



# Evaluating Parents' and Children's Assessments of Competence, Health Related Quality of Life and Illness Perception

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## Abstract

**Objectives** Research on participatory medical decision making in children is still scarce. At the same time, there is broad consensus that involving young patients in decision making processes increases their adherence to medical procedures and reduces anxiety. Thus, this cross-sectional study's objective was to assess mothers', fathers', and children's evaluation of the child's decisional competence in the context of psychosomatic and psychiatric care and test for possible predictors of competence such as illness perception, health-related quality of life (HrQoL), socioeconomic status, gender, and age.

**Methods** Fifty-four families (mother, father, child triads; total  $N = 143$ ) completed self-report questionnaires. Age of the children ranged from 6–16 ( $M = 11.68$ ,  $SD = 2.74$ ; 43% female), and the majority had a diagnosis of hyperkinetic, depressive or pervasive developmental disorders. 80% of children were German native speakers, and 27–37% of parents had a university degree.

**Results** Findings show that parents rate the consequences of the child's illness as more severe and report to understand it better than the child. Also, children indicate the proposed age for autonomous decision making as lower (13.55 years) than their parents (15.63, 16.58). Furthermore, age of child, mother, and father, HrQoL, illness coherence, and emotional illness representation emerged as significant predictors of the decisional competence subscales understanding, autonomy, decision making, and attitudes.

**Conclusions** This study demonstrates the importance of considering all parties in shared decision making. Future research is challenged to more comprehensively evaluate contributing factors to achieve a more valid picture of children's decisional competence.

**Keywords** Participatory decision making · Children · Parents · Illness perception · Health-related quality of life

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Respecting a child's will and considering its best interests are regarded key ethical standards in pediatrics and child psychiatry, irrespective of whether it is a matter of including a child in research (e.g., Flewitt, 2005; Hein et al., 2012; Helseth and Slettebø, 2004; Knox and Burkhart, 2007) or treating it for a medical illness or mental disorder (e.g., Alderson et al., 2006; Levy et al., 2003). There are manifold reasons for involving even young patients in decisions that affect them: Involvement may prevent misunderstandings, increase a child's compliance, courage and confidence as well as reduce anxiety (Alderson, 1993). Accordingly, most ethical guidelines (see Felnhofer et al., 2011) emphasize the importance of the child's active participation in the process (John et al., 2008). Yet, considerably little is still known about how participatory medical decision making is factually implemented and how it is perceived by those affected (Fundudis, 2003; Miller et al., 2004).

In many countries, children up to the age of 14 are not considered to be capable of providing legally valid consent. They are presumed to lack both the understanding of relevant information and the ability of evaluating this information thoroughly in order to reach a decision (Alderson, 2007). However, various studies call a general age cut-off into question (e.g., Billick et al., 1998; Tait et al., 2003) and stress that children, irrespective of age, should be meaningfully included in decisions that affect them (Gibson et al., 2011).

Another issue is the lack of a commonly accepted operational definition for decisional competence in children. There is some consensus that—in order to be deemed competent—a child should be able to understand and appreciate the nature of illness, to reason about the advantages and disadvantages of a given treatment and to reach a final decision (Hein et al., 2014). Overall, the child's ability to participate in the decision making process is thought to be influenced by a number of factors which have been comprehensively summarized by Miller et al. (2004). The model is based on a narrative review of according empirical studies including children and adolescents with a range of chronic somatic illnesses (e.g., obesity) and mental disorders (e.g., ADHD). Thus, it may be regarded as generalizable across several illnesses. Apart from predisposing aspects such as prior experiences, knowledge and attitudes, the model proposes that child specific factors (i.e., preference for involvement, health status) and parent factors (i.e., facilitation of involvement, understanding of consent) all contribute to the child's factual participation in clinical decision making.

Although child and parent factors are deemed equally crucial in Miller and colleagues' conceptual model (2004), there is a noticeable lack of research considering them. Especially parents' perspectives on their child's autonomy and decision making competence have thus far been largely neglected in empirical studies (Miller et al., 2004). One exception is the study by John and colleagues (2008), which showed that the majority of parents readily assume the role of decision maker, leaving their children unaware of the possibility of a veto. Consequently, children often underestimate their own decisional rights, resulting in the conviction that only their parents should make decisions (Ashcroft et al., 2003). Additionally, Alderson (1993) found that parents tend to evaluate their children's decisional ability depending on their gender, with daughters being deemed as ready to decide two years earlier than sons.

Similar to gender, parents' assessment of their child's capacity can also vary depending on the child's illness; hence, parents may allow their child more or less decisional authority depending on their attitude towards the child's illness, which in turn may affect the child's own illness perception (Singh, 2003). Illness representations—as

described by the widely used *Self-Regulatory Model* (Leventhal et al., 1984)—have generally been shown to exert a significant influence on a range of health-related outcomes such as coping, functional adaptation, quality of life, and adherence to medical procedures and recommendations (Broadbent et al., 2006; Moss-Morris et al., 2002). Thus, the belief that the child's illness is severe, that it entails grave consequences and is uncontrollable, is expected to lead to a less favorable parental evaluation of a child's decisional competence. In contrast, successfully coping with an illness may increase the child's knowledge about it, positively influence understanding of relevant medical concepts (Alderson, 2007; Hein et al., 2015) and, thus, lead to a more positive parental assessment.

In addition to the above mentioned factors, possible differences between mothers' and fathers' attitudes need to be considered. Generally, psychosomatic and psychiatric research on children and adolescents faces the challenge of including not only mothers but also fathers (Seiffge-Krenke, 2002). Most studies consider solely the mother as an informant, and among those which ask both parents, the majority does not account for parental differences in subsequent analyses (Phares et al., 2005). However, fathers play a crucial role in a child's development and exert influences on a range of child specific factors that differ significantly from those of mothers (Bögels and Phares, 2008; Flouri, 2010; Janse et al., 2008; Phares et al., 2005). Accordingly, fathers have also been found to evaluate illness-related aspects differently than mothers (Singh, 2003).

In sum, research on children's decisional competence and factual practices is still in its infancy, and especially the consideration of different perspectives poses a great challenge in research involving minors. Hence, our objective was to assess mothers', fathers', and children's attitudes towards the child's decisional competence in the context of psychosomatic and psychiatric care and test for possible differences between the family member's evaluations of the child's competence, illness perception and HrQoL. Furthermore, we set out to identify predictors (e.g., socioeconomic status, gender, age, HrQoL) of decisional competence.

## Methods

### Participants

Fifty-four families were recruited (see Table 1 for a more sample description and procedures for more detailed information on recruitment). Some of the family members were not available to fill out questionnaires or declined participation (fathers: 9 cases, mothers: 8 cases, children: 2 cases), resulting in a total sample of  $N = 143$ . Age of the children

**Table 1** Description of the study sample

|   | Father       | Mother       | Child                  |
|---|--------------|--------------|------------------------|
| % Female  | –            | –            | 43                     |
| Age ( <i>M</i> ( <i>SD</i> ))                                     | 47.77 (7.30) | 43.75 (7.63) | 11.68 (2.74)           |
| Range   | 29–62        | 24–57        | 6–16                   |
| Born in Austria (%)   | 67           | 71           | 98                     |
| If not: Years residing in Austria ( <i>M</i> ( <i>SD</i> ))       | 23.43 (6.17) | 21.40 (8.62) | 11.00 (–) <sup>a</sup> |
| German as native language (%)                                     | 65           | 67           | 80                     |
| University degree (%)   | 27           | 37           | –                      |
| Income not or hardly sufficient (% agreement)                     | 33           | 32           | –                      |
| Diagnosis   |              |              |                        |
| E10 Type 1 diabetes mellitus                                      |              |              | 1 (2%)                 |
| E66 Obesity   |              |              | 2 (4%)                 |
| F25 Schizoaffective disorders                                     |              |              | 1 (2%)                 |
| F32 Depressive episode  |              |              | 5 (9%)                 |
| F32 Depressive episode, F50 Eating disorders                      |              |              | 3 (6%)                 |
| F32 Depressive episode, F40 Phobic anxiety disorders              |              |              | 3 (6%)                 |
| F40 Phobic anxiety disorders                                      |              |              | 2 (4%)                 |
| F43.1 Post-traumatic stress disorder                              |              |              | 1 (2%)                 |
| F43.2 Adjustment disorders  |              |              | 1 (2%)                 |
| F45 Somatoform disorders  |              |              | 3 (6%)                 |
| F50 Eating disorders  |              |              | 2 (4%)                 |
| F84 Pervasive developmental disorders                             |              |              | 5 (9%)                 |
| F90 Hyperkinetic disorders  |              |              | 9 (17%)                |
| F90 Hyperkinetic disorders, F84 Pervasive developmental disorders |              |              | 2 (4%)                 |
| F91 Conduct disorders   |              |              | 4 (7%)                 |
| F93 Emotional disorders with onset specific to childhood          |              |              | 1 (2%)                 |
| F98.0 Nonorganic enuresis, F98.1 Nonorganic encopresis            |              |              | 1 (2%)                 |
| No diagnosis  |              |              | 2 (4%)                 |
| Missing   |              |              | 6 (11%)                |

<sup>a</sup>One child was not born in Austria

ranged from 6–16 ( $M = 11.68$ ,  $SD = 2.74$ ). With the exception of one stepmother, two stepfathers, one father who adopted his child, and four legal guardians (2 fathers, 2 mothers), all other parents were the biological parents of their child. The majority of children included in the sample had a diagnosis of hyperkinetic, depressive or pervasive developmental disorders (see Table 1 for detailed diagnosis).

## Procedure

The present study adhered to the Declaration of Helsinki and was approved by the institutional review board of the Medical University of Vienna, Austria in its current form (No. 164/2015). Children and their parents were contacted by study staff not involved in ongoing treatments at both the Psychosomatic and Psychiatric Daycare Unit as well as at the Psychosomatic and Psychiatric Outpatient Clinic of a public urban hospital. Inclusion criteria were 6–16 years of

age for the child patient, sufficient language capabilities and a psychosomatic illness or mental disorder (ICD-10, F-section diagnosis), which necessitated treatment at the Daycare Unit or the Outpatient Clinic. Exclusion criteria were an acute crisis and cognitive retardation (as determined by  $IQ < 70$ ). The age span of 6–16 years was chosen in order to assure inclusion of children and adolescents at different stages of cognitive development and, thus, gain more insight into age specific evaluations and attitudes of decisional competence.

Upon signing the written informed consent forms (parents and adolescents at ages 14–16 years) or providing oral assent (children at ages 6–13 years), children and their parents filled out the paper-pencil questionnaires separately (see section Measures). Participants could terminate or withdraw their participation at any time without consequences to their current treatments; also, they did not receive any remuneration for their participation. Overall, the procedure lasted approximately 20 min, after which the

families were shortly debriefed and released. Participants received no incentives for their participation in the present study.

## Measures

### Sociodemographic variables

Participants completed a brief sociodemographic screening (age, diagnosis, country of birth, and native language) and items to assess socioeconomic status (SES) of the families (educational background and financial situation, separately for mothers and fathers). We used a proxy-variable for the socioeconomic status of the families (Braveman et al., 2005) by computing the mean of the educational level (ranging from 1–no formal education to 10–PhD) and financial situation (ranging from 1–not at all sufficient to 5–very sufficient) of both parents. The possible range of this SES proxy-variable was from 1 to 7.5, the families in our sample reported a mean of 4.56 ( $SD = 1.45$ ). Apart from this screening, all participants (mothers, fathers, and children) were provided with the following self-report questionnaires:

### Decisional competence

Based on the research of John et al. (2008) and Shaw (2001), two German self-report questionnaires—the parent version and the child version of the *Decisional Competence Questionnaires* (DCQ)—were developed by the authors of this study to measure decisional competence and decision making practices. A total of 27 statements (5-point Likert scale: totally agree – totally disagree) were generated for the parental version (DCQ-P), and 25 items were included in the children’s version (DCQ-C). Based on theoretical considerations, items were assigned to the following 4 subscales (in both versions): (1) *understanding* (the child’s understanding of and knowledge about the illness and its treatment), (2) *autonomy* (the child’s ability to voice its wishes and reach a decision), (3) *decision making* (the degree of involving the child in daily decision making processes), (4) *attitudes* (general beliefs and attitudes about children’s decisional competence). Parents rated their children, while the children rated themselves. For item examples and an English translation see Appendix A and B.

Exploratory factor analysis using principal-axis factoring was initially conducted for the parents’ and children’s version separately. Because of the small size of the Kaiser-Meyer-Olkin (KMO) measure of sample adequacy (parental: .691; children: .486), factor analysis was possible only on the combined data of parents and children. Bartlett’s test of sphericity ( $\chi^2(351) = 1077.29$ ,  $p < .001$ ) and size of the KMO (.700) showed that the items of all three

family members combined had adequate common variance to conduct a factor analysis (Tabachnick and Fidell, 2005).

The internal structure of the DCQ supported the computation of four subscales, explaining 51% of the total variance. Varimax orthogonal rotation revealed no substantial cross-loadings and each item loaded with .40 or higher on one of the factors except for items 14 (‘My child knows exactly what it wants./I know exactly what I want.’), 17 (‘If my child does not agree with my decision, I try to persuade it./My parents try to persuade me if I do not agree with their decision.’), and 20 (‘Concerning my child’s disease, I always decide./Concerning my illness, my parents always ask me before they reach a decision on my behalf.’). After dropping the three items, the four factors explained 58% of the total variance. Cronbach’s alpha was .79 for *understanding*, .70 for *autonomy*, .74 for *decision making*, and .80 for *attitudes*.

### Illness perception

The modified German version of the *Revised Illness Perception Questionnaire* (IPQ-R; Moss-Morris et al., 2002) was used to evaluate mothers’ and fathers’ perceptions of their child’s illness. The 31-item questionnaire assesses the following aspects of parental illness perception on 7 subscales (5-point Likert scale: strongly agree–strongly disagree): (1) *timeline chronic* (item example: “The illness will last for a long time”), (2) *timeline cyclic* (e.g., “The illness is very unpredictable”), (3) *consequences* (e.g., “The illness has major consequences on my child’s life”), (4) *personal control* (e.g., “The course of my illness depends on my child”), (5) *treatment control* (e.g., “The treatment can control the illness”), (6) *illness coherence* (e.g., “I don’t understand the illness”), and (7) *emotional representation* (e.g., “My child’s illness makes me feel angry”). In the mothers’ version, one item was dropped from the *personal control* subscale (“There is a lot which my child can do to control his/her symptoms”) because the reliability of this subscale was unacceptably low ( $\alpha = .53$ ) if the item was retained. The subscale *treatment control* was dropped for both parents because of its low reliability (mothers  $\alpha = .59$ ; fathers  $\alpha = .37$ ). Cronbach’s alpha for the remaining subscales ranged from .63 to .87 for fathers and from .60 to .85 for mothers. The reliability for both parents combined ranged from .63 to .86.

For children, the *Brief Illness Perception Questionnaire* (Broadbent et al., 2006) was translated into German and item wording was modified to fit children. Furthermore, the Likert-type answers were converted to a visual analogue scale (VAS, 150 mm), resulting in a short version of 7 items, each item representing a subscale of the parents’ version of the IPQ-R. These subscales were transformed (each divided by 37.5) to match the scale of the parents’ version.

## Health-related quality of life (HrQoL)

A German version of the KINDL<sup>R</sup> questionnaire (Ravens-Sieberer, and Bullinger, 1998; <https://www.kindl.org/>) was used to assess children's HrQoL via both self-report and parent-reports. The KINDL<sup>R</sup> measures HrQoL with regards to (1) *somatic well-being*, (2) *psychological well-being*, (3) *self-worth*, (4) *family*, (5) *friends*, (6) *school*, and (7) *illness factors*. A cumulative single score reflecting total HrQoL may also be computed. The KINDL<sup>R</sup> has been shown to be a reliable and valid instrument, which may be used in children and adolescents between 3–17 years of age (Ravens-Sieberer and Bullinger, 2003). The subscale *illness factors* was omitted because its reliability was unacceptable for both fathers ( $\alpha = .51$ ) and children ( $\alpha = .56$ ). Cronbach's alpha for the remaining six subscales was acceptable in this sample (mothers: .60–.83; fathers: .68–.85; children: .63–.87). The combined reliability for all members of the family ranged from .69 and .82.

## Results

Data were analyzed using IBM SPSS version 23 (SPSS, Inc. Chicago, USA). A 3 (family member: mother, father, child)  $\times$  2 (gender of the child: female, male) ANOVA was computed to analyze differences between family members considering illness perception (IPQ-R), HrQoL (KINDL<sup>R</sup>), and decisional competence (DCQ) while taking into account the gender of the child. Tukey's HSD post-hoc tests were applied when main effects were significant and Bonferroni-corrected simple effect analysis was used to break down significant interactions. To analyze possible predictors of decisional competences, hierarchical regression was used with the four subscales of the DCQ as the outcome. Data of all family members was used in the regressions to explore possible remaining predictors, even after the role of the family member is held constant. We computed regressions with three steps; SES, family member (dummy coded), and age of each family members (step 1), the subscales of the IPQ-R (step 2), and the subscales of the KINDL<sup>R</sup> (step 3). Variables were forced into the equation at each step to explore possible relationships between predictors and the four scales of the DCQ. All the predictor values had tolerance and VIF values close to 1 excluding multicollinearity.

## Differences between Family Members

A significant main effect of family member emerged in the IPQ-R subscale *consequences* ( $F(2, 131) = 6.56, p = .002, \eta^2 = 0.09$ ) with mothers ( $M = 3.08, SD = 0.58$ ) and fathers ( $M = 2.88, SD = 0.68$ ) both evaluating the consequences of the illness significantly more severe than children ( $M = 2.45, SD = 1.14$ ; see Table 2 for ANOVAs and effect sizes).

A similar main effect of family member was found in the subscale *illness coherence* ( $F(2, 131) = 4.93, p = .009, \eta^2 = 0.07$ ), as mothers ( $M = 2.71, SD = 0.84$ ) and fathers ( $M = 2.62, SD = 0.87$ ) reported a significantly higher understanding and sense-making of the illness than children ( $M = 2.04, SD = 1.33$ ). Furthermore, we found a significant family member  $\times$  gender of the child interaction in the IPQ-R subscale *emotional representation* ( $F(2, 131) = 3.61, p = .030, \eta^2 = .05$ ). Simple effects analysis revealed that if the gender of the child is female, daughters ( $M = 2.78, SD = 0.95$ ) perceived less negative cognitive and emotional representations than fathers ( $M = 1.71, SD = 0.95$ ). This does not hold true if female children are compared to mothers ( $M = 2.37, SD = 1.00, p = .685$ ) or if family members are compared in male children ( $ps = .305$  and  $.295$ ). In contrast to the IPQ-R, no significant main effects or interactions emerged for the subscales of both the KINDL<sup>R</sup> and the DCQ (all  $ps > .05$ ).

Additionally, when directly asked at what age children should be allowed to decide on their own, a main effect of family member emerged ( $F(1, 122) = 7.70, p = .001, \eta^2 = 0.11$ ). Children ( $M = 13.55, SD = 5.04$ ) significantly diverged from mothers ( $M = 15.63, SD = 2.62$ , post-hoc:  $p = .028$ ) and fathers ( $M = 16.58, SD = 2.75$ , post-hoc:  $p = .001$ ). The gender of the child was not relevant for this item (no main effect of gender or interaction,  $p$ 's  $> .529$ ).

## Predictors of Decisional Competence

The hierarchical regressions for the subscales of the DCQ are depicted in Table 3. For the DCQ subscale *understanding*, we found that age of the mother and age of the child was significant such that younger mothers and older children were associated with a greater understanding of the illness or the treatment of the child (or, the child of its own illness and treatment). After adding the subscales of the IPQ, age of the mother and the child remained significant and one subscale of the IPQ, *illness coherence*, was significant. In the final step, we added the subscales of the KINDL<sup>R</sup>. Age of the mother and the child remained significant, illness coherence, however, did not. The final model explained 41.0% of the variance ( $F(18, 74) = 2.86, p = .001$ ) in *understanding* (DCQ).

For *autonomy*, none of the added predictors in step 1 or 2 were significant. Only in the final model, after adding the HrQoL subscales, age of the child emerged as a significant predictor, meaning that the older the child is, the more autonomy will be granted to him or her. The final model explained 28.5% of the variance, however, it did not remain significant ( $F(18, 74) = 1.64, p = .071$ ).

For *decision making*, SES was the only significant predictor in step 1. It remained significant in step 2, yet both of the models were not overall significant ( $p = .329$  and  $p = .319$ ). SES did not remain a significant predictor in the



**Table 2** ANOVAs of the subscales of the IPQ-R, KINDL<sup>R</sup>, and DCQ

| Variable                              | Father (f)<br>n = 43<br>M (SD) | Mother (m)<br>n = 44<br>M (SD) | Child (c)<br>n = 50<br>M (SD) | Family member<br>F | Gender of child (male/female)<br>F | Interaction<br>F | Tukey's post-hoc tests/simple effects |
|---------------------------------------|--------------------------------|--------------------------------|-------------------------------|--------------------|------------------------------------|------------------|---------------------------------------|
| <b>Illness perception</b>             |                                |                                |                               |                    |                                    |                  |                                       |
| Timeline chronic                      | 2.46 (0.96)                    | 2.57 (0.78)                    | 2.10 (1.13)                   | 2.847              | 1.744                              | 1.308            | –                                     |
| Consequences                          | 2.88 (0.68)                    | 3.08 (0.58)                    | 2.79 (0.89)                   | 6.558**            | 1.110                              | 0.724            | m > c* (d = 0.69), f > c* (d = 0.44)  |
| Personal control                      | 2.22 (0.82)                    | 2.19 (0.71)                    | 1.93 (1.10)                   | 1.574              | 0.566                              | 0.258            | –                                     |
| Illness coherence                     | 2.62 (0.87)                    | 2.71 (0.84)                    | 2.43 (1.09)                   | 4.932**            | 0.014                              | 1.477            | m > c** (d = .60), f > c* (d = 0.52)  |
| Emotional representation              | 1.90 (0.96)                    | 2.23 (0.90)                    | 2.30 (1.37)                   | 2.285              | 1.778                              | 3.614*           | Female: c > f** (d = 1.13)            |
| <b>Health-related quality of life</b> |                                |                                |                               |                    |                                    |                  |                                       |
| Total HrQoL                           | 2.61 (0.56)                    | 2.37 (0.61)                    | 2.41 (0.79)                   | 1.599              | 0.182                              | 0.571            | –                                     |
| Physical HrQoL                        | 2.62 (0.95)                    | 2.32 (0.87)                    | 2.26 (0.88)                   | 2.071              | 1.045                              | 0.169            | –                                     |
| Psychological HrQoL                   | 2.89 (0.71)                    | 2.46 (0.88)                    | 2.59 (1.01)                   | 2.692              | 0.616                              | 0.165            | –                                     |
| Self-esteem                           | 2.34 (0.77)                    | 2.13 (0.82)                    | 1.88 (1.18)                   | 2.777              | 0.379                              | 0.321            | –                                     |
| Family                                | 2.90 (0.61)                    | 2.66 (0.74)                    | 2.99 (1.04)                   | 1.705              | 0.060                              | 0.737            | –                                     |
| Friends                               | 2.29 (0.93)                    | 2.15 (0.95)                    | 2.42 (1.03)                   | 0.898              | 0.079                              | 0.145            | –                                     |
| School                                | 2.61 (0.87)                    | 2.53 (0.79)                    | 2.35 (1.08)                   | 1.159              | 0.603                              | 1.614            | –                                     |
| <b>Decisional competence</b>          |                                |                                |                               |                    |                                    |                  |                                       |
| Understanding                         | 2.63 (0.81)                    | 2.63 (0.70)                    | 2.40 (0.89)                   | 1.227              | 1.582                              | 0.411            | –                                     |
| Autonomy                              | 2.61 (0.54)                    | 2.49 (0.54)                    | 2.61 (0.74)                   | 0.551              | 0.306                              | 0.318            | –                                     |
| Decision making                       | 2.31 (0.42)                    | 2.33 (0.52)                    | 2.37 (0.93)                   | 0.011              | 0.929                              | 2.395            | –                                     |
| Attitudes                             | 2.51 (0.71)                    | 2.44 (0.55)                    | 2.53 (0.90)                   | 0.237              | 0.967                              | 0.863            | –                                     |

Note: Degrees of freedom (df) for main effect numerators were 2 for family member and 1 for gender of the child; df for the family member × gender of the child interaction were 2. Denominators ranged between 129–132, depending on missing values

IPQ-R illness perception questionnaire revised version, KINDL<sup>R</sup> Revised questionnaire to assess health-related quality of life in children and adolescents, DCQ decisional competence questionnaire

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

final model ( $F(17, 74) = 2.15, p = .012$ ) when the KINDL<sup>R</sup> subscales were added, as only the subscale family-related HrQoL was significant. A higher HrQoL in terms of family leads to a higher involvement of children in the decision making process. The final model explained 34% of the variance in *decision making* (DCQ).

For predicting *attitudes* (DCQ), no variable was significant in step 1. After adding the subscales of the IPQ, *emotional representation* of the illness significantly predicted *attitudes*, such that a positive representation of the illness leads to more positive attitudes and beliefs about a child's decisional competence. Emotional representation also remained the only significant predictor in the final model, which explained 16.8% of the variance, but overall it was not significant ( $p = .662$ ).

## Discussion

Actively involving children and adolescents in the process of participatory medical decision making undoubtedly has a multitude of beneficial effects such as—amongst others—the prevention of miscommunication, the increase of adherence to medical procedures as well as the reduction of treatment anxiety (Alderson, 1993). However, little data exists about how shared decision making is factually implemented in the context of child psychiatry and pediatric

psychosomatic medicine or about how it is perceived by all parties involved and about what factors may influence a child's competence (Fundudis, 2003). Thus, our main objective was to assess mothers', fathers' and children's positions on decisional competence and evaluate possible influencing factors such as illness perception, HrQoL, SES, as well as the child's gender and age. Given the predominant absence of fathers in pediatric research and thus, the lack of mother-father comparisons (Phares et al., 2005; Seiffge-Krenke, 2002), we set out to specifically recruit fathers for our study and to compare all family members. Also, we analyzed selected parent and child factors (as proposed by the *Conceptual Model of Children's Competence*; Miller et al., 2004) in terms of their ability to predict decisional competence. The according results are discussed in more detail below.

## Differences between Family Members

One of the most apparent differences between parents and their children pertained to the question of the appropriate age of consent for minors. In this study, the minimum age for autonomous decision making proposed by mothers and fathers was significantly higher (i.e., mothers: 15.63 years, fathers: 16.58 years) than the one suggested by their children. On average, participating children regarded

**Table 3** Stepwise hierarchical regressions onto the four subscales of the DCQ

|                              | Understanding |          | Autonomy |         | Decision making |         | Attitudes |         |
|------------------------------|---------------|----------|----------|---------|-----------------|---------|-----------|---------|
|                              | <i>B</i>      | $\beta$  | <i>B</i> | $\beta$ | <i>B</i>        | $\beta$ | <i>B</i>  | $\beta$ |
| <b>Step 1</b>                |               |          |          |         |                 |         |           |         |
| Mother vs. father            | 0.016         | .010     | −0.120   | −.092   | 0.023           | .017    | −0.066    | −.043   |
| Child vs. father             | −0.226        | −.132    | 0.003    | .002    | 0.065           | .046    | 0.026     | .017    |
| SES                          | 0.048         | .085     | −0.025   | −.058   | −0.118          | −.257*  | 0.024     | .047    |
| Age mother                   | −0.053        | −.511**  | −0.003   | −.043   | −0.003          | −.035   | −0.010    | −.104   |
| Age father                   | 0.021         | .188     | 0.015    | .172    | 0.006           | .063    | 0.009     | .086    |
| Age child                    | 0.125         | .421***  | 0.027    | .116    | 0.032           | .131    | 0.013     | .048    |
| Gender child                 | 0.021         | .013     | 0.087    | .070    | 0.165           | .124    | −0.096    | −.066   |
| <b>Step 2</b>                |               |          |          |         |                 |         |           |         |
| Mother vs. father            | 0.018         | .011     | −0.065   | −.049   | 0.053           | .038    | 0.008     | .005    |
| Child vs. father             | −0.082        | −.048    | 0.012    | .009    | 0.055           | .039    | 0.145     | .094    |
| SES                          | 0.074         | .133     | −0.004   | −.010   | −0.103          | −.223*  | 0.047     | .093    |
| Age mother                   | −0.055        | −.526**  | −0.008   | −.093   | −0.008          | −.097   | −0.019    | −.205   |
| Age father                   | 0.023         | .210     | 0.017    | .203    | 0.009           | .101    | 0.013     | .129    |
| Age child                    | 0.135         | .454***  | 0.040    | .174    | 0.045           | .183    | 0.033     | .124    |
| Gender child                 | 0.006         | .004     | 0.112    | .090    | 0.190           | .143    | −0.150    | −.102   |
| Timeline chronic             | −0.079        | −.096    | −0.116   | −.184   | −0.144          | −.214   | 0.004     | .006    |
| Consequences                 | 0.107         | .118     | −0.092   | −.133   | 0.028           | .038    | 0.039     | .048    |
| Personal control             | −0.035        | −.039    | 0.056    | .081    | 0.045           | .062    | 0.082     | .102    |
| Illness coherence            | 0.168         | .226*    | 0.081    | .141    | −0.002          | −.003   | −0.035    | −.052   |
| Emotional representation     | −0.106        | −.146    | −0.092   | −.165   | −0.052          | −.087   | −0.252    | −.382** |
| <b>Step 3</b>                |               |          |          |         |                 |         |           |         |
| Mother vs. father            | 0.057         | .033     | −0.019   | −.015   | 0.127           | .091    | −0.003    | −.002   |
| Child vs. father             | −0.039        | −.023    | 0.110    | .084    | 0.035           | .025    | 0.189     | .122    |
| SES                          | 0.115         | .205     | 0.012    | .028    | −0.068          | −.147   | 0.042     | .083    |
| Age mother                   | −0.071        | −.676*** | −0.007   | −.082   | −0.018          | −.214   | −0.017    | −.184   |
| Age father                   | 0.034         | .305*    | 0.020    | .232    | 0.015           | .164    | 0.013     | .127    |
| Age child                    | 0.150         | .505***  | 0.062    | .270*   | 0.058           | .238    | 0.032     | .121    |
| Gender child                 | 0.023         | .014     | 0.096    | .077    | 0.194           | .146    | −0.156    | −.106   |
| Timeline chronic             | −0.024        | −.029    | −0.056   | −.088   | −0.054          | −.080   | −0.015    | −.021   |
| Consequences                 | 0.212         | .235     | −0.021   | −.030   | 0.064           | .086    | 0.062     | .075    |
| Personal control             | −0.078        | −.087    | 0.026    | .038    | 0.013           | .017    | 0.085     | .104    |
| Illness coherence            | 0.157         | .211*    | 0.077    | .134    | −0.014          | −.023   | −0.033    | −.049   |
| Emotional representation     | −0.117        | −.161    | −0.050   | −.089   | −0.054          | −.090   | −0.247    | −.373** |
| Physical HrQoL               | −0.256        | −.288*   | −0.025   | −.036   | −0.141          | −.192   | −0.002    | −.002   |
| Psychological HrQoL          | 0.122         | .134     | 0.158    | .225    | 0.107           | .144    | 0.043     | .052    |
| Self-esteem                  | 0.168         | .200     | 0.050    | .078    | 0.010           | .014    | 0.034     | .045    |
| Family                       | 0.219         | .226*    | 0.003    | .004    | 0.359           | .449*** | −0.139    | −.157   |
| Friends                      | 0.006         | .008     | 0.045    | .070    | −0.014          | −.021   | 0.013     | .018    |
| School                       | −0.021        | −.024    | 0.096    | .142    | −0.003          | −.005   | 0.005     | .006    |
| <i>R</i> <sup>2</sup> Step 1 | 0.210**       |          | 0.054    |         | 0.100           |         | 0.016     |         |
| $\Delta R^2$ Step 2          | 0.072         |          | 0.122*   |         | 0.050           |         | 0.134*    |         |
| $\Delta R^2$ Step 3          | 0.128*        |          | 0.109    |         | 0.194**         |         | 0.017     |         |
| <i>R</i> <sup>2</sup> total  | 0.410**       |          | 0.285    |         | 0.343*          |         | 0.168     |         |

Note: Reference category father was dummy coded as 0, mother and child as 1

SES socioeconomic status, proxy variable by computing the mean of the educational level (ranging from 1–no formal education to 10–PhD) and financial situation (ranging from 1–not at all sufficient to 5–very sufficient) of both parents; possible range of SES was 1–7.5 *HrQoL* health-related quality of life. *N* = 143

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001

adolescents of 13.55 years of age as competent to decide for themselves.

This discrepancy between parental and child perceptions is generally in line with prior literature. For instance, one study

(John et al., 2008) found that caregivers tend to *a priori* assume the role of the decision maker, leaving their children mostly unaware of the fact that they may (co-)decide. The authors hypothesize that this notion may stem from the

parents' habit of making decisions on behalf of their child on a daily basis, starting with their birth, which is generalized to the context of medical care. Another explanation for less lenient parental judgements about children's competency is that parents of chronically ill children tend to act more overprotective than parents of healthy children (Holmbeck et al., 2002). The *Uncertainty in Illness Theory* (Mishel, 1990) may prove useful as a basis for explaining these findings. It has been expanded over time to include not only acute and chronic somatic illnesses but also mental disorders (for a study on chronically ill children with depression see Carpentier et al., 2007). The model proposes that perceived ambiguity about the illness, the complexity of the treatment, a lack of information and the unpredictability of the further course all contribute to the experience of illness uncertainty, which may in turn lead to overprotective parental behaviors (Mullins et al., 2007). Interestingly, however, children—despite of their illness—seem to be more confident regarding a minor's ability to decide. Their estimation of an age cutoff for autonomous decision making is closer to the true legal age of consent of 14 years than their parents' suggestion. This is in contrast to past research (e.g., Ashcroft et al., 2003), which shows that children rather tend to underestimate their own abilities and rights and are often convinced that only their parents should decide. The current results, in turn, point towards a larger self-confidence in children and possibly the wish to be more involved in decisions that affect them.

Furthermore, differences between parents and their children were found for the IPQ subscale *consequences*, with parents rating the impact of the illness as more severe than their child. Similarly, parents showed more *illness coherence* than their children. Hence, the increased parental understanding and ability to make sense of their child's illness may have also led to a more realistic estimation of its effects and consequences. Additionally, we found an interaction between gender and family members regarding the *emotional representation of the illness*, with fathers rating the emotional impact of the illness on their daughters' as more negative than daughters did for themselves. No such effects were detected for any other family dyad. Also, no differences between family member ratings were found for the child's HrQoL or the four factors of decisional competence: *understanding, autonomy, decision making, and attitudes*.

In an attempt to interpret the current results on the basis of past research, one is confronted with a lack of studies on the subject. A majority of comparisons between pediatric patients or child psychiatry patients and their parents have been done in the area of HrQoL and most results point towards differing perceptions between parents and their affected children, especially regarding the social or emotional domains of HrQoL (Eiser and Morse, 2001). Here, parents tend to differ most in their assessments, while they seem to have less trouble in judging the child's HrQoL in the physical domain.

This difficulty of correctly assessing emotional HrQoL in their child may also help explain why fathers and daughters differed in the current study regarding their emotional representation of the illness. At the same time, we did not find any differences in the HrQoL-measure.

Furthermore, the *Self-Regulatory Model* (Leventhal et al., 1984) on which the construct of illness perception is based, assumes that illness representations are processed in three stages, which include (1) being confronted with the threat, (2) coping with it, and (3) appraising the efficacy of the coping behaviors (e.g., Broadbent et al., 2006). Hence, the evaluation of illness perception may be time dependent or, in other words, dependent on the stage of treatment that the patient is currently in. It may, thus, be useful to account for this issue in future research. Finally, the type of illness may constitute another influencing factor when evaluating illness-related parameters. The sample used in the present study was chosen independently of their diagnosis in order to assure a representative selection of patients who are typically treated at a psychiatric and psychosomatic inpatient and outpatient clinic; and because the issue of participatory decision making pertains to all in the same matter. However, future studies should make an effort to test for possible differences between groups of psychiatric disorders and/or somatic illnesses.

## Predictors of Decisional Competence

Age—being one of the most broadly discussed determinants of decisional competence in children (e.g., Miller et al., 2004)—also emerged as a significant predictor of the DCQ subscale *understanding* in this study: Younger mothers and older fathers rated their children as more capable of understanding their illness and the associated treatment; and similarly, older children evaluated their own ability to understand as significantly more positive. The latter may generally be seen in accordance with the typical trajectory of cognitive and emotional development in children, which follows an incremental gain in concrete intellectual operations such as reasoning and logic (Piaget and Inhelder, 1987). Hence, older children are expected to show a better appreciation of their own illness than younger, less cognitively developed children (Fundudis, 2003). Interestingly, however, a younger age of the mother and an older age of the father were also associated with a more positive evaluation of their child's ability to understand the illness. Future studies on participatory decision making should therefore not only take the child's age into account, but also consider their parents' age as it seems to significantly impact parental evaluations of their children's competence.

Furthermore, HrQoL regarding the physical domain showed a negative association, and HrQoL regarding the family showed a positive association with understanding. Hence, if the family climate is rated as positive and the



communication between parents and children is perceived as beneficial, more understanding is ascribed to the child by all involved parties. In line with this is the finding that if HrQoL regarding the family is high, the child is also more actively involved in the decision making process (DCQ subscale *decision making*). Interestingly, if the child's physical health is regarded as unfavorable, the child is also perceived as being able to better understand his/her illness. This may be due to an increased contemplation of illness-related factors, which in turn may lead to a heightened appreciation of associated issues. Generally, the present results demonstrate that HrQoL is a meaningful contributing factor. In the context of the *Conceptual Model of Children's Competence* (Miller et al., 2004), HrQoL may be attributed to the predisposing or situational factors (including amongst others prior experiences, family values and coercive influences upon the decision at hand) and should be included in future studies as a covariate.

Finally, a more positive emotional representation of the child's illness was associated with more positive parental and child attitudes towards minors' decisional competence in general. Thus, the less negative emotional impact the child's illness had on each family member, the more lenient they were in their judgements of children's overall abilities to reach a decision, to take on responsibility and to engage in logical reasoning.

## Limitations

The study presented here has to be regarded as preliminary, since data on the subject at hand is still rather scarce. Hence, the current results pave the ground for further research and may provide a valuable basis for the formulation of directional hypotheses. However, there are several limitations to the study, which have to be regarded when interpreting the results. Due to the small sample size, a thorough analysis of the validity of the DCQ was not possible. Future studies are advised to validate the DCQ in larger samples and with multi-group confirmatory factor analysis techniques to ensure validity across all three family members. Also, our sample was very heterogeneous in terms of represented mental disorders and chronic illnesses. It is, however, expected that significant associations exist between the type of illness and illness perception as well as, consequently, the evaluation of the child's decisional competence and attitudes towards participatory decision making. Finally, only specific factors from the *Conceptual Model of Children's Competence* (Miller et al., 2004) were considered in the present study. Future research should strive towards a more comprehensive evaluation of contributing factors to achieve a more valid picture of children's decisional competence in the context of psychiatric and psychosomatic care.

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**Author Contributions** A.F.: designed the study and wrote the introduction and discussion. T.B., J.X.K., H.Z., and C.K.: executed the study. T.B. and J.X.K.: collaborated with the interpretation of the results and writing of the study. A.G. and O.D.K.: analyzed the data and wrote the methods and results. D.K.: collaborated in the writing and editing of the final manuscript. O.D.K.: supervised the execution of the study. All authors contributed significantly to the conceptualization and the writing of the manuscript and all approved the final manuscript.

## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Ethics Approval** The present study adhered to the Declaration of Helsinki and was approved by the institutional review board of the Medical University of Vienna, Austria in its current form (No. 164/2015).

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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