

Development of Competence for Decision-Making in Chronically Ill Children

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Assessing children's capacity for decision-making is a challenging task frequently faced by physicians. Despite its importance, a review of the literature revealed very little empirical data on the development of children's competence. This experimental study compared the decision-making ability of 20 healthy and 20 chronically ill children between the ages of nine and fourteen. A case-based interview protocol was used which defined four scales of competence: Evidence of Choice, Reasonable Outcome, Rational Reasons, and Understanding (subdivided into Rote Recall and Inference). The two groups of children performed equally well on the scales of Evidence of Choice, Reasonable Outcome, and Rational Reasons. On the scale of Understanding, the healthy children scored a mean of 11.4% higher than the chronically ill group ($p=0.02$). This difference was present across the two subscales ($p=0.03$ and $p=0.05$ for Rote Recall and Inference respectively). Thus, in determining the proper role of ill children in medical decision-making, it is inappropriate to extrapolate from developmental data obtained from healthy children. Further study must be done to clarify the magnitude and reasons for differences in the development of competence in chronically ill children as compared to healthy children. In addition, further research is needed to determine whether similar case-based interviews could and should be used in a clinical setting to help assess the child's appropriate degree of involvement in decisions about his or her own health care.

INTRODUCTION

Assessing the appropriate role of children in decision-making presents challenges for us today not previously seen. In the past, medical decisions were made by parents and doctors. Now, however, there are increasing social and legal expectations that children be involved in medical decision-making to the extent permitted by their competence. Unfortunately, medical training has not kept up with societal and legal demands in this area. As a result, many physicians feel ill-equipped to assess the competence of children and involve them appropriately in medical decision-making. Parents and health professionals share the essential duty to assess and enhance children's developing capacity. Indeed, one of the explicit goals of parenting is the child's social and cognitive development into an adult with full decision-making ability (1). As children develop, it is important that they are

given a role in decision-making commensurate with their abilities. This not only respects children in accordance with the ethical principles of autonomy and dignity, but also provides a forum in which their decision-making abilities can be further developed (1). Other benefits include fostering open communication, facilitating cooperation with treatment, and promoting a sense of control which may also assist in positive adjustment (2).

At almost any age and degree of competence, children should be involved in decision making. This involvement takes the form of a continuum ranging from no involvement, by infants, to informed consent, by older adolescents. Young children who are not competent to give valid informed consent should still be involved through the process of assent. As with informed consent, emphasis must be placed on discussion and the sharing of information and values. However, only a preference for participation is required for assent, whereas evidence of understanding and reasoning ability is required for informed consent (3).

The group of children in which the issue of competence is most unclear is children in the 9-14 age range. Below age 9, most chil-

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dren are not competent to be the primary decision-makers, although assent should be sought. The limited available data suggests that adolescents age 14 and over have decisional skills equivalent to most adults (4-6). The degree of development of competence is less clear in children in the 9-14 age range; thus, it is with this group that physicians have the greatest need for skills and tools for assessing competence of children.

INFORMED CONSENT

In order to assess the capacity for participation, parents and health care providers need to be aware of the three prerequisites for informed consent: disclosure, competence and voluntariness (7).

Disclosure of information is essential to the process of informed consent. In pediatrics, the method of disclosure, with appropriate attention to the age and maturity of the child, and the identity of the individual providing the information are extremely important. The same child who might not be able to understand information presented to him/her by a stranger might be able to comprehend and respond during a discussion with loving parents or a known and trusted physician.

Competence may be defined as the capacity to receive and communicate information, understand the information that is communicated, and appreciate the effect of an intervention and its alternatives (including no treatment) on the individual involved (8). Each of these three aspects of competence is undergoing development in children, and thus each must be carefully assessed in the determination of their competence.

Voluntariness, the ability to accept or reject without coercion, is frequently very difficult to determine in a pediatric setting. Voluntariness can be limited by internal factors such as fear, or by external factors such as coercion and persuasion.

CAPACITIES REQUIRED FOR COMPETENCE

The assessment of the individual child requires attention to three broad categories of capacities that are required for competence:

1. Capacities for communication and understanding of information
2. Capacities for reasoning and deliberation
3. Capacity to have and apply a set of values or conception of the good (4).

Medical terms and concepts are difficult to understand for both adults and children. However, it is not primarily an understanding of technical medicine which is required, but an understanding of the effect of treatment alternatives on the person's life. Children may be shy and intimidated by health care personnel and thus could be perceived as incompetent based on their apparent lack of ability to comprehend and communicate. This error may be minimized by having a trusted adult present the information to the child. In general,

comprehension and communication skills have developed to a significant extent before the child begins to develop formal operational thinking and the ability to apply a set of values. Thus, although systematic data is lacking, it is unlikely that children who are able to reason and who have and apply a set of values will be considered incompetent due to lack of capacity for communication and understanding (4).

There are a large number of issues underlying capacities for reasoning and deliberation. Some of the capacities needed for reasoning include the ability to sustain "one's attention to the task, ability to delay response in the process of reflecting on the issues, ability to think in a sufficiently differentiated manner (cognitive complexity) to weigh more than one treatment alternative and set of risks simultaneously, ability to abstract or hypothesize as yet nonexistent risks and alternatives, and ability to employ inductive and deductive forms of reasoning"(9). Children develop many of these abilities in what Piaget called the formal operations stage of cognitive development which occurs in most children between the ages of eleven and thirteen (4).

Based on available information regarding development, estimates have been made suggesting that by age 14 or 15, children have usually developed the capacities necessary to be considered competent to give informed consent (4). However, to our knowledge, only one investigator has explicitly tested these estimates with children (5,6). In that study, four scenarios of health care decisions were used to assess competence in healthy people aged 9, 14, 18, and 21 years. The study was designed to test the law's presumption of the competence of minors which contends that "the moral and intellectual maturity of the 14-year-old approaches that of the adult"(10). Weithorn found no significant difference between the competence of 14-year-olds and adults, while 9-year-olds were clearly less competent (5,6). The investigation did not attempt to assess competence of individual minors between the ages of 9 and 14, nor did it explore the applicability of such data to minors with chronic illnesses.

Available estimates regarding children's development of competence have been based on developmental data from a population of healthy children. Children with serious and/or chronic illnesses comprise a large group of those with whom the question of competence to make informed decisions arises. Terminally ill children have been found to attain a mature understanding of death much earlier than the age predicted by developmental data from healthy children (11). If this group of children is advanced in their ability to understand abstract ideas such as death, it is possible that they may also develop reasoning skills earlier than healthy children. Their experience in the health care setting may permit them to understand things that would be incomprehensible to healthy children. Also, it is possible that some components of formal operational thinking, such as abstract thinking, may not be required for chronically ill children to make competent decisions about their own treatment since certain aspects of the decision-making may be more concrete than might be anticipated. For example, ill children do not need to imagine the discomfort of frequent injections, nor the inconvenience of taking daily medication.

This study uses part of the measure of competence designed by Weithorn (5,6) to test developmental estimates of competence in a group of children with chronic illnesses. Our hypothesis is two-fold: 1) chronically ill children will perform better than healthy children on measures of competence due to their familiarity and experience with the field of medicine, and 2) the difference between the two groups will be especially marked in the Inference Subscale of the Scale of Understanding since the ill children have first-hand experience on which to draw.

METHODS

Ethical Approval

The project was approved by the Research Ethics Committee of the IWK/Grace Hospital for women, children, and families in Halifax, Nova Scotia.

Subjects

The sample consisted of 40 children between the ages of 9 and 14 years, 20 who were healthy and 20 with chronic illnesses. The group with chronic illnesses was recruited through the cystic fibrosis clinic (n=14) and the general medicine team (n=6) at the Izaak Walton Killam - Grace Hospital for Women, Children, and Families. With the help of the social worker in the cystic fibrosis clinic, families with children between age 9 and 14 years who attended the clinic during a two-week period were given a written summary of the project. Interested candidates were then approached by CW for further discussion and written consent. Children were recruited from the general medicine team in a similar manner with the help of the residents on service. These children included those with asthma, juvenile rheumatoid arthritis, and Crohn's disease. Exclusion factors included obvious mental handicap, illness or sedation severe enough to preclude the child's participation in an interview, and inability of the child to communicate clearly and in English. The healthy group consisted of children attending a church group (n=10) and their neighborhood friends (n=10). Each family in the church with children of the required age was given the written protocol and followed up with discussion as with the chronically ill children. These children served as contacts to find the remaining ten healthy subjects among their neighborhood friends, whose families were approached in the same manner. Exclusion factors included obvious mental handicap, and inability of the child to communicate clearly and in English.

Informed Consent

In addition to obtaining the consent of the parents, assent by the minors was obtained prior to the study. Both parents and children were provided with complete information about the study prior to obtaining their consent/assent.

Measure of Competence

One of the four scenarios and question schedules/scoring criteria developed by Weithorn (5,6) was used. The authors felt that the length of the entire measure of competence (MOC) (four scenarios) as described by Weithorn was impractical for use with ill children in the hospital setting. The

use of only one scenario was intended to maximize the scores of the ill children since it was felt that they might find it difficult to concentrate throughout the entire MOC due to discomfort or other illness-related causes.

Dilemma

The dilemma chosen was that of a child with epilepsy. The subjects were instructed to put themselves in the place of the character in the story and to consider which treatment alternative they might select in that situation. The information in the story included a description of epilepsy, alternative treatments (phenobarbital, phenytoin, a trial of both, or no treatment), expected benefits and side effects of these treatments, and consequences of failure to be treated (5,6).

Interview Schedule and Scoring Criteria

The interview schedule and scoring criteria were used as described by Weithorn (5,6). Briefly, four scales corresponding to the four tests of competency were used:

I. Scale of Evidence of Choice - One point was the maximum score on the Scale of Evidence of Choice, earned simply by the expression of a preference.

II. Scale of Reasonable Outcome - This scale ranked the four alternative treatment options based upon judgements of "reasonableness" by a panel of 20 experts. A trial of both medications was considered by far the most reasonable, followed by only one of phenobarbital or phenytoin, and finally, no treatment.

III. Scale of Rational Reasons - A maximum of seven points could be earned on the Scale of Rational Reasons. Subjects were asked to identify things they had considered when making their decision. One point could be earned for each of the following factors: continuation of seizures is the expected result of untreated epilepsy; continuation of seizures could lead to personal injury; continued seizures could interfere with social functioning or academic work; the medications could control the seizures; there are certain practical factors such as inconvenience associated with a regimen of daily medication; and, each of the medications has specific side effects (2 points if side effects of each medication are mentioned).

IV. Scale of Understanding - On the final scale, the Scale of Understanding, nine specific, standardized questions were asked to assess the subject's understanding of the story. This scale was divided into two subscales: Rote Recall (measuring factual understanding), and Inference (measuring appreciation). All the information necessary to answer the rote recall questions was available in the story. Two examples of questions assessing rote recall are "What are the disadvantages (or "bad things") about phenobarbital?" and "What might happen to the epilepsy if Fred/Fran doesn't do anything for it?" To answer the inference questions, subjects were required to infer their responses from the facts given in the story. An example of a question designed to test appreciation (inference) is "What might happen if Fred/Fran was in class and had a seizure?" The maximum score obtainable on the Scale of Understanding was 18 (12 on rote recall and 6 on inference).

Procedure

Each subject was tested individually by the experimenter (CW). After a review of the purposes and procedures of the study, the dilemma was read to the subject, following which the questions of the MOC were presented in interview format. After completion of MOC, subjects were asked several questions about certain experiences such as whether they knew anyone with epilepsy, had seen a seizure, or had taken medication on a daily basis. In addition, a brief health history was obtained and subjects were asked about their reactions to the story. The entire procedure required 15-20 minutes.

Statistics

Means and standard deviations were calculated for the Scales of Rational Reasons, Understanding, and both subscales. Two-tailed two-sample T-tests assuming equal variance were used to calculate p values.

Parental Reactions

Parents of the subjects were asked the following two questions: "How important do you think it is that your child is informed about his/her own health situation and be given the opportunity to participate in decisions?" and "How well do you think your child understands his/her situation and possible treatment options, if any?" For the healthy children, this question was usually answered in the context of a minor illness or injury that the child had. The health history obtained from the child was also confirmed with the parents.

Table 1: Means and Standard Deviations for Scale 3 (Rational Reasons) for healthy and chronically ill groups.

	Scale 3 score
Healthy Children	2.7 (1.42)
Children with Chronic Illnesses	2.1 (1.29)
Weithorn - healthy children aged 9	2.58 (1.25)
Weithorn - healthy children aged 14	4.33 (1.05)

to try only the phenobarbital. The ages of these children were 11.9, 12.4, and 13.1 years. One chronically ill child chose to try only the phenobarbital (age 11.5), and the remaining child chose to do nothing and put up with the seizures (age 9.3).

Scale of Rational Reasons

The mean scores of the healthy and chronically ill children were 2.7 (SD = 1.42) and 2.1 (SD = 1.29) respectively (Table 1). This difference was not statistically significant (Figure 1).

Scale of Understanding

The means and standard deviations for scale IV (Scale of Understanding) and the two subscales (Rote Recall and Inference) for the healthy and chronically ill groups are given in Table 2. On all three scales, the healthy children obtained significantly higher mean scores than the ill children (p=0.02, p=0.03 and p=0.05 for Scale of Understanding, Rote Recall and Inference respectively)(Figures 2-4).

RESULTS

Population Characteristics

The mean age in the healthy sample was 11.5 years with a range of 9.1 to 14.4 years. The group of chronically ill children had a mean age of 11.2 years with a range of 9.1 to 13.8 years. There were 13 females in the chronically ill group and 12 in the healthy group. Eight of the healthy children had had some minor illness or injury that they or their parents recalled. These included mild asthma, strep throat, laceration, hockey injury, and moderate hearing deficit corrected with a hearing aid. One child had had a single episode of hospitalization for asthma.

Scale of Evidence of Choice

All subjects expressed a treatment preference, thus all scored one point on this scale. None chose to waive decision-making authority.

Scale of Reasonable Outcome

Seventeen healthy children and eighteen children with chronic illnesses chose a trial of both medications, the option judged to be by far the most reasonable alternative in the original study (5,6). The three remaining healthy children all chose

Parental Reactions

Two parents of the chronically ill children and four parents of the healthy children were not available for comment due to physical distance (hospitalized children from outside the city) or business (healthy children with working parents). Of the remainder, all parents in the healthy group and all but one in the chronically ill group thought it was

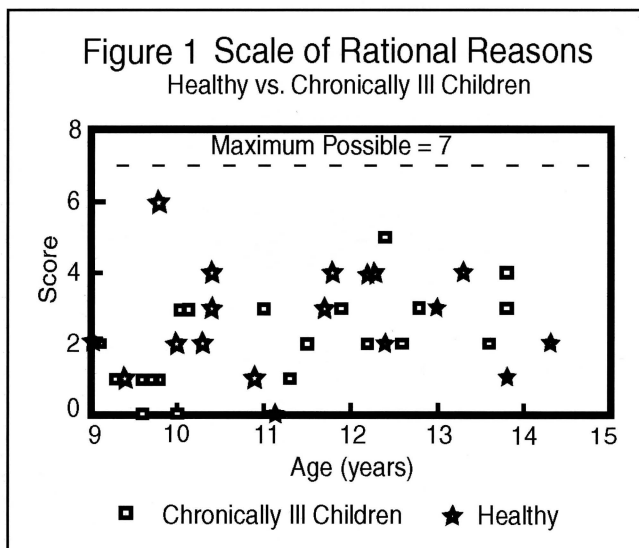


Table 2: Means and Standard Deviations for Scale 4 (Test of Understanding) and subscales for healthy and chronically ill groups.

	Total scale 4 score	Rote recall	Inference
Healthy Children	12.45 (2.665)	7.6 (2.87)	4.85 (1.226)
Children with Chronic Illnesses	10.4 (2.817)	6.25 (2.137)	4.15 (1.023)
Weithorn - healthy children age 9	11.83 (3.19)	7.38 (2.16)	4.46 (1.38)
Weithorn - healthy children age 14	15.79 (1.77)	10.21 (1.32)	

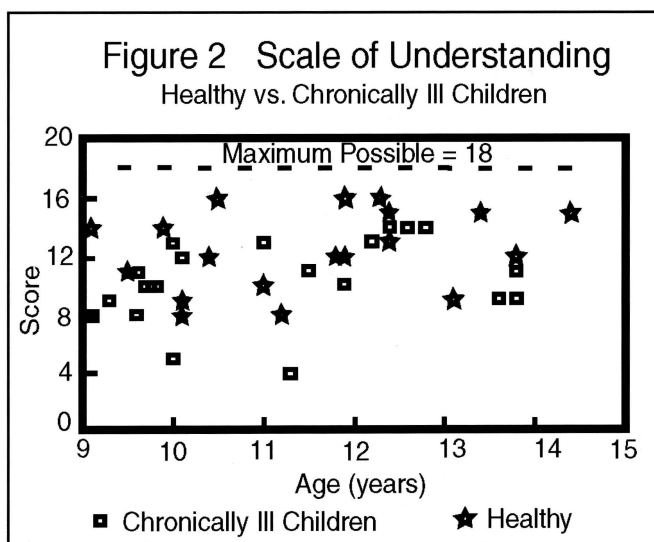
important or very important that their child be involved in his/her own health care decisions. Almost all said that they routinely involved their children in health care decisions on a gradually increasing basis as the children demonstrated understanding and desire for involvement. In most cases, however, the parents still made the final decision. Most parents felt their child understood his/her health situation reasonably well, and several said they thought their child understood it better than they themselves did. Although several parents mentioned the involvement of the child in decisions as a key factor in allowing the child to feel in control and thus reduce anxiety, two others noted that giving their child too much information caused an increase in anxiety. These two parents stressed the need for parents to be consulted and involved in the disclosure of the information, since they felt they knew better than the physicians how much information their child could handle.

ing and its two subscales. There was no significant difference between the two groups on the other three scales of competence. In general, on scale III (Rational Reasons), IV (Understanding), and both subscales (Rote Recall and Inference), the mean scores of the healthy group compare favorably with Weithorn's results (5,6), lying between this investigator's mean scores for two groups of healthy 9 and 14 year olds, respectively (Tables 1 and 2). In contrast, the mean scores for the group of chronically ill 9 to 14 year-olds lies well below Weithorn's mean scores for the healthy 9 year old group on scales III and IV (overall and both subscales). Of particular note, this poorer scoring by the chronically ill children was also evident on the inference subscale, despite their first-hand experience with the health care setting.

Other studies have found a similar effect of chronic illness in delaying the attainment of Piagetian conservation tasks (12), and the development of general reasoning skills and conceptualizations of illness causation and bodily function (13). Even the presence of an ill sibling may be enough to lower a child's illness conceptualization level as compared with children with healthy siblings (14).

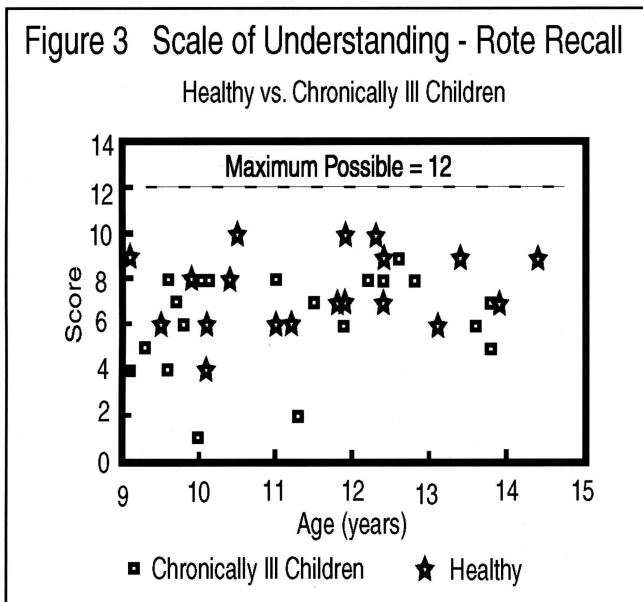
There are numerous factors which may play a role in delaying the development of competence in a seriously or chronically ill child. Anxiety or depression may impair the child's ability to understand, remember, concentrate, and reason, as may fatigue, pain, medications, and a variety of other physical factors. The very presence of chronic illness may limit children's interaction with their environment due either to physical limitations or parental overprotection. Contrary to intuition, chronically ill children may actually have less of an opportunity to develop responsibility and practice decision-making because parents and health care professionals feel obliged to enforce treatment on a daily basis. This may in turn promote learned helplessness and delay the development of an internal locus of control which is necessary for competence in decision-making.

Despite the lower scores on scales III and IV in the chronically ill group, all children in both groups appeared competent by the standard of scale I (Evidence of Choice), and many children chose the most rational outcome on scale II (Reasonable Outcome). As in Weithorn's study (5,6), however, a small percentage of children chose to try only the phenobarbital, a choice which Weithorn attributed to the concerns of early adolescents about body image, given that phenytoin may affect teeth and gums and cause hirsutism. Of the four children choosing to try only phenobarbital, two had higher than average scores on both scale III and scale IV, and



DISCUSSION

The purpose of this study was to assess whether children with chronic illnesses are more mature than healthy children in their development of capacity to provide informed consent. The study compared the performance of 20 healthy and 20 chronically ill children aged 9 to 14 on a measure designed by Weithorn (5,6) to assess competence according to four legal standards of competence. Despite the small size of our sample, the healthy children scored significantly higher than the chronically ill children on the Scale of Understand-



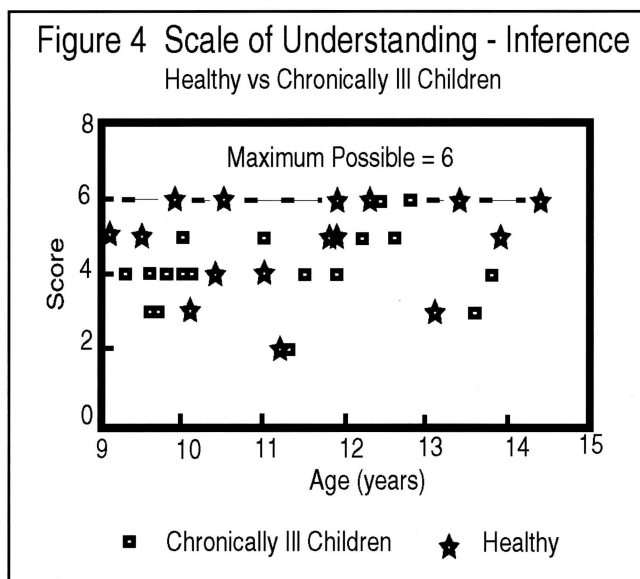
the other two had higher than average scores on either scale III or scale IV. Thus, it seems unlikely that the choice to try only phenobarbital is attributable to a lower level of cognitive functioning. Instead, it underlines the importance of assessing issues other than cognitive development in determining ability to give informed consent, such as voluntariness and a relatively stable concept of what is important to the individual.

Some difficulty in attempting to assess children's development of competence in this study is encountered due to the imprecision of children's terminology. For example, children frequently make statements such as the medication will "make it go away" or "hopefully get rid of the seizures" or "stop it completely". It is often difficult to assess whether the child means that the medication will "control the seizures completely" (a correct answer) or "cure the problem" (incorrect). Indeed, the distinction between pathology and symptomatology is a difficult one, and many children may be unable to conceive a difference between absence of seizures and absence of pathology. To ensure consistency, in this study all children who gave ambiguous statements like those mentioned above were scored as though they meant "control the seizures completely". Only if a child explicitly mentioned "curing" the illness was s/he given zero on that question. Since this imprecise terminology was used by several children in both the healthy and the chronically ill groups, and was limited to one question, a different scoring of the response is unlikely to affect the outcome.

It is important to remember that competence is decision-specific. A child may be competent to give consent to receive an antibiotic for an ear infection, but the very same child is not likely to be considered competent to consent to chemotherapy for leukemia. For this reason, it is likely that standardized stories and questions will be of less use in the clinical setting than in the research setting. However, the same principles used to measure competence in this study may be used in a clinical assessment of competence. For example, it

is first necessary to ascertain whether the child wishes to participate in the decision, or defer to someone else (Evidence of Choice). Even young children may be competent according to the scale of Reasonable Outcome (i.e., they may choose what is, in professional opinion, the most reasonable option). The scales of Rational Reasons and Understanding may also be modified for use with the patient's own "story" of illness. It is important to ask specific questions to assess both components of understanding: rote recall and inference. It is also essential, however, to ask the child to explain in his own words the reasons for his choice (Rational Reasons). This helps to assess the ability of the child to process several different options at once and enables the examiner to better understand the level of the child's reasoning process. It is possible for a child with a good memory to answer specific questions appropriately, but lack both understanding of the situation and the ability to integrate the pieces of information and apply them to the decision at hand. In certain cases, the measure of competence may be useful as a screening tool in the assessment of competence. This may give the health professional an idea of the approximate level of development of the child's thinking process. If it is used in this manner, however, it must be followed with an assessment of the child's competence with regard to his particular situation, since competence is decision-specific.

This study raises important questions about the appropriateness of extrapolating data on the development of competence from healthy to chronically ill children. However, it does have several limitations. For logistical reasons, children comprising the healthy group were drawn from those attending a church group and their neighborhood friends rather than, for example, a public school. All were from a middle or lower middle class background. Discussion with the social worker in the cystic fibrosis clinic confirmed that the socioeconomic status of the children with cystic fibrosis was roughly equivalent to that of the healthy children, however formal tests were not made. In addition, it is not known what proportion of the ill children attend a church



group, nor whether such attendance has any effect on the development of competence.

The sample size, although large enough to attain statistical significance, is nonetheless small and further study should be done with a larger sample size. Because of the small sample, we were unable to evaluate subgroups of children who had a specific illness, more severe course, or sibling with chronic illness. It is quite possible that there are differences in the development of competence in such subgroups. Other variables, such as parenting style, intelligence, and amount of time spent in hospital may also affect the rate of development of competence. Further research must be done to clarify the magnitude and reasons for differences in the development of competence in chronically ill children as compared to healthy children. If reasons for delayed development of competence in chronically ill children become clear, it is possible that interventions might be developed to assist in the normal development of competence. In addition, more research is needed to determine whether similar case-based interviews could and should be used in a clinical setting to help assess the child's appropriate degree of involvement in decisions about his or her own health care.

CONCLUSION

In determining the proper role of ill children in medical decision-making, it is inappropriate to extrapolate from developmental data obtained from healthy children. There appear to be differences in the development of competence in healthy and chronically ill children, and further research is required to clarify the magnitude and reasons for these differences. Chronically ill children form a large group of those children who are involved in medical decision-making. Thus, it is important that we understand as much as possible the development of competence in this group so we can involve them appropriately in decision-making.

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