Illness perceptions in patients and parents in paediatric oncology during acute treatment and follow-up care

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Abstract

Objective: Recent evidence suggests that illness perceptions in paediatric patients and their parents may differ, with parents holding more negative views compared to their children. Little is known about illness perceptions of very young patients and their parents. This study investigates illness perceptions in paediatric cancer patients aged 4–18 years and their parents in acute treatment or follow-up care, distinguishing patients by age (4–11, 12–18) and stage of medical treatment.

Methods: N = 45 patient–parent dyads in acute treatment and n = 95 dyads in follow-up care were examined. Parents and older children aged 12–18 years completed the Illness Perception Questionnaire—Revised (IPQ–R) and younger children aged 4–11 years were examined using an age-adapted hand puppet interview containing the IPQ–R questions. Difference scores of illness perceptions (symptoms, timeline–acute/chronic, timeline–cyclical, personal control, illness coherence, consequences, emotional representations) between children and parents were tested for significance using Wilcoxon signed-rank tests.

Results: Overall, parents perceived more symptoms associated with their child’s illness/treatment than the children themselves. In acute treatment, younger children indicated more negative and older children more positive views regarding chronicity than parents. Younger children held less negative views on consequences, and all children reported less negative emotional representations than parents. In follow-up care, all children held less negative views on consequences and emotional representations. Older children reported less negative views on chronicity, cyclicity and illness coherence.

Conclusion: Differences in illness perceptions of paediatric patients and their parents should be considered during and after treatment/medication and psychosocial care to support illness coping in person- and family-centred interventions.
1 | BACKGROUND

Every year, approximately 1 in 400 children in Germany is diagnosed with cancer. In the last decades, treatment options have improved significantly, leading to increased survival rates of 82% for any cancer diagnosis, and even 90% for acute lymphoblastic leukaemia. Despite improved prognosis, the cancer diagnosis and treatment remain extremely burdensome, and many paediatric patients and their relatives develop adverse psychological symptoms during and after acute treatment (syn., intensive therapy) such as anxiety and depressive symptoms. Posttraumatic stress symptoms, lower health-related quality of life (HRQoL) and elevated fear of progression, indicating the importance of psychosocial support for the family during and after treatment.

One influential explanatory model on adverse psychological reactions due to illness is the Common-Sense Model of Illness Representation (CSM). It poses that individuals create cognitive representations of a perceived health threat, for example, a cancer diagnosis. These so-called illness perceptions are based on available information (e.g., conversations with others, information by medical staff, own experience with the illness) and launch a self-regulation process which aims to overcome the health threat. They include perceptions on physical symptoms associated with the illness, expected timeline, consequences of the illness on the individual’s life, causes, controllability and curability of the illness, and illness-related emotions (for further information, see Section 2).

In paediatric oncology, the diagnosis of a chronic or life-threatening illness is not only a personal experience for the affected child but also burdensome for parents. When patients and parents are confronted with the cancer diagnosis, they may be exposed to each other’s perceptions and anxieties. Research suggests that illness perceptions in patients and parents may differ. Studies revealed that children (aged 8–18 and 12–24 years, respectively) suffering from chronic illness such as cancer or spinal muscular atrophy held more positive views concerning their illness than their parents during acute treatment. These findings highlight the importance of examining both the patients and the parents to ensure appropriate medical treatment and psychosocial care. For example, if parent and child indicate different assumptions regarding duration, this could be addressed in a family-centred intervention to talk about realistic expectations based on current professional knowledge.

Illness perceptions are also important for children and parents in follow-up care, for example, in psychosocial interventions to support coping. However, research on illness perceptions in child survivors of paediatric cancer and their parents is sparse. Evidence shows that adult survivors tend to hold more positive views as compared to their partners/carers who express more anxiety, more negative perceptions on the survivor’s personal control and illness consequences.

Finally, child’s and parent’s illness perceptions may be associated with the child’s HRQoL, as has been shown in different samples during acute treatment (e.g., 8–12-year-old cancer patients, 8–18-year-old children suffering from spinal muscular atrophy, parents of young children with head and neck cancer). Similarly in follow-up care, adult survivor’s illness perceptions may be associated with their HRQoL. Interestingly, one study on diabetes indicated that higher agreement (syn., similarity) between child’s and parent’s illness perceptions may be associated with better emotional adjustment in the child.

Taken together, previous studies on illness perceptions refer to children aged 8 years or older, adolescents or young adults and are often assessed with the well-established Illness Perception Questionnaire—Revised (IPQ-R) (or shorter adaptations). Research on illness perceptions of younger children and their agreement with their parent’s perceptions is lacking due to the absence of a comprehensive assessment instrument. This study aims to investigate (dis-)agreement in illness perceptions in paediatric cancer patients and their parents using an age-adapted puppet interview based on the IPQ-R to assess children aged 4–11 years and the IPQ-R questionnaire to assess children aged 12–18 years and parents (research question 1, exploratory analysis). To disentangle illness perceptions during different treatment periods, this study investigates children and parents in acute treatment and in follow-up care. Moreover, associations of child’s illness perceptions and (dis-)agreement between child and parent with the child’s HRQoL are investigated (research question 2). With our results, we strive to support psychosocial healthcare provision and early targeted intervention.

2 | METHODS

2.1 | Participants

N = 45 child–parent dyads in acute treatment and n = 95 dyads in follow-up care were available for this study. Socio-demographic and illness characteristics are summarized in Table 1.

2.2 | Procedure

Participants in acute treatment were recruited in the acute wards for paediatric oncology at the university hospitals in Dresden and Leipzig, Germany. Participants in follow-up care were recruited in the parents’ associations in Dresden and Leipzig (Sonnenstrahl e.V. Dresden, Elternhilfe e.V. Leipzig). One parent was also invited to
participate. Overall, $n = 220$ families were eligible for inclusion and informed about the study. Of those, $n = 183$ (83%) families wished to participate (Figure 1).

After obtaining written informed consent, children and parents completed measures of illness perceptions. Information on socio-demographic characteristics, diagnosis and treatment was obtained from the parent. Ethics approval was obtained from the ethics committee of the Technische Universität Dresden (EK-514112015). The study has been pre-registered at the German Clinical Trials Register (DRKS-00022034).

Inclusion criteria were (1) oncology patients aged 4–18 years and one parent (mother or father; ‘Would you describe yourself as the current main caregiver for your child?’: $n = 123$ answered ‘yes’, $n = 17$ answered ‘no’), (2) for children in acute treatment: first diagnosis at least one month ago, (3) for children in follow-up care: first diagnosis at least two years ago. Exclusion criteria were (1) inability to understand questionnaire/interview, (2) lack of German language knowledge, (3) inability to interact with hand puppets, (4) palliative care. To be included into analysis, IPQ-R data of child and parent had to be available.

### TABLE 1 Sample characteristics

|                              | Acute treatment ($n = 45$) | Follow-up care ($n = 95$) |
|-----------------------------|---------------------------|--------------------------|
| **Children**                |                           |                          |
| Gender ($n$, %)              |                           |                          |
| Male                        | 19 (42.2)                 | 62 (65.3)                |
| Female                      | 26 (57.8)                 | 33 (34.7)                |
| Diverse                     | 0 (0.0)                   | 0 (0.0)                  |
| Age ($M$, SD)               | 9.0 (3.8)                 | 12.4 (3.5)               |
| Age group ($n$, %)           |                           |                          |
| 4–11 years                  | 30 (66.7)                 | 31 (32.6)                |
| 12–18 years                 | 15 (33.3)                 | 64 (67.4)                |
| Diagnosis ($n$, %)           |                           |                          |
| Leukaemia                   | 17 (37.8)                 | 36 (37.9)                |
| Tumour of the central nervous system | 8 (17.8)       | 22 (23.2)                |
| Lymphoma                    | 7 (15.6)                  | 10 (10.5)                |
| Tumours of peripheral nerves | 1 (2.2)                   | 4 (4.2)                  |
| Soft-tissue sarcoma         | 2 (4.4)                   | 1 (1.1)                  |
| Kidney tumour               | 1 (2.2)                   | 5 (5.3)                  |
| Bone tumour                 | 6 (13.3)                  | 3 (3)                    |
| Other$^a$                   | 3 (6.7)                   | 14 (14.7)                |
| Time since diagnosis in months ($M$, SD) | 8.6 (17.5)   | 78.2 (42.9)               |
| Time since end of acute treatment in months ($M$, SD) | -                   | 48.4 (36.3)               |
| Treatment ($n$, %—multiple responses possible) |                      |                          |
| Chemotherapy                | 41 (91.1)                 | 83 (87.4)                |
| Radiotherapy                | 7 (15.6)                  | 22 (23.2)                |
| Surgical measures           | 18 (40.0)                 | 36 (27.9)                |
| Bone marrow/stem cell transplant | 2 (4.4)           | 11 (11.6)                |
| Other$^b$                   | 0 (0.0)                   | 3 (3.2)                  |
| **Parent**                  |                           |                          |
| Participating parent ($n$, %) |                           |                          |
| Mother                      | 39 (86.7)                 | 78 (82.1)                |
| Father                      | 6 (13.3)                  | 17 (17.9)                |
| Age ($M$, SD)               | 37.9 (6.7)                | 42.9 (6.0)               |

$^a$For example, dysgerminoma.

$^b$For example, immune therapy, BRAF inhibitor therapy.
2.3 Measures

2.3.1 Illness Perception Questionnaire—Revised

The IPQ assesses illness perceptions according to the CSM. Different versions exist (e.g., Brief-IPQ, Child-IPQ, IPQ-R). For this project, the short German IPQ-R was used. It consists of seven dimensions, relative to the CSM: symptoms related to the illness/treatment (illness identity), timeline-acute/chronic (duration), timeline-cyclical (illness trajectory as constant or cyclical), personal control (patient’s influence over the illness), illness coherence (comprehension of the illness), consequences (impact of the illness on their life) and emotional representations (illness-related emotions). The IPQ-R assesses the symptom-dimension with 14 items (dichotomous format: yes/no) and the other dimensions with 18 items (three per dimension) on a five-point Likert-scale ranging from 1 (strongly disagree) to 5 (strongly agree). The dimension scores are calculated by summing the items after reverse scoring. Higher scores indicate more associated symptoms, more negative perception of chronicity, cyclicity and emotional representations, and more positive perception of personal control and illness coherence. The German IPQ-R has been validated with a sample of rehabilitation patients and shows sufficient internal consistency with alpha values between 0.72 and 0.86 (except timeline-cyclical). 6-month-test–retest reliability of the English original was good, with >0.5 for all scales (except timeline-cyclical) in a sample of adult patients with rheumatoid arthritis.

Parents and 12–18-year-old children (from now on referred to as ‘adolescents’) completed the IPQ-R questionnaire. Parents were asked about their own perceptions regarding their child’s illness (e.g., ‘I get depressed when I think about my child’s illness’). Adolescents were given a paper–pencil questionnaire similar to the parent’s version (e.g., ‘I get depressed when I think about my...’).
illness'). 4–11-year-old children (referred to as ‘children’) were examined using an age-adapted hand puppet interview containing the IPQ-R questions (available on request). For the puppet interview, the items have been dichotomised and two hand puppets tell the child about their opposing views of their own illness (e.g., ‘I am sad because of my illness’ vs. ‘I am not sad...’). The child then decides which puppet’s view corresponds with his/her own perception.

2.3.2 KINDL-R

The KINDL-R was used to measure the child’s HRQoL. It contains Likert-scale items on physical well-being, emotional well-being, self-esteem, family, friends, daily functioning (school, pre-school/nursery school) and illness. The HRQoL KIscore is calculated by taking the mean of the items after reverse scoring. Higher scores indicate higher HRQoL. The KINDL-R shows acceptable to good internal consistency and high convergent and discriminant validity.

2.4 Statistical analysis

Analyses were performed using IBM SPSS Statistics 27.0. IPQ-R dimension scores were calculated only if no item from this dimension was missing. Analyses were run separately by stage of medical treatment (acute treatment, follow-up care) and age group (4–11, 12–18).

To measure level of agreement between child/adolescent and parent for the dimensions, the difference between child’s/adolescent’s and parent’s scores was computed: \( d_{\text{dimension}} = \text{IPQ-R}_{\text{child/adolescent}} - \text{IPQ-R}_{\text{parent}} \). For parents of children, we dichotomized the IPQ-R items by splitting each item (0 = scores 1 [strongly disagree] to 3 [neither disagree nor agree]; 1 = scores 4 [agree] and 5 [strongly agree]) to get an item format analogous to the IPQ-R-Puppet format (except symptom-dimension, as it is already dichotomous). The variable \( d \) is continuous and describes the direction and strength of agreement. It ranges from \(-3\) to \(+3\) (for child–parent dyads) and \(-12\) to \(+12\) (for adolescent–parent dyads). Positive \( d \)-scores indicate higher IPQ-R scores for children/adolescents, that is, more associated symptoms, more negative perception on chronicity, cyclicity, consequence and emotional representations, and more positive perception on personal control and illness coherence. Shapiro–Wilk tests were significant for most \( d \)-scores, indicating non-normal distributions. Therefore, non-parametric tests were used.

To examine research question 1 on differences between child’s/adolescent’s and parent’s illness perceptions, we conducted an exploratory analysis and therefore did not correct for multiple testing. To see if the \( d \)-score is significantly different from zero, Wilcoxon signed-rank tests were performed.

To examine research question 2 on associations of child’s/adolescent’s illness perceptions and \( d \)-scores with the child’s/adolescent’s HRQoL, Kendall–Tau correlations were performed. For all tests, \( p < 0.05 \) was considered statistically significant.

3 RESULTS

3.1 Comparison of child’s and parent’s perspective and level of agreement (research question 1)

Independent-samples t-tests (adjusted for multiple testing) revealed gender differences between adolescent boys and girls in follow-up care, with girls reporting more negative perceptions concerning cyclicity (\( T(58) = -2.937, p_{adj} = 0.030 \)) and emotional representations (\( T(60) = -2.973, p_{adj} = 0.028 \)) (Appendix, Table A1). Table A2 shows IPQ-R scores and \( d \)-scores for this subsample, distinguishing by gender.

3.1.1 Symptoms related to illness/treatment (illness identity)

Overall, children/adolescents in acute treatment and follow-up care reported significantly fewer symptoms as part of their illness/treatment than their parents (Table 2). Moreover, children in acute treatment (\( z = -4.018, p < 0.001 \)) and follow-up care (\( z = -4.227, p < 0.001 \)) reported fewer symptoms than adolescents (Mann-Whitney test).

Among the most frequently experienced symptoms were nausea, fatigue, pain and asthenia (Figure 2).

3.1.2 Timeline (acute–chronic, cyclical), personal control, illness coherence, consequences, emotional representations (Table 2)

Among dyads in acute treatment, there were significant differences on the timeline-acute/chronic dimension. However, while adolescents viewed the illness as being less chronic than their parents, children viewed the illness as being more chronic and having a longer duration. Moreover, children perceived significantly fewer negative consequences than parents, while there was no significant difference among adolescent-parent-dyads. Children and adolescents reported significantly less negative emotional representations than parents. There were no significant differences between children/adolescents and parents concerning perceptions of cyclicity, personal control, and illness coherence.

In follow-up care, adolescents (but not children) viewed their illness as less chronic, less cyclical and more comprehensible than parents. Children and adolescents viewed their illness as having fewer negative consequences and less negative emotional
|                          | Children (age group 4–11) | Adolescents (age group 12–18) |
|--------------------------|---------------------------|-------------------------------|
|                          | Child's score (M, SD)     | Parent's score (M, SD)        | Difference in child's and parent's scores (d = IPQ_child − IPQ_parent) | Adolescent's score (M, SD) | Parent's score (M, SD) | Difference in adolescent's and parent's scores (d = IPQ_adolescent − IPQ_parent) |
|                          | n^a d (M, SD) Wilcoxon (z, p) | n^a d (M, SD) Wilcoxon (z, p) |                            | n^a d (M, SD) Wilcoxon (z, p) | n^a d (M, SD) Wilcoxon (z, p) |                            |
| Acute treatment          |                           |                               |                            |                           |                               |                            |
| Sum of symptoms associated with the illness | 3.30 (2.88) 5.90 (3.40) | 30 −2.60 (3.15) −3.564 (<0.001) | 8.07 (3.08) 9.20 (3.10) | 15 −1.13 (1.77) −2.354 (0.023) |
| Timeline-acute/chronic   | 2.27 (1.00) 1.43 (0.90)  | 26 0.77 (1.24) −2.723 (0.006) | 7.67 (2.50) 8.87 (2.26) | 12 −1.50 (1.73) −2.300 (0.023) |
| Timeline-cyclical        | 1.57 (0.88) 1.70 (0.79)  | 28 −0.14 (0.93) −0.876 (0.361) | 9.85 (1.28) 10.79 (2.22) | 13 −0.85 (2.12) −1.390 (0.199) |
| Personal control         | 1.76 (1.27) 1.48 (1.12)  | 23 0.22 (1.59) −0.824 (0.436) | 9.62 (2.66) 9.00 (3.62) | 13 0.15 (3.91) −0.199 (0.859) |
| Illness coherence        | 1.79 (0.93) 1.29 (0.76)  | 22 0.41 (1.44) −1.342 (0.206) | 10.00 (3.06) 9.33 (2.87) | 14 0.64 (3.95) −0.593 (0.602) |
| Consequences             | 1.48 (0.73) 2.17 (1.07)  | 22 −0.64 (1.09) −2.462 (0.014) | 9.86 (2.71) 10.57 (2.71) | 13 −0.46 (2.11) −1.223 (0.246) |
| Emotional representations | 1.43 (1.04) 2.27 (1.01)  | 23 −0.91 (1.28) −2.781 (0.005) | 9.29 (3.22) 12.27 (2.46) | 14 −3.14 (4.19) −2.317 (0.018) |
| Follow-up care           |                           |                               |                            |                           |                               |                            |
| Sum of symptoms associated with the illness | 2.90 (2.48) 7.38 (2.29) | 27 −4.22 (2.56) −4.325 (<0.001) | 6.35 (3.47) 7.76 (3.29) | 59 −1.42 (3.79) −3.110 (0.002) |
| Timeline-acute/chronic   | 1.56 (1.25) 1.57 (1.04)  | 27 −0.11 (1.63) −0.354 (0.778) | 7.90 (3.47) 9.38 (3.27) | 59 −1.61 (2.16) −4.649 (<0.001) |
| Timeline-cyclical        | 1.36 (0.83) 1.55 (0.78)  | 26 −0.31 (1.05) −1.435 (0.161) | 7.97 (2.64) 8.90 (2.51) | 56 −0.89 (2.67) −2.427 (0.015) |
| Personal control         | 1.46 (1.10) 1.07 (1.07)  | 24 0.58 (1.50) −1.798 (0.084) | 8.80 (2.48) 9.13 (2.77) | 56 −0.52 (2.85) −1.383 (0.167) |
| Illness coherence        | 1.24 (1.13) 1.19 (1.08)  | 25 0.00 (1.83) −0.141 (0.908) | 10.47 (3.29) 8.64 (2.62) | 55 1.56 (3.52) −3.246 (0.001) |
| Consequences             | 0.93 (0.78) 1.90 (1.08)  | 25 −0.92 (0.91) −3.719 (<0.001) | 8.67 (3.10) 10.41 (3.08) | 60 −1.92 (3.28) −4.218 (<0.001) |
| Emotional representations | 0.88 (0.88) 2.16 (1.10)  | 25 −1.20 (1.50) −3.065 (0.001) | 8.44 (3.15) 11.35 (2.77) | 60 −2.87 (3.77) −4.882 (<0.001) |

Note: Bold characters indicate a significant result (p < 0.05).

Values may differ from the overall sample size due to missing items in the IPQ-R dimensions. In case of n < 30, the exact test was performed.
representations than parents. There were no differences between children/adolescents and parents concerning perceptions of personal control.

3.2 | Association with HRQoL (research question 2)

In both treatment phases, there were negative correlations (adjusted for multiple testing) between adolescent’s consequence-dimension and HRQoL, indicating that the perception of fewer negative consequences was related to higher HRQoL (Appendix, Table A3). Moreover, adolescent’s illness coherence in follow-up care was positively correlated with HRQoL. No associations were found for children’s illness perceptions with HRQoL, and for d-scores with HRQoL.

4 | DISCUSSION

Previous studies demonstrated that illness perceptions of chronically ill children, adolescents and adults may differ significantly from those of their parents/partners, with patients typically reporting more positive views.\textsuperscript{15,16} It is important to measure both the paediatric patient’s as well as the parent’s perceptions, as they may yield different approaches and topics for their respective psychosocial support.

This is the first study investigating illness perceptions of paediatric cancer patients aged 4–18 years and their parents in acute treatment and follow-up care.

Both in acute treatment and in follow-up care, parents reported significantly more symptoms associated with their child’s illness/treatment. A similar result has been found by Fischer and colleagues\textsuperscript{16} in a sample of children with spinal muscular atrophy and their parents. One possible reason might be that parents receive more information on the illness, potential side effects, and long-term effects by medical staff and therefore recognize more symptoms as part of the illness than their child. Children/adolescents, on the other hand, might see a wide range of causes for a symptom, such as fatigue after play or tummy ache after having eaten too much. Interestingly, children in acute treatment and follow-up care reported significantly fewer symptoms than adolescents. In follow-up care, this may be due to memory effects, as children probably were quite young during acute treatment and might not remember this time correctly. Children in acute treatment may receive less illness-related information than adolescents and therefore recognize fewer symptoms as part of the illness/treatment.

In both treatment phases and for all age groups, children/adolescents reported significantly less negative emotional representations than parents. A similar result has been found by Fischer and colleagues.\textsuperscript{16} A reason might be that patient’s and parents’ roles during cancer treatment differ substantially: Patients often try to...
distract themselves or are actively invited by hospital staff to spend time with music, art, or physical therapists, whereas parents may be more worried about their child’s survival, monitor them closely to detect symptoms or changes in well-being, spend a lot of time providing care either in the hospital or at home, and deal with other daily demands (e.g., care for other children, work).33,34

Interestingly, dyads both in acute treatment and in follow-up care did not differ concerning their perceptions of the child’s/ adolescent’s personal control over the illness. This result is supported by two studies with paediatric patients during acute treatment, whereas a study with adult cancer survivors found that they held significantly more positive perceptions concerning their own control over the illness than carers.35 Possibly, the shared perception of controllability is due to children assuming their parent’s cognitive patterns as communicated by them (e.g., illness as stroke of fate vs. illness as something that needs to be ‘fought’).

In acute treatment, no differences between children/adolescents and parents were found concerning perceptions of cyclicity and illness coherence. This is supported by findings from a sample of 11–17-year-olds with diabetes and their mothers.22 In follow-up care, adolescents (but not children) reported less negative perceptions concerning cyclicity and coherence than parents. Possibly, patients and parents in acute treatment have not experienced cyclicity yet as they encounter most symptoms for the first time. In follow-up care however, patients and parents might have experienced and perceived cyclicity differently. Concerning coherence, patients and parents in acute treatment were recently provided with a similar level of knowledge about the illness/treatment by medical/ psychosocial staff. Over time, knowledge and interpretation of symptoms might change, leading to differences in coherence among follow-up care patients and parents.

An important finding in our study was that children in acute treatment held more negative views concerning the chronicity of their illness than parents, whereas adolescents both in acute treatment and follow-up care held more positive views. A possible explanation might be that children apply a different time frame than parents (or adolescents)36: When asked if they think that their illness will last a long time, they might consider a couple of weeks in hospital already a very long time and respond accordingly.

Children in acute treatment perceived fewer negative consequences than parents, whereas adolescent-parent-dyads did not differ in their view on consequences. This might be because children are informed differently about their illness (e.g., survival rates, potential side/long-term effects) than parents or adolescents. Given that children’s cognitive ability to assess risks is still developing, age-appropriate information about the consequences is an important part of psychosocial care. In follow-up care, both children and adolescents perceived fewer consequences than parents. A similar result has been found by Dempster and colleagues18 in a sample of adult oesophageal cancer survivors and their carers.

### 4.1 Study limitations

To our knowledge this is the first study that investigated illness perceptions in paediatric cancer patients from the age of 4 and their parents. The absence of a comprehensive assessment instrument and of similar studies for comparison limits the interpretation of our findings. To assess illness perceptions of younger children aged 4–11 years, we developed a puppet interview based on the IPQ-R. This allowed us to investigate illness perceptions in children and adolescents from a broad age range, as well as their parents, using the same items. It could be argued that the dissimilarity in illness perceptions between children and parents was due to the different assessment methods. However, the puppet interview is a state-of-the-art approach to conduct assessments in young children, and the items of the IPQ-R were carefully age-adapted, retaining their meaning. We used the German short version of the IPQ-R, which has been shortened through item reduction to 32 items as opposed to the 46 items of the full version. On the upside, this allowed the puppet interview to be much shorter and therefore more suitable for very young children. On the downside, the dimension ‘treatment control’ is not included. The puppet interview has been piloted with n = 11 children in acute treatment and follow-up care and showed good validity, comprehensibility and feasibility.25,26

Response rates in acute treatment and follow-up care were high. Nevertheless, sample sizes for child-parent dyads in acute treatment and follow-up care, and for adolescent-parent dyads in acute treatment were small to medium and therefore only able to detect medium to large effect sizes. Future research should incorporate sufficient samples for all age groups. Moreover, future studies should explore differences between cancer types (e.g., leukaemia vs. brain tumour) as they might pose different situations for the affected family. Sample sizes should be big enough to enable research to investigate this.

As we were the first to investigate differences in illness perceptions in cancer patients aged 4–18 years and their parents both during acute treatment and in follow-up care (research question 1) we conducted an exploratory, hypothesis-generating analysis and therefore did not correct for multiple testing for these analyses.

All families in acute treatment, as well as many families in follow-up care received psychosocial support at the time of the study. To which extent this influences the participants’ illness perceptions and coping cannot be resolved here.

### 4.2 Clinical implications

In line with other research and in accordance with clinical experience, our study suggests that child’s/adolescent’s and parent’s illness perceptions differ significantly from one another. Therefore, parental reports should not be used as proxy reports on the child’s/adolescent’s illness perceptions and children/adolescents should be asked to report on their own view. This might also
enhance their need for control and autonomy, and might have positive effects for their psychological well-being. However, we would nevertheless like to stress the importance of the parent's self-report as an additional source of information. Obtaining a comprehensive report of both members of the dyad is vital for the medical and psychosocial staff to support children and parents according to their individual needs and views on the illness. Studies with adult patients have shown that interventions directed at changing maladaptive illness perceptions may improve self-management behaviours.

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In a family/parent-focussed intervention, the differences between child's/adolescent's and parent's illness perceptions could be addressed: Parental (more negative) perceptions may be relevant for the child's perceptions and thereby obstruct the child's coping. On the other hand, the child's more positive perceptions could be used as a resource for the family and may be a relief for the parents. Therefore, family- and parent-focussed interventions would benefit the whole family system. Future research should focus on creating and evaluating such interventions.

5 | CONCLUSIONS

In summary, our study showed that children/adolescents in paediatric oncology and their parents hold different illness perceptions, with parents in general holding more negative views. This was true both in acute treatment and in follow-up care. As illness perceptions are strongly related to HRQoL, psychosocial staff should assess both the child's as well as the parent's illness perceptions, and, if necessary, change them to more positive perceptions using interventions including the whole family system.

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CONFLICT OF INTEREST

All authors declare that they have no financial relationships that might be perceived as a potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data file and syntax are available upon reasonable request to the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher’s website.

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