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# Evaluating agreement between children and proxy measures of symptoms via the Memorial Symptom Assessment Scale (MSAS)

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NHS

*Part of  
Symptom study*

Evaluating agreement between children and proxy measures of symptoms via the Memorial Symptom Assessment Scale (MSAS)  
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# Background: What does the literature tell us about **Symptom Assessment Scales**

Children and young people (CYP) experience multiple symptoms towards the end of life

Many studies of symptoms in CYP with palliative care- retrospectively using proxy report or case notes review

A systematic review of symptom assessment tools in CYP:

8 different cancer scales (Dupuis 2012)

No validated measure to assess symptoms in palliative care (Coombes, 2016)

**The Memorial Symptom Assessment Scale (MSAS) looked promising for use in CYP with Life limiting conditions**

# Aims and objectives

**Wider study aim:** To develop a comprehensive inventory of symptoms experienced by children and young people (CYP) with life limiting conditions using the Memorial Symptom Assessment Scale (MSAS)

**Objectives: To identify**

- ▣ symptom prevalence
- ▣ any important symptoms missing from the MSAS
- ▣ any items in the MSAS are not relevant to those receiving palliative care
- ▣ which symptoms cause the most distress
- ▣ the degree of severity of each symptom
- ▣ trends between phase of illness and symptom profile, severity and distress

**Current presentation:**

**Aim:** To assess agreement between parent, child and nurse score on the MSAS (Baggott, 2014)



# Methods

## Longitudinal study:

- CYP, Parents, nurse complete the MSAS
- 1-2 weeks if POI =unstable, deteriorating or dying
- 4 weeks if POI= stable
- minimum 4 times with option continue

Inclusion criteria: 2-17yrs under specialist PPC service

## Memorial symptom Assessment scale (MSAS)

- Three versions: adult, 10-18 yrs, 7-12 yrs
- Severity + distress of each symptom
- 7-12years: 8 items; 10-18year: 30 items
- Plus: Extra questions added**

## Data collection:

Demographic, disease related and phase of illness (POI)

Proxy reporter- same MSAS as the CYP



▪ 2-4yrs MSAS: proxy only

▪ 7-9yrs MSAS: (7-12)

▪ 5-6 yrs MSAS:(7-12) read aloud

▪ 10-18yrs MSAS: (10-18)

# Results

Data collection from 2016 to 2019

Of 49 CYP:

- 6 were < 5years
- 17 were non-verbal
- 19 died during the study

For the proxy agreement:

Total pairs (dyads)= 137

- Nurse – child = 23
- Parent – child = 49
- Parent – nurse = 55



CYP (N=49)	
Age (range)	10.04 yrs ( 2-17)
Gender (M:F)	26:23
Diagnosis:	
Cancer	33 (67.3%)
Neurological	12 (24.4%)
Metabolic	3 (6.1%)
Congenital	1 (2.0%)
Relationship to patient	
Mother	42 (82.4%)
Father	9 (17.6%)

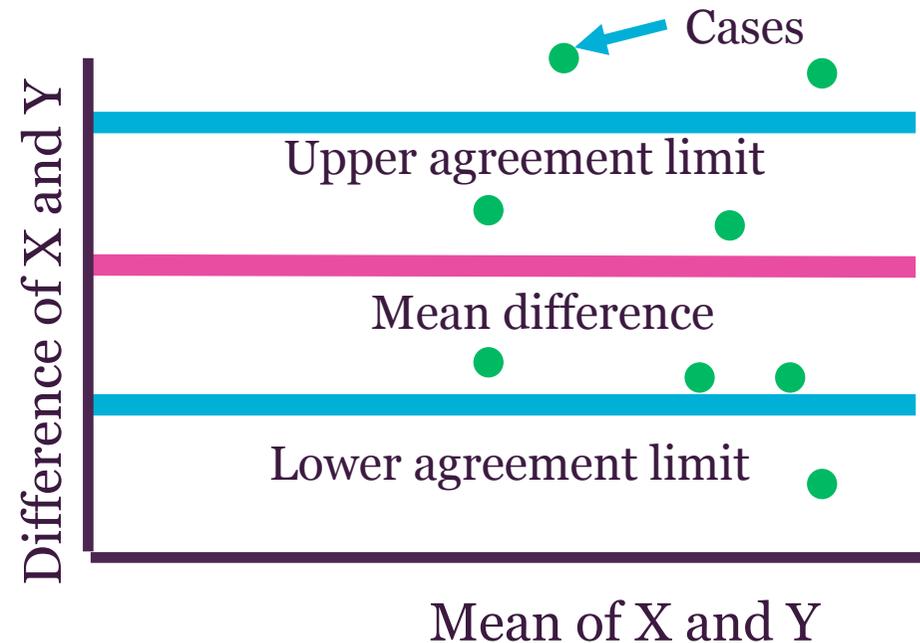
Age	CYP
2-4	6
5-9	17
10-17	26

# Bland-Altman Plots

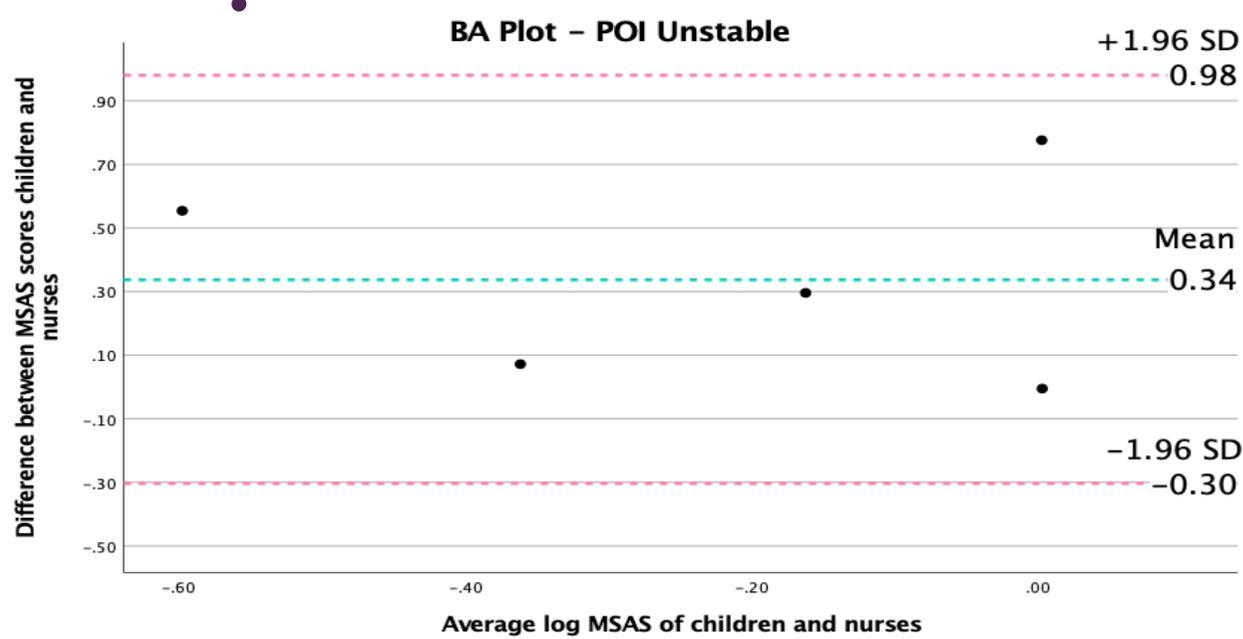
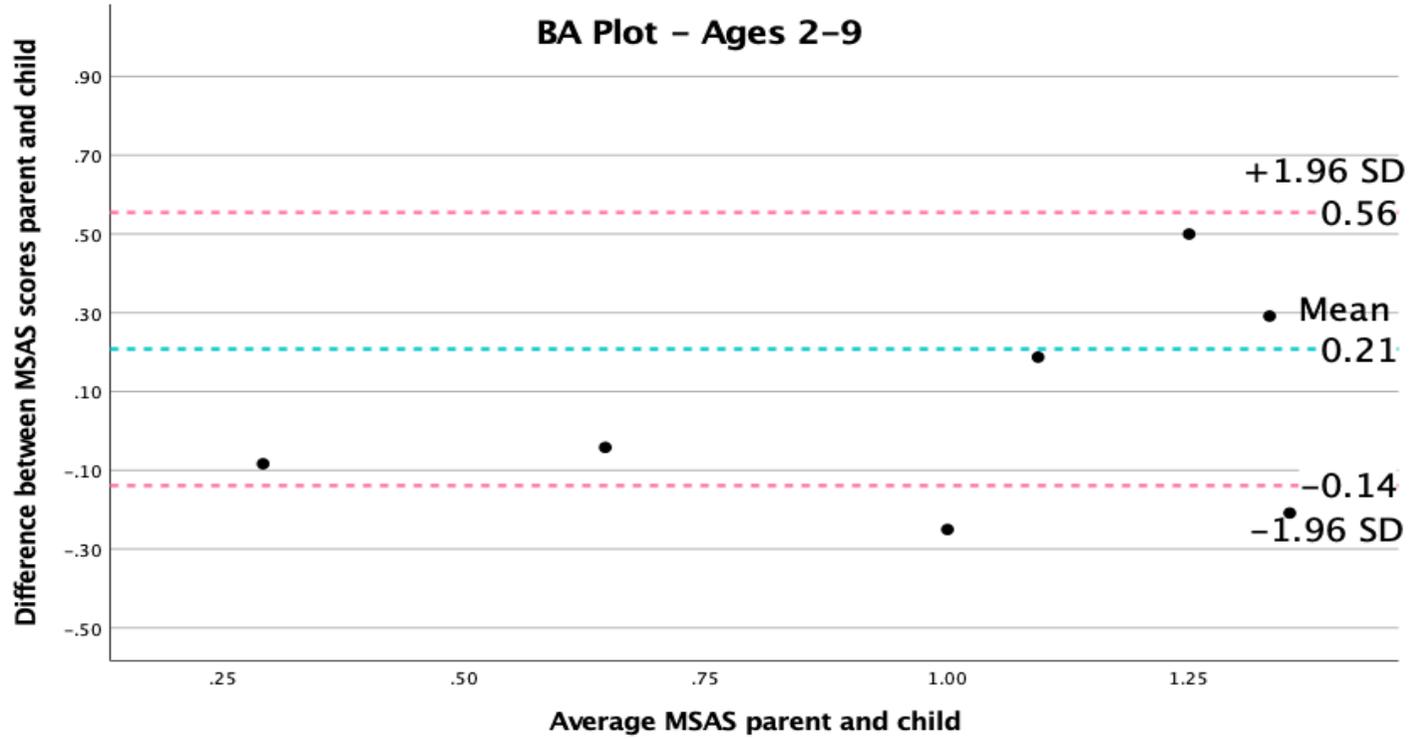
- ☐ Scores standardized to ensure comparability between MSAS versions

Difference =  $\frac{\text{each dyad's score}}{\text{average of each other}}$

- ☐ A priori limits of agreement to establish clinical significance<sup>1</sup>  
+/-0.5 clinically significant
- ☐ Intervals falling outside of this range = poor agreement.



1. Bland & Altman (2010) & Engelberg (2005)



## Proxy agreement analysis

**None** of the pairs (dyads) demonstrated clinically acceptable levels of agreement

	Overall	2-9yr	10-18yr	POI stable	POI not-stable
Parents & Children	-0.623 – 0.878	<u>-0.138</u> – <u>0.555</u>	-0.597 – 0.820	-0.632 – 0.907	-0.621 – 0.815
Parents & Nurses	-0.573 – 0.939	-0.675 – 0.948	-0.533 – 1.053*	-0.689 – 1.292	-0.639 – 0.775 *
Children & Nurses	-0.591 – 1.035*	<u>-0.449</u> – <u>0.755</u> *	0.611 – 1.108*	-0.671 – 1.049*	<u>-0.303</u> – <u>0.981</u> *



\*Log transformation due to non-normative data

lower level falls w/in limit

# Discussion

Our research adds to the dearth of research on children's voice on symptom experience questionnaires

Clinicians need to ensure they seek all voices/perspectives in order to fully capture a child's experience

## Wider literature:

Parents report higher symptom burden than children (Mack (2020); Montgomery (2020); Weaver (2021)).

One end-of-life study at home with proxy nurses and carers with total number of symptoms reported (Weaver, 2022)

## Limitations in our study:

- Low numbers for 2-9 yr age group
- Fewer non-oncology children

• MCSAS scores collected in driving phase

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Thank you for  
listening!

Special thanks  
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