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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%)

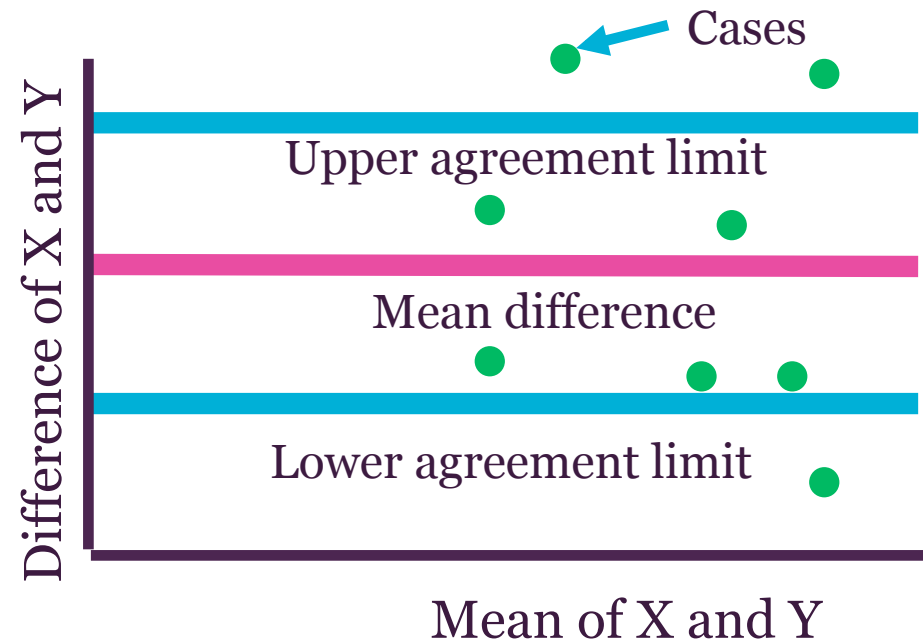
Age	CYP
2-4	6
5-9	17
10-17	26

Bland-Altman Plots

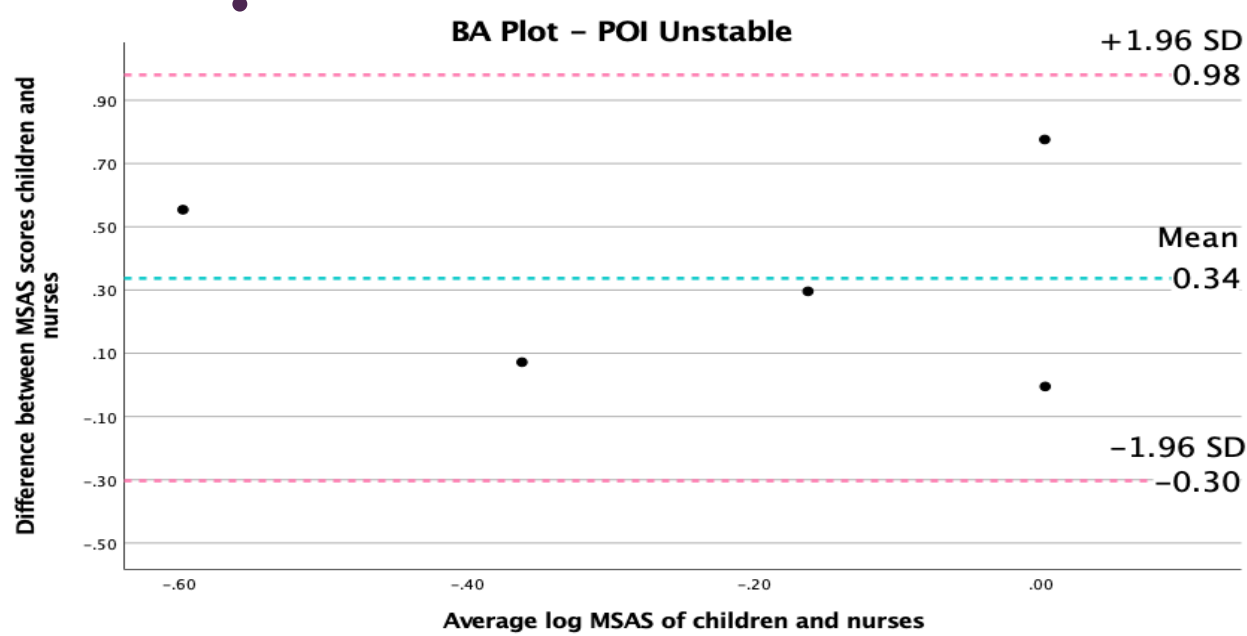
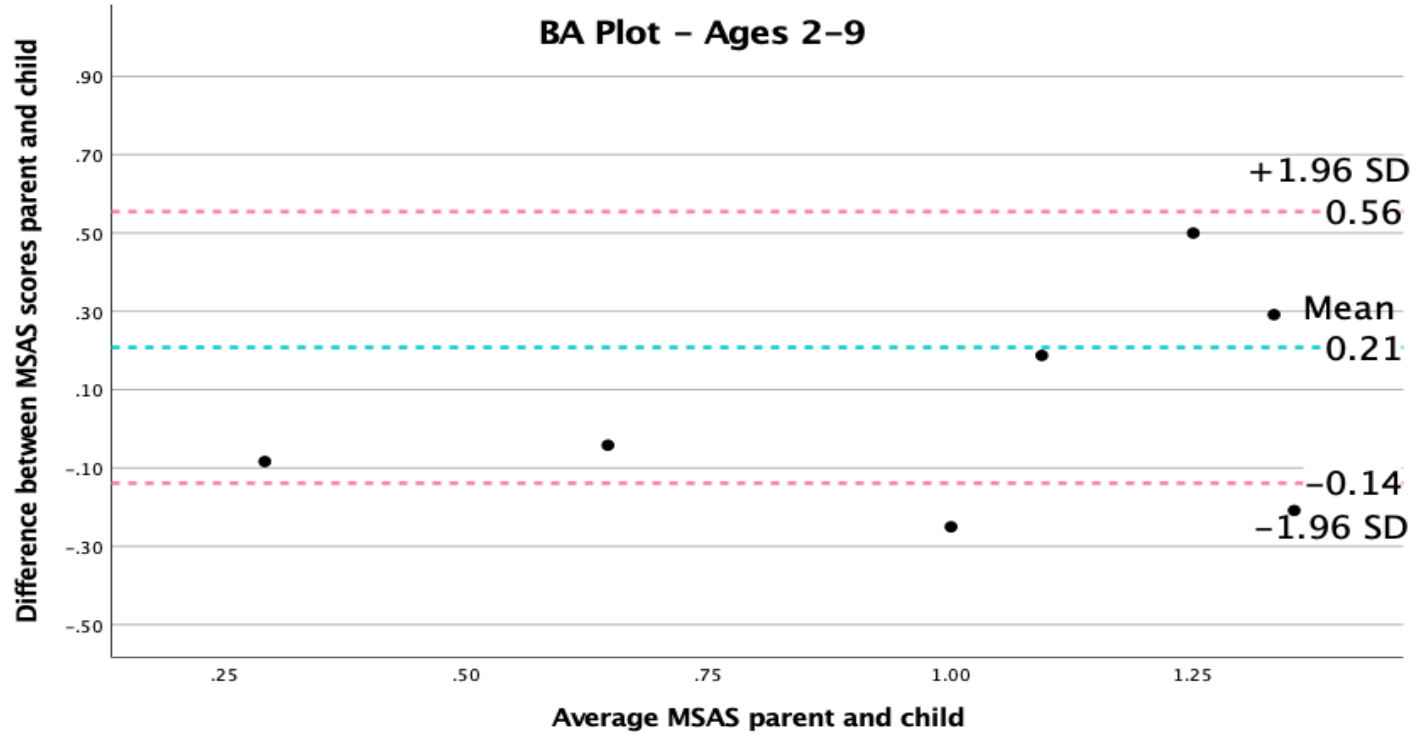
- ❑ Scores standardized to ensure comparability between MSAS versions

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

- ❑ A priori limits of agreement to establish clinical significance¹
+/-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 clinic phase

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Thank you for
listening!

Special thanks
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