

Quality of Life in People with Neurological and Developmental Conditions

Reflections on the Issues

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Here is a common situation...

- A colleague calls or writes to you, because...
- ...they want to assess the 'quality of life' of their patients, or the parents of their patients, or their colleagues, and...
- ...they know that you are interested in this field and have perhaps done some research, **so**...
- ...they ask what measure to use!

• **What do you ask them?**



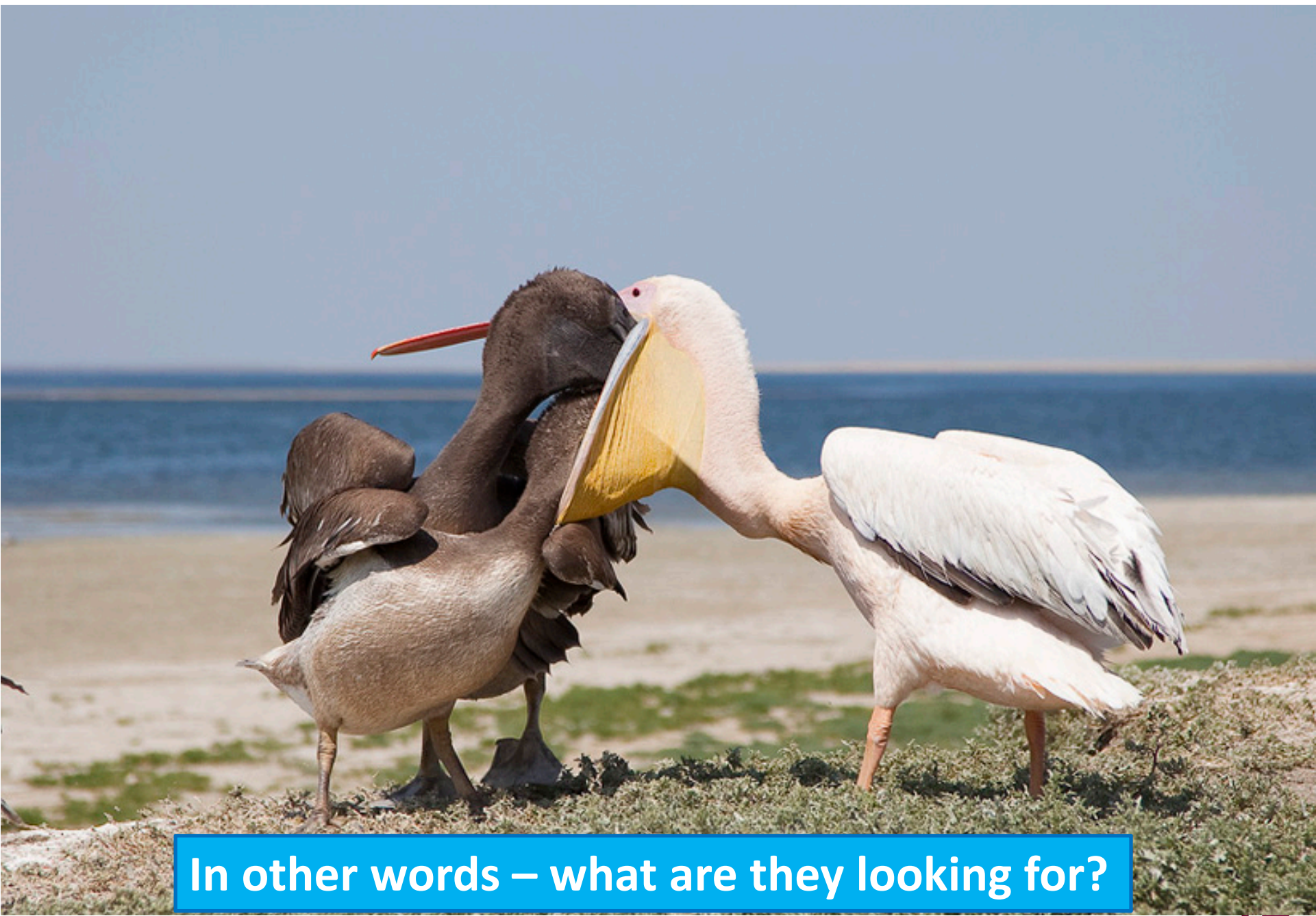
Think of my talk on CLASSIFICATION

- Hopefully your answer to your colleague is:

WTQ?

- I'd like us to explore this together





In other words – what are they looking for?



What I'd like US to do today...

- Let us start by exploring what people here mean by 'quality of life' ...
 - there are many ideas and no 'wrong' answers – so I encourage people to share their views...
- Then we can look at what the WHO says...
- That will put the discussion into a perspective that I hope will be helpful



What are your thoughts?



Hopefully now we have an idea what our colleague is asking us – and why!

- There are some further considerations about the whole QoL issue.
- These issues have very broad importance beyond QoL





A: What is Health?

- Absence of disease or infirmity?
- Complete physical, mental and social well-being?
- In the US (2012) 117 millions, half of all adults, had one or more chronic conditions
- What does *health* mean to those people?



What does Health mean to Patients?

- To be healthy does not mean that you are free of all diseases; it means that you can function, do what you want to do, and become what you want to become...

[Dubois 1981 \(cited by Levine et al. 1983\)](#)

- Health is ‘the ability to adapt and self-manage in the face of social, physical and emotional challenges’

[\(Huber et al. 2011\).](#)

- In other words, **functioning** (however it is done, regardless of ability/disability) can be understood as the **evidence of health**.



B: The Concept of Patient-Reported Outcomes (PROs)



- “Any report coming *directly* from people, without interpretation by physicians or others, about how they function or feel in relation to a health condition and its therapy” [Patrick et al](#)
- The term PRO is often used to refer to the things being measured
- PROMs are PRO Measures that are used to measure these persons’ reports



C: Why do we need PROs?



- Do patients share *our* perspectives about *their* health, wellbeing and quality of life?
- ...or do they have additional or different concerns about these aspects?
- If so, what constructs should we assess?
- What frames of reference should we use as our guide?



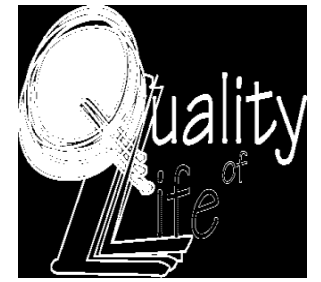
D: Why Use PROMs?



- How can we tell whether our patients are in fact ‘better’ after interventions?
- By what yardsticks can we evaluate
 - *Their health?*
 - *Their wellbeing?*
 - *Their quality of life?*
 - *The changes in **their** health over time, and in relation to what we recommend?*



SO: What is Quality of Life?



- An individual's *perceptions* of their position in life in the context of the *environment* in which they live, and in relation to their *goals*, *expectations* and concerns
(WHOQOL 1993)
- In children it is also dependent upon the *stage of development* & the *illness trajectory*
(Taylor 2008)



Subjective Wellbeing

Based on a factor analysis N = 1108, >25 yrs

1. *Autonomy*
2. *Environmental mastery*
3. *Personal growth*
4. *Positive relations with others*
5. *Purpose in life*
6. *Self acceptance*

Ryff & Keyes 1995



Finally, we are ready to start to answer our colleagues' question!

- We have learned what their focus is, and what their research question is!
- WE helped THEM arrive at the answer, so we can start to offer ideas.
- Who knew it was this complex?!
- So: What measure(s)? It depends!...



What is the **Content** of the Measure?

- What (content) do **they** want to know?
(**As always: What's the Question!**)
 - Does the tool measure what we want to know?
 - How was the measure created?
 - Whose perspectives are reflected in the content?
 - The following example might illustrate these issues.



For example: “Quality of Life” (QoL)

- WHO says: “...the **individual’s** perception of **their position in life** in the **context** of the **culture and value systems** in which they live, and in relation to **their goals, expectations, standards and concerns**”
- I think of this PERSONAL (PRO) view as ‘existential’



Or: “Health-related QoL” (HRQoL)

- ‘Health-related’ implies an interest in the **impact of the condition** on the person and on their ‘QoL’
- In effect, HRQoL **equates** Functional Status and ‘Quality Of Life’.
- WHOSE view is this?
- What do people think about this idea:
 - Usefulness?...
 - Limitations?...



A Personal Research Example...

- We looked at 'existential' and HRQoL QoL in 203 adolescents with CP who covered the GMFCS range
- We used the HUI-3 [for the HRQoL] and a measure of Being, Belonging, Becoming [for the existential QoL]
- We ran these against the GMFCS levels, and against one another as part of the analysis.
- **Ref.: Rosenbaum et al. DMCN 2007, 49: 516–521**



Findings: 1

- We found significant differences in mean overall HRQoL scores across all GMFCS levels... except GMFCS Levels II and III (**$p=0.82$**), indicating a **strong, negative relationship** between HRQoL and gross motor function (**$r=-0.81$**).
- **However, existential 'QoL' scores did not vary significantly by GMFCS level!**



Findings: 2

- HRQoL values were significantly, but weakly, correlated with scores on the 'existential' QOL Instrument for Being ($r=0.37$), Belonging ($r=0.17$), Becoming ($r=0.20$), and Overall QOL ($r=0.28$).
- The HRQoL scores explained between 2.9% and 14% of variance in QOL Instrument scores.
- **In other words – they are very different measures (because they are very different concepts)!**



QoL: Whose Views Matter?

- There are many possible perspectives on QoL:
 - The person who has 'it' ('existential')
 - A parent or other observer (a so-called 'proxy')
 - A health professional (which ones, and does it matter?)
 - A 'community' perspective
- Why does this issue matter?...
- How might these perspectives differ – and why?



Measures of QoL: The **Content/Items**


- Look carefully at the concepts and the items in any measure...
- Where did the items come from?
 - E.g., professionals, parents, children, people with the condition, community citizens...
- What are the items asking about?
- As always, we need to think: Is this what WE want to know?



Examples of 'QoL' Measures

- **HRQoL tools**
 - HUI-3 – a 'utility' measure
 - SF-36 or SF-12 – adult function
 - PedsQL – mainly emotional status
- **Intrapersonal tools**
 - KIDSCREEN...
 - HRQL Epilepsy
 - QoLPWDD



A toucan with a large, colorful beak (yellow, orange, and red) and a blue eye is perched on a light brown branch. The background is a dark, blurred blue.

So beware! Just because
you hear 'everyone
is using it...' doesn't mean
we should too!



Measuring (or even Talking About) QoL

- What do **WE** want to know, and why?
(Remember: **What's the Question?**)
- It is essential to have a good answer to this issue
(i.e., **we need to ask a good, clear, specific question**) before we start to measure QoL (or anything else)!



In Other Words... Ask Ourselves

- Why are we asking this question at this time?
- And... what will we do with the answers?
 - To describe?
 - To discriminate?
 - To understand things analytically?
 - To 'explain' a phenomenon?



In Other Words...

- What led us to ask the question in the first place?
- What do we think is going on with the person that might have an impact on the 'QoL' outcome of interest?
- What impacts might there be, and on what aspects of people's lives, and how and why?





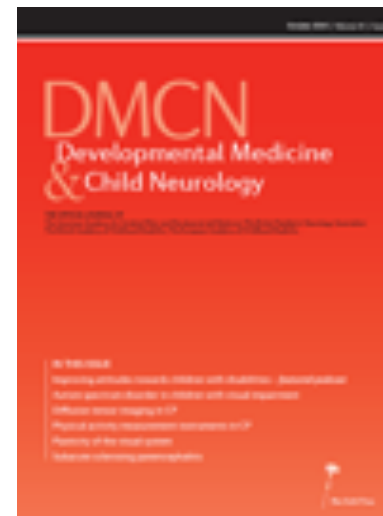
Health-related quality of life in childhood disorders: A modified focus group technique to involve children

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Health-related quality of life in childhood epilepsy: the results of children’s participation in identifying the components

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Choosing measures

Epilepsy specific Measure	QOL	Health status	S-self P-proxy raters	Dominant ICF-CY components
HARCES	●	●	P	Activity & participation; nc-epilepsy
EFA	●	●	S	Activity & participation; nc-epilepsy
QOLIE-AD-48	●	●	S	Activity & participation; nc-epilepsy
QOLPES	●	●	S	nc-seizure; activity & participation
ICI	●	●	P	activity & participation; nc-injury
QOLCE	●	●	P	Activity & participation; function
IPES	●	●	P	nc-epilepsy; activity & participation
ECQ	●	●	S	nc-epilepsy; activity & participation
ICNDS	●	●	P	Function; activity & participation
CHEQOL-25	●	●	S + P	Activity & participation; environment
Generic measure				
CHQ	●	●	S + P	Activity & participation; environment
PedsQL	●	●	S + P	Activity & participation; body function



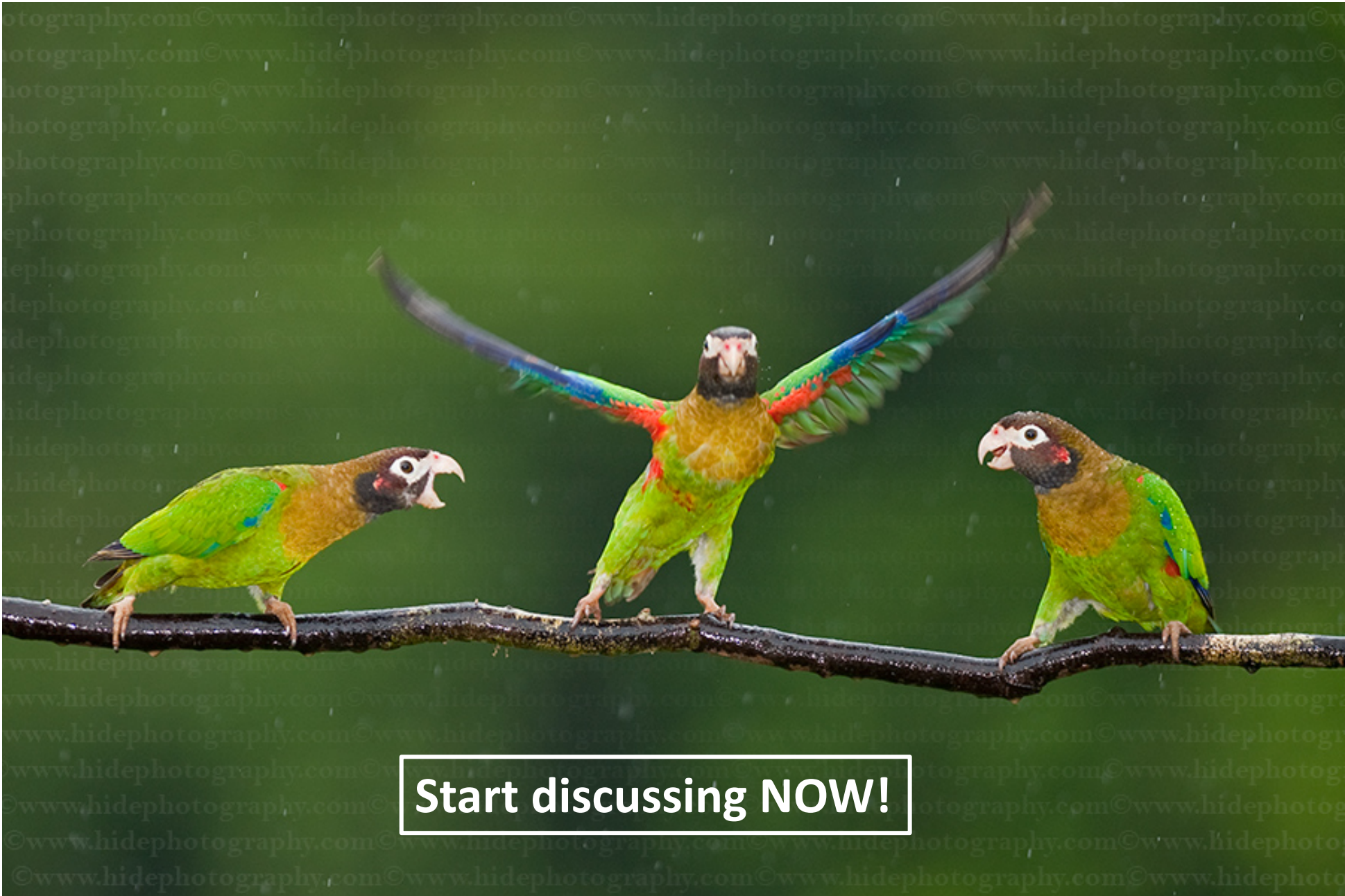
To conclude...

- I hope these ideas are useful to you – both about QoL and about ‘outcomes’ in general!
- A parent summed up the big issue that reflects our perspectives as professionals and their as parents:

YOU HAVE TEXTBOOKS, WE HAVE STORYBOOKS!

- Thanks for listening and sharing!





Start discussing NOW!

