

The experience of pain in children with Growth Hormone Deficiency and psychosocial correlates: preliminary data from a longitudinal prospective study

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BACKGROUND

Pain represents one of the most common and stressful experiences among children undergoing medical therapies (Kortelnuoma, 2008), and is generally associated with anxiety, avoidance behaviours, somatic symptoms and increase in parental distress. Nevertheless, excluding diabetes, the experience of pain is underrepresented in literature for what concerns paediatric endocrinology.

Children consider injections one of the most painful, frightening and distressing procedures (Fassler, 1985). The treatment for patients with Growth Hormone Deficiency requires daily subcutaneous injection, performed by parents or patients themselves. This may represent a burden for family members and have an impact on Quality of Life (QoL) (Brod et al., 2017; Bullinger et. al, 2009) as well as in other areas of functioning of the patient.

STUDY AIMS

Present study aims to evaluate the following variables in children and adolescents under treatment for GHD with rhGH:

- Assess the presence and intensity of perceived pain associated with rhGH administration;
- Assess the patient Quality of Life (QoL) as perceived by patients themselves and one of their parents;
- Assess the emotional and behavioural characteristics of GHD patients, as described by one of their parents.
- Assess the impact of treatment on both patients and parents, identifying the most distressing areas;

METHODS

PARTICIPANTS

80 patients (males=57.5%, M age=12.07, SD=3.51) undergoing daily treatment with rhGH injections and one parent (mothers=75%) were recruited at Meyer Children's Hospital in Florence, Italy.

Inclusion criteria: 3-18 years old children, undergoing treatment with rhGH, absence of cognitive impairment and consent to participate in the study.

INSTRUMENTS AND PROCEDURES

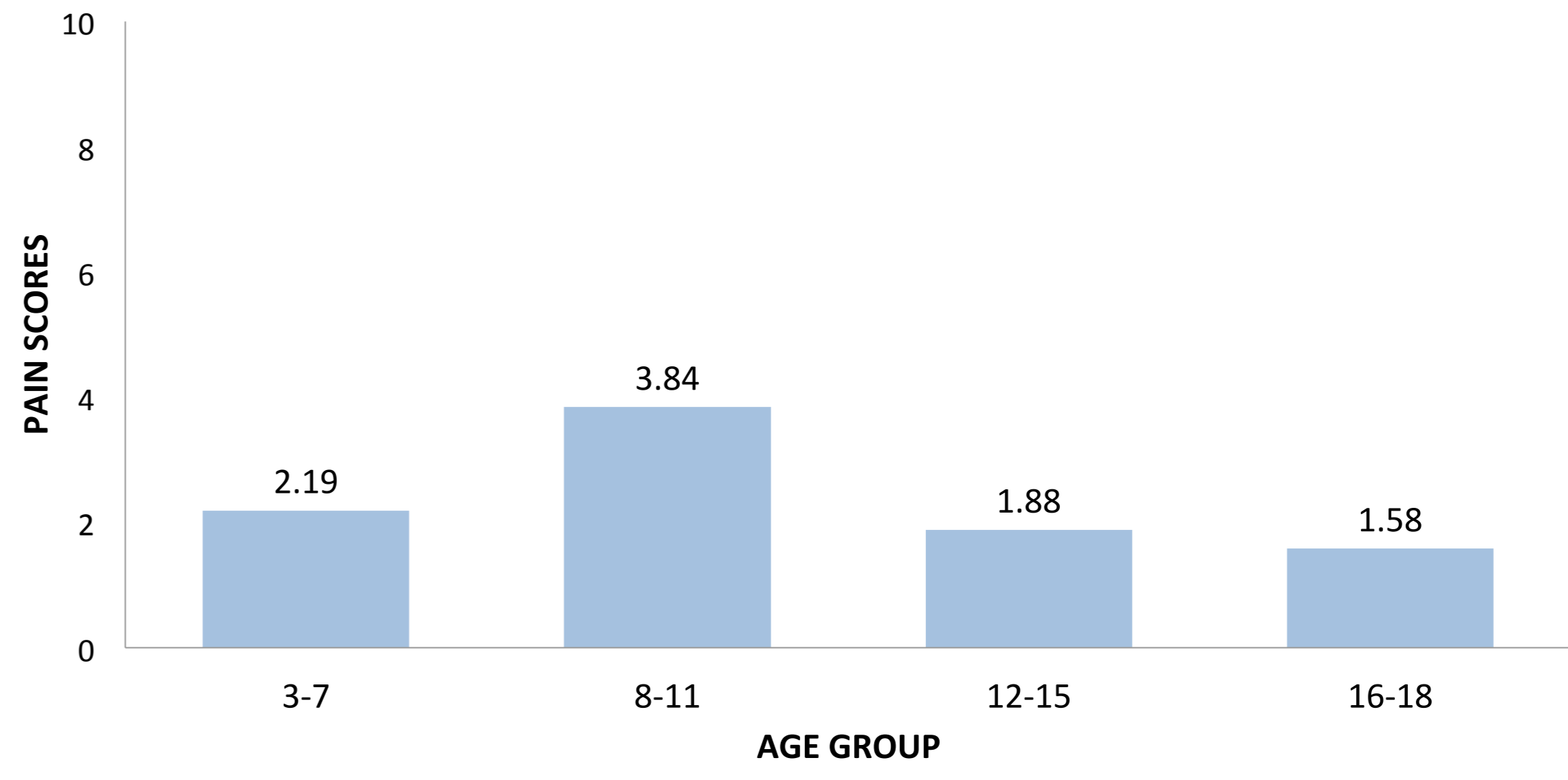
Patients and parents completed some questionnaires before clinical visit:

1. **QoLISSY** (Quality of Life in Short Stature) is a self-report instrument to assess quality of life on a 5-point likert scale. Comprehends 50 items and 6 sub-scales for the C-form (children, from 12 years old) and 66 item and 8 sub-scales for the P-form (parent perception of child QoL).
 2. **CBCL** (Child Behavior Checklist) is a self-report parent questionnaire assessing emotional and behavioural characteristics of the child. Comprehends 100 or 113 item (version 6-18 years of age or 1.5 – 5 years respectively) measured on a 3-point likert scale.
 3. **Treatment Burden Questionnaire** is a specifically designed, self-report questionnaire, to assess Burden related to rhGH therapy. Comprehends 18 items for child version (from 8 years old) and 12 for parent version.
- At the end of this first assessment, the family is given a 7-day **Pain Diary** composed by **Wong Baker Faces scale for children** or **VAS**, based on child age, measuring pain perception of rhGH injection on a 0-10 point scale. The family is asked to return it to the researcher when completed, filled out by the patient right after rhGH injections.

RESULTS

Pain: 77.6% of families returned the pain diary to the researcher. Average perceived pain score was 2.25 (SD=1.69). The 8-11 years old children group experienced significantly higher pain (M=3.84, SD=1.9) [$p < .05$] than older children between 12-15 and 16-18 years old. No significant difference was found between 3-7 years old children (M=2.19, SD=1.71) and the other age groups; as well as between the two older age groups (Fig. 1).

Figure 1. Patients' perceived pain mean scores for age groups



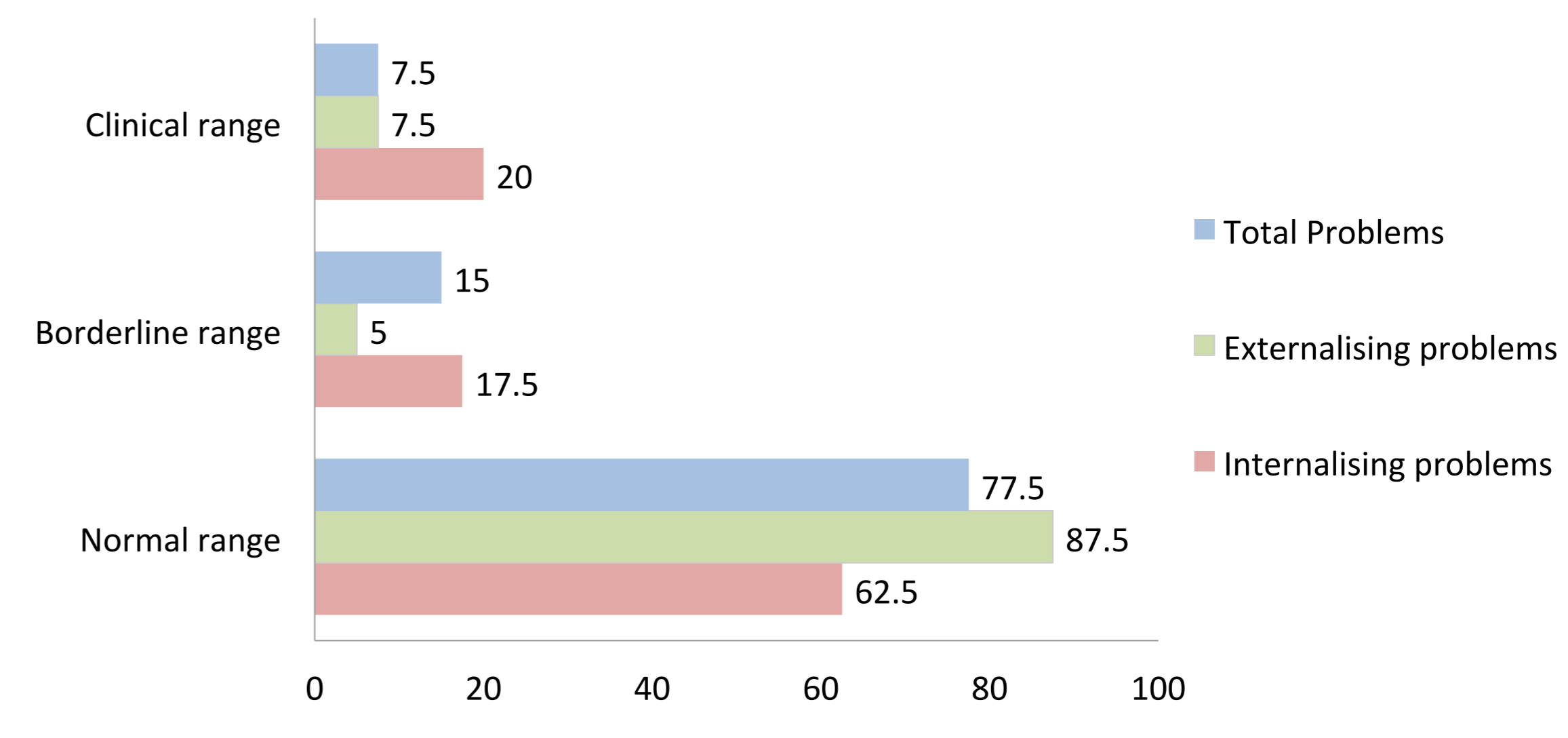
Quality of Life: QoL was satisfying for 85.7% of patients and 60% of parents (Tab. 1; Tab. 2). A high number of participants described an insufficient QoL in subscales regarding perception of coping abilities (53.6%) and treatment beliefs (46.4%). Same subscales were also the most critical for parents, who described a general perception of lower QoL with respect to their child in all the subscales. Despite this difference in the patient QoL evaluation, total QoL scores of parents and children were positively correlated ($r = .61$, $p < .05$).

Tables 1-2. Perception of total and sub-scales Quality of Life by patients and parents

QoLISSY-C Scales	Satisfying QoL score (%)	Unsatisfying QoL score (%)	QoLISSY-P Scales	Satisfying QoL score (%)	Unsatisfying QoL score (%)
Physical	78.6	21.4	Physical	65	35
Social	78.6	21.4	Social	55	45
Emotional	82.1	17.9	Emotional	60	40
Coping	46.4	53.6	Coping	40	60
Belief	75	25	Belief	57.5	42.5
Treatment	53.6	46.4	Treatment	12.5	87.5
Total QoL	85.7	14.3	Effects	57.5	42.5
			Total QoL	60	40

Behavioural and emotional functioning: Considering both scores in the clinical and the borderline clinical range, 37.5% of parents reported the presence of internalising problems, while 12.5% described externalising problems (Fig. 2). Within internalising problems, anxiety-depression is the most represented (20%) although the majority of patients were described as belonging to the borderline clinical range (17.5%). Also, in line with the previous scales results, in the DSM-IV scales the most problematic disorders resulted to be Affective disorders and Anxiety disorders, with respectively 5% and 15% of patients that might satisfy the criteria for diagnosis, with an additional 15% and 2.5% of patients that collocates in the borderline range. The other scales resulted to be less problematic.

Figure 2. CBCL Internalising, Externalising and Total Problems as described by parents



DISCUSSION AND CONCLUSIONS

Present preliminary results highlight the presence of pain in young children in therapy with rhGH, as well as some problems for what concerns QoL and emotional/behavioural well-being, suggesting the need to pay attention to such issues in order to plan a better care of patients and families.