, but no randomized-controlled trial (RCT) was found within the topic. Search terms used and adapted according to the prerequisites of each database were: decision making, treatment refusal, consent, competence, participation and paediatric nursing, which were also used in various combinations. The rationale for using search terms was to narrow decision-making competence and elements in amount of detail. All database searches were limited to the English language, age up to 18 years old and the period 1998 until July 2006. Articles were selected because of their relevance to the purpose of this study and had to be original articles. Studies about sexuality, risk behaviours in adolescents, juridical circumstances,

participation in research and parental consent were excluded as were studies about children belonging to a religion that does not accept blood transfusion. All these themes chosen as exclusion criteria are juridically regulated in one way or another. Except for these, there are no legal standards or policy concerning children's participation in decision-making in their own health care (Beidler & Dickey 2001, Deatrick *et al.* 2003). This literature review was intended to contribute knowledge regarding different aspects of everyday decision making of children in health care; because it is in everyday life decisions are made.

Table 1: Search history CINAHL

No. Search terms	Matches
1 Decision making/or decision making, ethical/	7521
2 Treatment Refusal/	1548
3 Consent/or 'minors (legal)'/	5117
4 Competence. mp.	15467
5 Participation. mp.	16711
6 No. 1 or 2 or 3 or 4 or 5	43902
7 Pediatric Nursing/	4947
8 No. 6 and 7	302
9 Limit No. 6 to [research and English and (infant <1–23 months >or preschool child <2–5 years >or child <6–12 years >or adolescence <13–18 years >) and year = 1998–2006]	2619
10 Limit No. 8 to [research and English and (infant <1–23 months >or preschool child <2–5 years >or child <6–12 years >or adolescence <13–18 years >) and year = 1998–2006]	30
11 Decision making competence. mp.	761
12 Limit No. 11 to [research and English and (infant <1–23 months >or preschool child <2–5 years >or child <6–12 years >or adolescence <13–18 years >) and year = 1998–2006]	20
13 No. 9 or 10 or 12	2619

To assess the quality of the articles, two forms of critical appraisal were used, trial without randomization and qualitative research (Critical Appraisal Forms 2005). These appraisals are available from the internet and are updated each year. Figure 1 summarizes the total literature searching process and shows how 5315 matches in search strategy were reduced to 15 articles in review. The major decline was in articles concerning parental consent and thus participation in research, which represented the absolute majority.

Table 2: Search history Medline/Pub Med

No. Search terms	Matches
1 Limits: All Child: 0–18 years, English, Humans, Medline, Publication Date from 1998/01/01 to 2006/07/28	484903
2 'Decision Making' [MeSH] limits: No. 1	5751
3 'Treatment Refusal' [MeSH] limits: No. 1	779
4 'Informed Consent' [MeSH] limits: No. 1	2600
5 'Mental Competency' [MeSH] limits: No. 1	327
6 'Patient' Participation [MeSH] limits: No. 1	586
7 No. 2 or 3 or 4 or 5 or 6 Limits: No. 1	8986
8 'Pediatric Nursing' [MeSH] limits: No. 1	3226
9 No. 7 and 8	215
10 Decision making competence limits: No. 1	239
11 No. 9 or 10	440

Table 3: Search history PsycINFO

No. Search terms	Matches
1 Exp. Decision Making/	31052
2 Exp. Treatment Refusal/	403
3 Exp. Informed Consent/	1784
4 Exp. COMPETENCE/	7204
5 Exp. PARTICIPATION/	8177
6 No. 1 or 2 or 3 or 4 or 5	47084
7 Paediatric nursing. mp	4
8 Pediatric nursing. mp	51
9 No. 7 or 8	54
10 No. 6 or 9	47138
11 Decision making competence. mp.	37
12 No. 10 or 11	47145
13 Limit No. 12 to (peer reviewed journal and English language and (100 childhood <birth to age 12 years >or 200 adolescence <age 13 to 17 years >) and year = 1998–2006)	2256

Firby (1995) has introduced guidelines for critique of ethical aspects of a research study. Concerning literature reviews, readers have to consider whether the researcher had referenced all articles or just those which support their ideas (Firby 1995). There were ethical

discussions in all included studies in this literature review, as well as all articles relevant for the purpose of the study have been referenced.

Figure 1: Summary of the literature searching process.

Results

Results are displayed in two initial overviews of 15 articles in review, containing four quantitative (Table 4) and 11 qualitative (Table 5) studies. The thematic review gave six major themes that the results could be principally included into: measurable issues, values and beliefs, power, parental related communication, trust and self-determination.

Table 4: Overview of quantitative articles in review

Study/setting	Purpose	Method	Sample	Results
Billick et al. (1998) USA	Assess competence to consent to child psychiatric hospital care and treatment	CQ-ChP [†] A 17-item competency questionnaire	n = 25 Consecutive inpatients 9 girls, 16 boys 9·9+–2·0 years	Statistical significance p < 0·05 association between reading level at the 5th-grade standard and competence using CQ-ChP [†]
Billick et al. (2001) USA	Evaluate competence to consent to treatment in paediatric care	CQ-Peds [‡] A 19-item competency questionnaire	n = 92 consecutive in- and outpatients 42 girls, 50 boys 5–18 years old mean age 10·6 years	Good understanding of illness and treatment, age and competence assessed

Hanna and Guthrie (2003) USA	Describe and explore the behavioural autonomy, both independent functioning and decision making	The Daily Diabetes Management Checklist 14 item The Non-daily Diabetes Management Checklist 20 item	n = 32 adolescents with Type 1 diabetes 11–18 years old 14·7+–2·0 years	with CQ-Peds [‡] Strong relationship between independent decision making and functioning
McAliley et al. (2000) USA	Examine if teenagers are interested in and are able to talk about advanced directives	HCAT [§] Questionnaire advanced directives. Demographic form	n = 107 teenagers ability to pass HCAT 69 girls, 38 boys 15–18 years old 16·4 +–1·0 years	They were interested in and able to talk about advanced directives and health care choices in end of life situations

[†]CQ-ChP = Competency Questionnaire – Child Psychiatric.

[‡]CQ-Peds = Competency Questionnaire – Pediatric Outpatient Modified Version.

[§]HCAT = Hopkins Competency Test.

Table 5: Overview of qualitative articles in review

Study/setting	Purpose	Method	Sample	Results
Coyne (2006) UK	Explore children's, parents' and nurses' opinions on participation in care in healthcare setting	In-depth interviews questionnaires observations. Grounded theory	n = 11 children 10 parents 12 nurses	Children verbalized need for consultation and information. Nurses viewed the child's participation as dependent on cognitive development
Meng and McConnell (2002) USA	Examine how children with asthma and their parents make decisions about treatment	Focus groups interviews. Thematic analysis	n = 28 children who had been in an asthma camp programme 11 girls, 17 boys 7–12 years old 21 parents	Symptoms of asthma were the most important for children to treat themselves and the biggest force to make them talk to their parents
Miller (2001) UK	Investigate how paediatric nurses see themselves facilitating young people in decision making	Focus group interview. Thematic analysis	n = 8 female paediatric nurses in a district hospital	They felt supporting decision making was important through: knowing the individual and the context, by age-appropriate information and

				considering ethical, legal and professional dimensions.
Noyes (2000) UK	Describe ventilator-dependent young people and their parents views and experiences of health and social care and education	In-depth interviews. Different techniques communication with children, NSPCC 1997 [†] . Analyses with UNCRC and national law as guidelines	n = 18 ventilator-dependent children 8 girls, 10 boys 6–18 years old 25 relatives, most of them parents	Articles in UNCRC were not paid attention to by staff. Some young people did not have access to a suitable communication system and could not freely give their opinion
Runeson et al. (2000) Sweden	Identify everyday situations in nursing where staff allowed or denied children participation	Narrative interviews with children and parents. Qualitative analyses with 'Scale of Degrees of Self-determination' to value participation	n = 26 children 16 girls, 10 boys 6–17 years old 21 parents	Children were permitted to participate to different degrees, from the lowest where staff did not listen to the highest, where staff respected the child's opinion
Runeson et al. (2001) Sweden	Identify important factors for children's participation in their own care	Critical incident technique. Qualitative analyses	n = 140 people working with children in hospital gave 92 written narratives	Children could affect their situation in some cases but violating actions were also performed
Runeson et al. (2002) Sweden	Identify everyday situations in nursing where children's level of participation is described	Observations of children, parents and staff. Qualitative analyses with 'Scale of Degrees of Self-determination' to value participation	n = 24 children two girls, 22 boys 5 months–18 years old	Level of participation was not always optimal. No situation was assessed as too high a level of participation of the children
Tates et al. (2002a) Netherlands	Explore the nature of communication in the doctor–parent–child triad and in terms of child-centred and family-focused	Videotaped observations. Cross-sectional comparison. Analysis of interaction by RIAS [‡] .	n = 106 children being videotaped 55 girls, 51 boys 4–12 years old	Children's participation during examination was limited. Child's age was positively correlated with participation with the doctor
Tates et al. (2002b) Netherlands	Classify adult behaviour in terms of supportive vs. non-supportive to children's participation in the medical interaction	Videotaped observations.	n = 105 children being videotaped 4–12 years old	In 72% of the medical encounters, behaviour on the part of the adults was non-supportive to the child's participation
Woodgate (1998) USA	Describe chronically ill adolescents' view of how healthcare	Focus group Interviews. Thematic analysis	n = 23 teenagers 12 girls, 11 boys 13–	They describe attributes of healthcare professionals that helped

	professionals best can take care of them		16 years old	promote positive interactions
Young et al. (2006) UK	Explore children, parents and practitioners' report s of shared decision-making	Semi-structured interviews. Focus group	n = 11 children 12 parents 10 practitioners	Children negotiated about how interventions were put into practice

[†]NSPCC 1997 = The National Society for the Prevention of Cruelty to Children's Turning Points resource pack, 1997.

[‡]RIAS = Roter Interaction Analysis System.

Measurable issues

Age, reading ability and memory are measurable issues that occur in this review to assess decision-making competence. McAileay *et al.* (2000) used Hopkin's Competency Test (HCAT) (Janofsky *et al.* 1992) to measure competence for entry to a study of use of advance directive in 107 adolescents. HCAT assesses ability to read, understand and retain a text. The participant reads a short text about informed consent and power of attorney, while the researcher simultaneously reads the same text aloud. The researcher then removes the text and the participant answers six questions verbally, the answers are scored. All 107 adolescents, with the exception of one, were defined as competent according to HCAT.

The Competency Questionnaire-Child Psychiatric (CQ-ChP) consists of 17 items used to measure competence only (Billick *et al.* 1998). Two girls and five boys of 25 children were assessed as being incompetent. In the competent group, mean age was 10.1 years and in the incompetent group, 9.6 years. This study does not support the belief that competence is related to age (Billick *et al.* 1998).

The Competency Questionnaire-Pediatric Outpatient Modified Version (CQ-Peds) (Billick *et al.* 2001), comprising 19 items, emphasizes developmental aspects of competence in children and is a modified version of CQ-ChP. There is a statistically significant linear correlation ($p < 0.003$) between age and competence evaluated in CQ-Peds. The article contains two consolidated studies of a total of 92 children, 42 girls and 50 boys (Billick *et al.* 2001).

Billick *et al.* (1998, 2001) wished to determine an age when competency was achieved, but results did not allow this. However, reading level at the 5th grade standard, on a six grade scale, is related to competence as measured by CQ-ChP and CQ-Peds and can be compared with the stage of concrete operational thinking from the age 11–12 years (Inhelder & Piaget 1958).

Values and beliefs

Attitudes of healthcare professionals to children are mainly grounded in personal values and beliefs. A study by Coyne (2006) points out how 12 nurses viewed children's involvement in their own care as dependent upon cognitive maturity. Miller (2001) shows that eight paediatric nurses in a district hospital find it important for young people to participate in

decision making in their own care, they stressed that one of their obligations is to contribute to them becoming competent decision makers. An interview study of 26 children and 21 parents by Runeson *et al.* (2000) describes how nursing staff may allow children to participate in their own care. The Scale of Degrees of Self-Determination (Hermerén 1996), which describes five levels of self-determination, was used in the analysis. In 63 situations, out of 100, staff did not pay attention to the child, although they listened to the child in 30 of these situations. In the remaining 37 situations, staff listened and respected the child's points of view, wishes or values, totally or partly (Runeson *et al.* 2000).

Power

Power to influence nursing care situations was seen in the following studies. Runeson *et al.* (2001) analysed 92 written narratives about children's participation in decision making in their own care. The results show six factors that affected children's participation in a positive or negative direction: (i) protest of the child; (ii) age and maturity of the child; (iii) role of the parent; (iv) attitudes of the staff; (v) time factor and (vi) alternative ways to solve problem. This study shows that children are dependent on adults and their attitudes towards them (Runeson *et al.* 2001).

In an observational study of 24 children, Runeson *et al.* (2002) analysed 137 situations concerning children's participation in their own care. The Scale of Degrees of Self-Determination (Hermerén 1996) was used to evaluate level of participation. The child's opinion was ignored in 72 situations although they were listened to in 65 of these situations. In the remaining 65 situations, staff listened and acted more or less according to the child's desires. Nursing staff reiterated what was going to happen without presenting any alternative or asking for the child's opinion. Nurses were sometimes involved in an ethical conflict between supporting the child and following routines of the ward. It is important to view children as potential autonomous persons and one of the main tasks of staff is to support children's participation in their own care (Runeson *et al.* 2002).

In the study by Noyes (2000) of 18 ventilator dependent young people, results show that nurses took neither the UNCRC nor national legislation in the UK into consideration when caring for these patients. Authorities show an inability to co-operate in the best interests of the child (article 3 in UNCRC). Not all the young people had access to a communication system corresponding to their needs and they were not able to express their opinion freely (article 12 in UNCRC). Neither did they always have access to adequate information and were thereby frequently excluded from making important decisions in their own lives (article 17 in UNCRC). Some of them did not receive competent care and treatment (article 24 in UNCRC). The study contains strong evidence that nurses decided what needs the young people and family had. The young people, however, wished to decide over their own lives but were not allowed to do so and they were critical towards several aspects of their care (Noyes 2000).

Young *et al.* (2006) conducted semi-structured interviews with 11 children with cerebral palsy and 12 of their parents and two focus groups with 10 physiotherapy practitioners. Practitioners are responsible for making decisions about the interventions while children are mainly restricted to discussing performance.

Parent-related communication

Two studies showed a communication pattern where the child was involved in a mainly parental related way. *Tates et al. (2002a)* present the medical interview as having two main purposes – information sharing and a possibility of creating a good interpersonal relationship. Interaction was analysed according to a modified version of the Roter Method of Interaction Process Analysis (RIAS) (*Roter 1989*). At beginning of the medical examination, physicians joked to decrease the child's stress. Seventy six per cent of the medical information concerning the child was directed towards parents. There was a difference in parents and physicians' attitudes towards the child. Physicians encouraged older children to participate, while parents limited the child's participation irrespective of their age. The medical meeting was dominated by the adults, 52% of the time was taken by the physician, 38.4% by the parents and the child had 9.6% of the time. This result implies that physician's communication is parent-related. The study has been continuing for approximately 20 years with videotaping, but there is no evidence of changes over time with regard to children's participation and physicians' attitude towards the medical encounter. *Tates et al. (2002a)* view information process as a prerequisite for decision making. Through encouraging children's participation, physicians show that collaboration in the medical encounter is desirable and indicates children as being autonomous participants.

In another article by *Tates et al. (2002b)*, the adult (doctor and parent) behaviour in the medical history taking, as well as in the part of diagnosis and advice, was analysed. Adults were supportive in 6% of consultations while in 72% of consultations they were non-supportive towards the children. Children were actively involved in medical history taking in 48% and passively in 19%. Forty-two per cent of interaction involved the children when discussions surrounded diagnosis and giving advice. Parental manners influence the doctor in shifting from a supportive to a non-supportive behaviour towards the child. When parents ask many questions and expresses emotional concerns, doctors have to focus on the parent instead of the child (*Tates et al. 2002b*).

Trust

Trust is to be seen as a certainty founded on past experience: children relied on themselves and on their parents in situations that arose and that was supportive in the decision-making process. *Meng and McConnell (2002)* studied the degree to which 28 children with asthma who had been in an asthma camp programme made treated-related decisions. Six themes emerged: (i) worries; (ii) knowledge about asthma; (iii) school issues; (iv) medication; (v) parental support and (vi) a wish to be viewed as normal. The children thought that worry related to symptoms was the most important factor when treating them. Disruptions from daily life were of secondary significance, despite the children being anxious about their asthma; they sometimes permitted symptoms to escalate before they chose to treat themselves. Sometimes the children made a decision to ignore symptoms. They were not motivated to take medication to prevent symptoms of asthma; they used medication to treat symptoms present.

Self-determination

Self-determination is power of making free choices unrestricted by external influence. Coyne's study (2006) of 11 children, 10 parents and 12 nurses, shows how children express their wish for consultation and information to understand their disease, participate in their own care and prepare themselves for procedures. Woodgate (1998) states that the 23 chronically ill teenagers thought that nursing staff should have sufficient knowledge and ability to show them trust and sensitivity. The teenagers gave some directions to the staff: treat me as a person, try to understand me, do not treat me differently, give me some encouragement, do not force me, give me freedom to choose, have some humour and have knowledge about what you are doing (Woodgate 1998). A study by Hanna and Guthrie (2003) of 32 adolescents with type 1 diabetes shows that metabolic control was correlated to the adolescents' independent decision making ($r = 0.39$, $p = 0.02$). Two checklists were used, the Daily Diabetes Management Checklist and the Non-daily Diabetes Management Checklist. In early adolescents, ≤ 14 years, there was less independence in daily diabetes management functioning than in late adolescence, ≥ 17 years.

The synthesis that emerges from analysis of the findings is that children's decision-making competence in health care is mostly dependent on parents' and healthcare professionals attitudes, rather than on their own capacity. Results of measurable issues explore efforts to assess children's decision-making competence with the minimal bias feasible. Healthcare professionals work according to their values and beliefs and that may result in powerful behaviour and, consequently, collaboration from the parents' point of view. Children show trust in their parents, as they seek their support while having symptoms of the disease, despite not having taken medication as prescribed. The importance of children's self-determination to maintain good metabolic control has been observed.

Discussion

Method

General standards for systematic searching are most valuable in finding the required literature (Hek *et al.* 2000). The method of searching in databases is not only limited by search terms but databases themselves also have limitations. Individuals submitting articles to respective databases use terms in form of key words, but it is each individual who chooses which key words to use. This can be illustrated by an article, present in two separate databases, having different key words in each of the database, as for example Noyes (2000), where decision making is used in CINAHL but not in Medline. The explanation of Mesh terms also differs slightly between the databases. There are several articles that occurred in more than one database, but it is important to view all databases, so that nothing is missed (Hek *et al.* 2000). Duplicates, because of the search strategy, occurred between CINAHL and Medline, but there were no duplicates to PsycINFO. Figure 1 shows five articles in review from CINAHL and just one article in review from Medline/Pub Med, simply because priority of databases searched, CINAHL before Medline/Pub Med. Surprisingly, all articles in review were to be found in Medline/Pub Med, with varying search terms, when searching by author name. There is a common opinion that a literature review is a very distinct method (Hek *et al.* 2000), but there must be an awareness of these basic prerequisites.

Results

Children's decision-making competence in health care is a most challenging discussion topic. It has been questioned if every person wants to make a decision and, of course, they want to. A decision can simply be to leave to another person to make the decision (Degner *et al.* 1997). Previous studies deal mostly with the child's decision-making competence in the context of the family and health care, such as that of Hallström and Elander (2005). Children's almost natural position of dependence on their parents and healthcare professionals makes it easy to damage the child's integrity (McPherson & Thorne 2000). Integrity cannot be substituted (Bischofberger *et al.* 1991), but is this not what is happening now and then to children in health care? Most often it is in the name of the child's best interests. After all, there is a deep concern for the best interests of the child (Lowden 2002). This is what makes it problematical: to do good but not to harm. The child is not a miniature adult, so there are difficulties when a concept such as competence is related to children, assessed not to be competent because of age. The following discussion intends to focus on the articles in review from a child's point of view. The composition of articles in review, with both qualitative and quantitative approaches, results in considerations involving several aspects.

Decision-making competence was measured by reading ability (Billick *et al.* 1998), reading ability and having reached a certain age (Billick *et al.* 2001) and reading ability, understanding and ability to remember a text (McAliley *et al.* 2000). Constructions of the measuring instruments may depend on these parameters being something that is measurable. The CQ-ChP (Billick *et al.* 1998) has been adapted for situations in the USA; in Sweden, it would be impossible to ask a child some of questions about juridical circumstances. Except for juridical questions, the instrument seems to be useful in other countries and may be helpful in assessing children's decision-making competence. It is, however, questionable whether children who have been admitted to child psychiatric care should be asked if they consent to contribute to a study. These children must be viewed as being in a very vulnerable position, the mean age of these children was only 9.9 years and there was no case of decline (Billick *et al.* 1998). Some of the questions in CQ-Peds (Billick *et al.* 2001) might be difficult for a 12 year old child, such as question 12: 'is there anything bad about the medicine or your treatment?' Children probably do not have an answer to this question, as this kind of information is seldom given to the children (Tates *et al.* 2002a). Children usually receive more information the older they are (Tates *et al.* 2002a), resulting automatically in them being assessed as competent according to age. Billick *et al.* (2001) support 12 years as a common age when decision-making competence is reached, just as in the study of Weithorn and Campbell (1982). The results are based on same grounds, Piaget's stage of concrete operational thinking from the age of 12 years (Inhelder & Piaget 1958). Contradictory to that, Billick *et al.* (2001) show that child much younger than 12 years of age may be assessed as competent accord to CQ-Peds. If reading ability is a measure of competence, a person with dyslexia may not be deemed to be competent and that is not realistic. Pearce (1994) stresses that it is not logical that competence is automatically reached at a specific age.

Hopkin's Competency Test was used in one particular study (McAliley *et al.* 2000), because it had been used earlier with adults participating in studies because of advanced directives and adults are always seen as competent decision makers. This instrument specifically evaluates reading ability and memory, rather than competence.

In the study by Miller (2001), paediatric nurses found supporting the transition of responsibility from parents to the young people in their own care to be of importance. Facilitating children to become competent decision makers is also one of nurse's tasks (Penticuff 1990, Fulton 1996, Brook 2000, McPherson & Thorne 2000). Penticuff (1990) intends paediatric nurses to protect children's self-determination by carefully preparing them for examinations. Fulton (1996) points out that paediatric nurses need education to be able to assess children's competence. Coyne (2006) elicits how some paediatric nurses perceive children's involvement as dependent on their assessment of the child's cognitive development. The information process is crucial in making it possible for children to participate in their care and make decisions (Brook 2000). Children's thoughts and feelings must be valued by nurses in the power structure where they take place (McPherson & Thorne 2000).

Nursing staff allow children to participate to different degrees (Runeson *et al.* 2000, 2002). This may depend on what approach they have, if they are 'liberationist', 'protectionist' or 'pragmatist' (Fulton 1996). Children need help from adults when meeting new situations and are in a position of dependence upon them and their values (Lögstrup 1997) and are obliged to be listened to because of article 12 in United Nations (1989). Brook (2000) emphasizes that working with children demands a relation involving mutual respect and trust and Bricher (1999) found that paediatric nurses worked in a trustful manner with children. It is very serious when nurses adopt a confidence-inspiring behaviour, but if things are going in wrong direction, they do exactly what it takes to get things done (Bricher 1999). Kitching (1998) stresses that paediatric nurses have to be aware of their own values. Children may affect some nursing situations but nursing is sometimes performed in humiliating ways (Runeson *et al.* 2000, 2001). Difficulties arise when children's integrity is not taken into consideration. Values of nursing staff and parents influence their attitudes towards children (Kitching 1998, Noyes 2000). The level of participation is not always optimal but intimidating, when research seems to indicate a lack of emotions in paediatric care (Runeson *et al.* 2002). Children are vulnerable to adults and their attitudes and paediatric nurses ought to respect children as future autonomous persons, as well as support children in becoming competent decision-makers (Lowden 2002, Runeson *et al.* 2002).

Physicians may take children's age into consideration during the medical examination (Tates *et al.* 2002a,b). This attitude is emphasized by King and Cross (1989) although in a more structured manner. The medical appointments (Tates *et al.* 2002a) lasted on average seven minutes, which may contribute to the parental-centred information, which was the easiest and fastest way to go. This relative lack of time can also explain why there has not been any change over 20 years in the cross-sectional comparison (Tates *et al.* 2002a). Needs of parents and children may differ in the medical encounter, but the human right to be respected as a person never differs according to age reached (Tates *et al.* 2002a,b).

Children with asthma thought that symptoms were the most important reason for giving themselves medication (Meng & McConnell 2002). Buchanan and Brock (1998) indicate that competence focuses on the process of argumentation and not on the solid decision. Some children think they cannot prevent symptoms; on the other hand they usually took medication when they experienced symptoms (Meng & McConnell 2002). Lögstrup (1997) implies trust as a wish to be listened to, to be listened at and to be taken seriously. Some of the focus group questions seemed to be leading, such as '...*what* was your biggest *worry*...?' The question assumes children to be worried related to asthma and the analysis gave a theme 'worry'. Some of the questions were abstract, even adults might find it difficult to explain how they thought in a certain situation.

Ventilator-dependent children are in a weak position not always having a communication system adapted to their needs (Noyes 2000). This harms their autonomy, which depends on language, (Bischofberger *et al.* 1991) thus occurs when a person cannot speak and thus has no say in the matter. Taylor (1999) considers that nursing staff have an obligation to listen to the needs of parents and make it possible for parents to make decisions according to their own values. However, children with cerebral palsy (Young *et al.* 2006) were permitted to participate in decisions concerning physiotherapeutic interventions, depending on the decision to be made. The most essential findings in the study of adolescents with type 1 diabetes are the importance of parental assistance in growing autonomy and decision-making ability of the adolescents (Hanna & Guthrie 2003). Friedman Ross (1997) points out that nursing staff harm children when they, instead of asking for a point of view, think they know what is best for them. This paternalistic attitude from staff cannot be viewed as relevant (Dickey & Deatrick 2000, Noyes 2000, Bates *et al.* 2002a,b). Paternalism means caring for a person without the person's permission and the purpose of the action is caring (Beauchamp & Childress 2001).

Conclusion

Knowledge of what influences children's decision-making competence in health care has been elicited. There are measuring instruments to be used; they need to be adapted to individual countries. It is a challenge to equalize the power in the interaction between the child, parent and healthcare professional. When this is achieved, it gives rise to the possibility of children feeling trust and to using self-determination. This is most important to the growing human being, all acts have their consequences. Children's decision-making competence is mostly dependent on their parents and healthcare professionals, rather than on their own capacity. Most of the previous research deals with adults' care in the best interests of the child. The result of searches in databases, 15 articles in review out of 5315 matches, emphasizes this. This makes it most important to continue research in this area from the children's viewpoint, to obtain teamwork between children, parents and healthcare professional in children's health care. This teamwork should integrate knowledge, aiming to improve progress and affect values and beliefs.

The issue is a most complex one, on the one hand the child is a person in a state of integrity and, on the other hand, they need support and guidance from adults. To be noticed, children always have the right to express their opinion, whether being assessed as competent or not. This is necessary for children to become potential competent decision makers in their own health care.

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