

# Reporting of Symptom-associated Distress by Children and Young People with Life-limiting and Life-threatening Conditions and their Proxies

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## Background

For children and young people ('children') with life-limiting conditions (LLC), distress is an important facet of symptom assessment at end-of-life. Proxies often report symptom experience and most research has focussed on children with cancer.

## Research Aim

This study aims to explore the symptom-associated distress of children with a range of LLC from the perspectives of children and their proxies.

## Methodology

- Prospective longitudinal study.
- Data collected between March 2016 and July 2019.
- Recruitment from a tertiary UK paediatric palliative care service.
- Symptom assessment questions: Memorial Symptom Assessment Scale (MSAS) 7-12yrs ('younger' children) and 8-17yrs ('older' children). Supplemented for carers/nurses with symptoms commonly reported in the literature.
- Younger children + their proxies asked < questions (8, 20 items respectively) vs older children + proxies (30, 37 items respectively).
- Completed minimum weekly.
- Data analysed using descriptive statistics.

## Results

- 100 participants (48 parents 2-17yrs, 20 children 5-17yrs, 32 nurses).
- Median distress:
  - Younger children (Figure 1) + their proxies (Figure 2): 56.5% .
  - Older children (Figure 3) + their proxies (Figure 4): 31.5%.
- Most distressing:
  - Proxies: physical symptoms (e.g., pain and seizures)
  - Younger children: pain (100%)
  - Older children: hair loss (75%) and problems urinating (66.7%).
- Younger children + their proxies more likely to report psychological distress (e.g., worrying, sadness) than older children + their proxies.
- Younger children + their proxies reported higher symptom distress than older children + their proxies.
- Younger children's proxies report more symptoms highly distressing than children.
- Proxies of older children reported lowest number of symptoms highly distressing while proxies of younger children report highest.

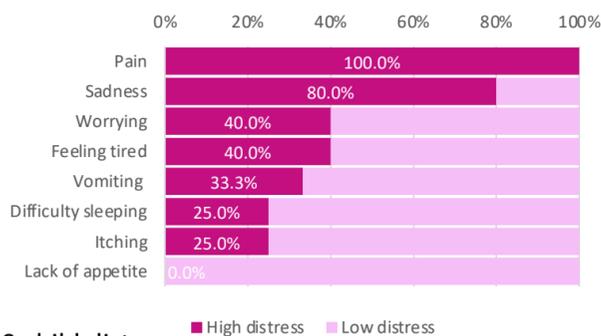


Figure 1. 2-9 child distress.

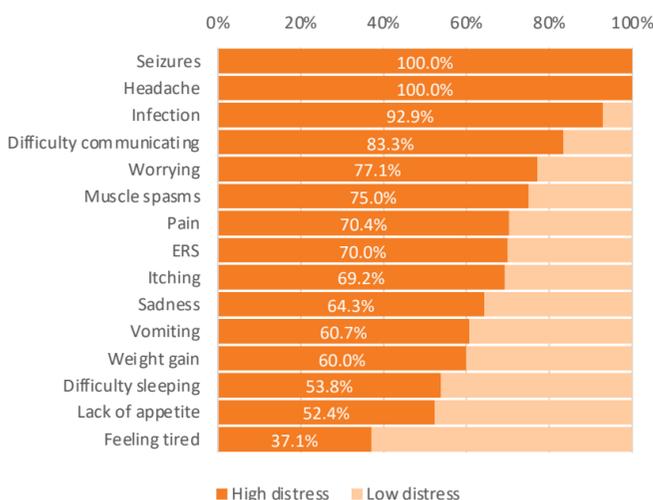


Figure 2. 2-9 proxy distress.

## Results: Continued

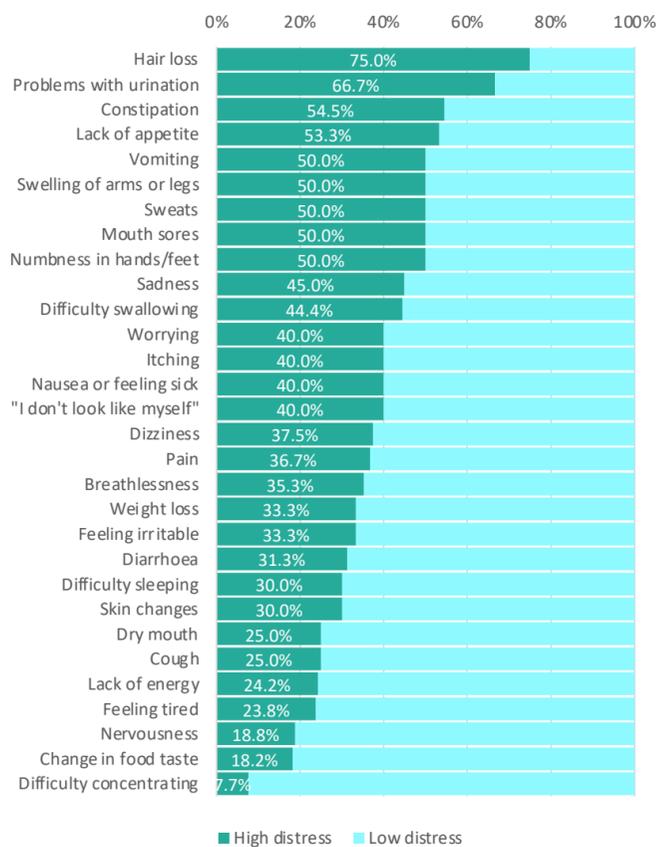


Figure 3. 10-18 child distress.

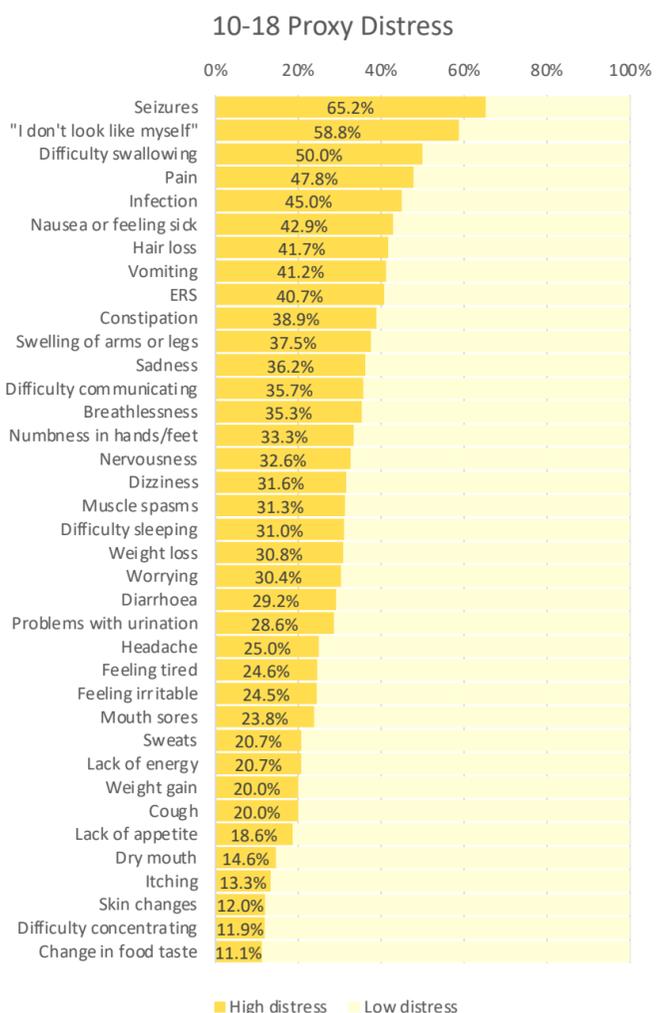


Figure 4. 2-9 proxy distress.

## Conclusion

- Proxies and children report different symptoms distressing (more pronounced amongst older children/their proxies).
- Despite being asked fewer questions, younger children's proxies tend to overestimate distress while older children's proxies underestimate. .
- Measures of symptom-related distress are an important tool in amplifying the child's voice in palliative care.