

Shared decision making for parents expecting an extremely premature infant

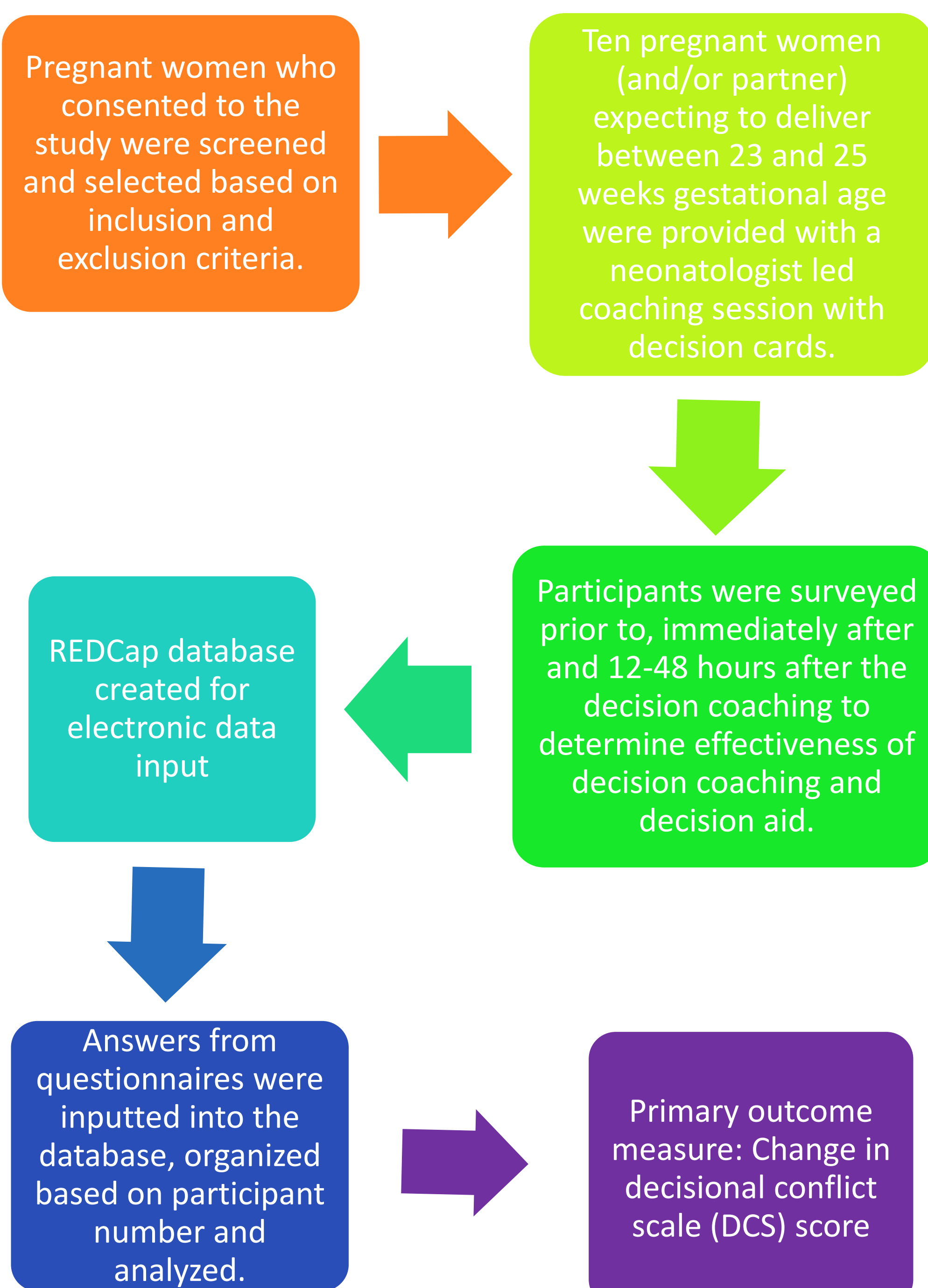
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Introduction

For parents that are at high risk for delivering an extremely premature infant (EPI), there are options in terms of the care to provide if their EPI is born alive: early intensive care or palliative care. Some antenatal factors, such as birth weight and gestational age, affect the morbidity and mortality rates of an EPI but none allow a physician to accurately determine whether the baby will survive or have any neurodevelopmental impairments; only estimates of the risk of these outcomes can be provided. The most studied impairments, in order of frequency, are cognitive delay, cerebral palsy, deafness and blindness. Since early intensive care or palliative care are both acceptable care options given the relatively high risk of morbidity or mortality in EPIs, parents need to understand the options, the risks and benefits of the options, and the related information about potential outcomes. Decision coaching with decision cards can provide unbiased guidance and information on the options, outcomes, and prognostic factors. The decision aid used in this study was modified from one that had only been tested in simulated cases. After modifications, the decision cards developed by Dr. Moore and colleagues received a drastically improved score from the International Patient Decision Aid Standards Checklist and the aid was ready to be tested with real patients.

Methodology



Results

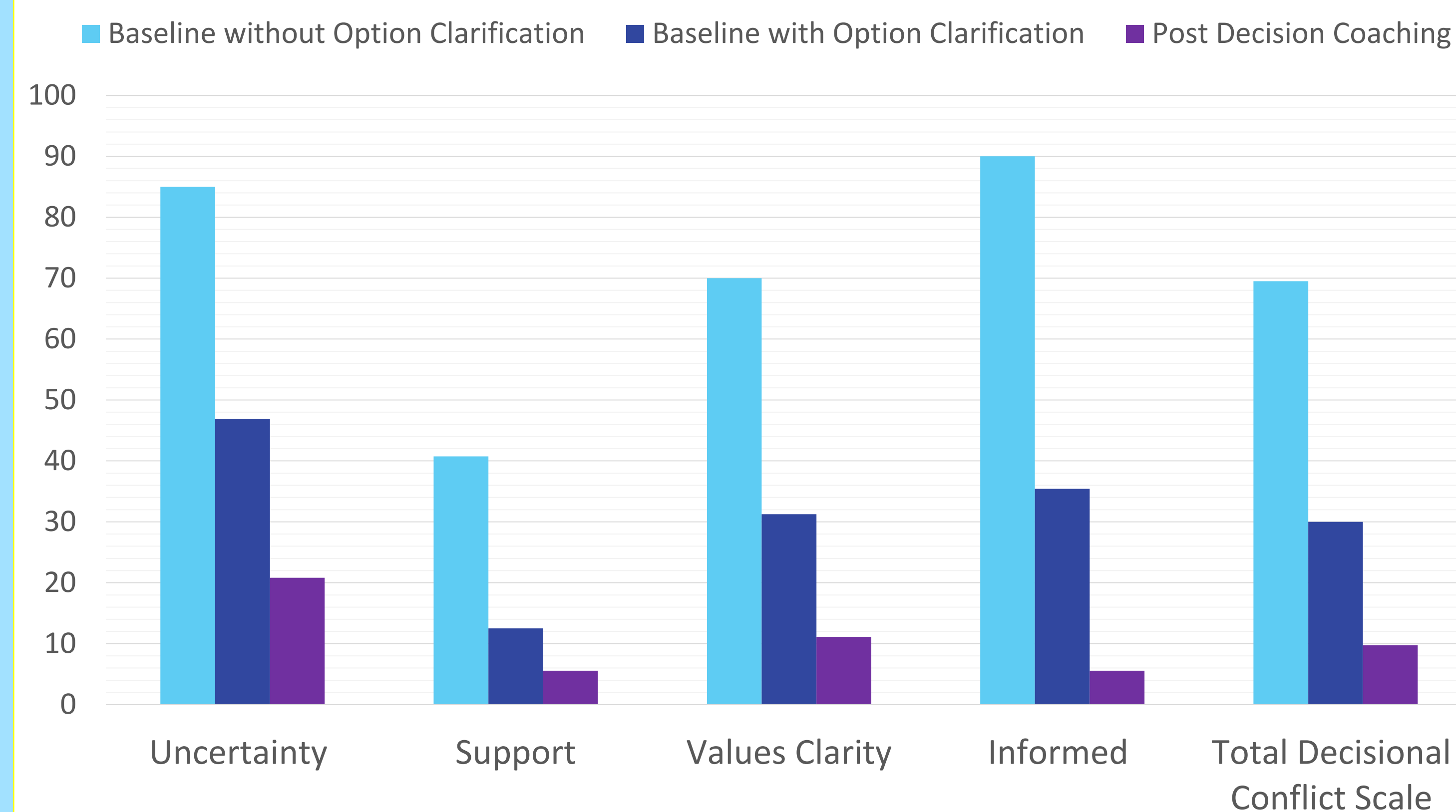
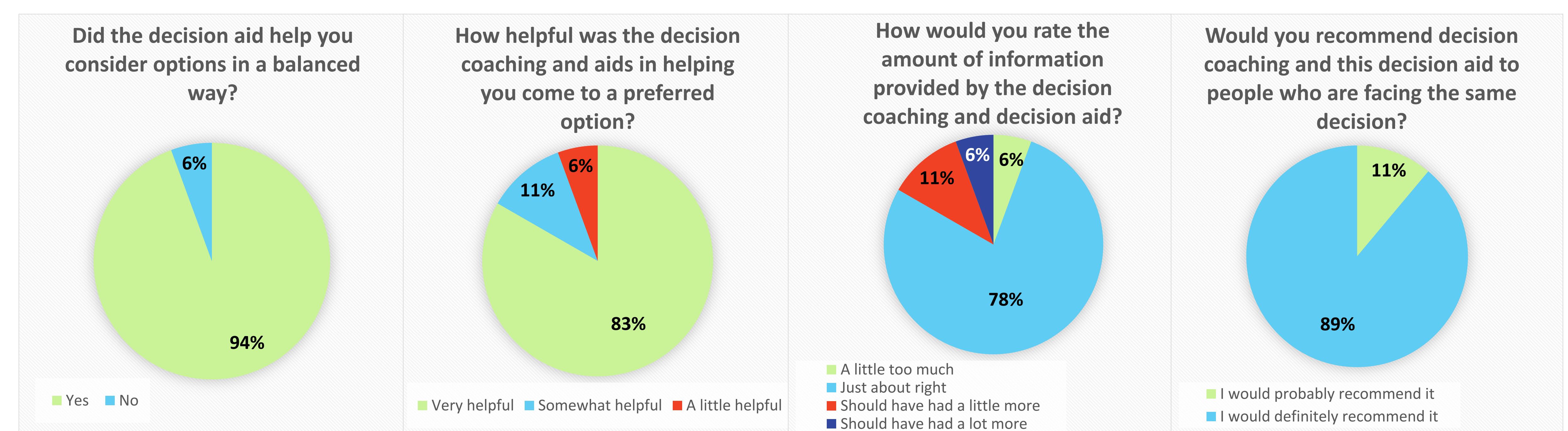


Figure 1. Improvement in decisional conflict scale (DCS) with option clarification and decision coaching

DCS scores can range from 0-100 and are calculated based on a 'yes', 'unsure' or 'no' answer (where either 0, 2 or 4 points are assigned respectively) to ten questions (Low Literacy version). The DCS has subscales of 'uncertainty', 'support', 'values clarity', and 'informed' (e.g. "Do you know which options are available to you?" is a question categorized under 'informed'). A decreased score shows improvement. A score less than 25 suggests a person can make a 'good' decision.

Demographic Characteristics	n (%) or Mean ± SD
Age (years)	33 ± 7
How far along is the current pregnancy? (weeks)	23 ± 0.5
What is your sex?	
Female	10 (56)
Male	8 (44)
What is your marital status?	
Married/common-law	16 (89)
Single	2 (11)
What is your primary language?	
English	13 (72)
French	1 (6)
Other	4 (22)
What is your highest level of completed education?	
Some high school	1 (6)
High school diploma	4 (22)
Trade certificate/diploma	3 (17)
University – undergraduate studies	4 (22)
University – graduate studies	6 (33)
Have you ever made a similar decision regarding an EPI in the past?	
Yes	1 (6)
No	17 (94)
Did parents receive option clarification prior to the consult?	
Yes	8 (44)
No	10 (56)

Table 1. Demographic characteristics (n = 18) of parents receiving a decision coaching session



Figures 2-5. Parental satisfaction with decision coaching and the decision aid (n=18)

Results from four selected questions from the 'Post Decision Coaching Questionnaire', completed by parents immediately following their decision coaching by one of four neonatologists at CHEO.

Conclusion

In **Figure 1**, it is evident that there was drastic improvement ($p < 0.01$) in all subscales of the decisional conflict scale once the patient received decision coaching. Even patients who had option clarification prior to the coaching session showed improved understanding of the options and ability in making a decision after seeing the decision aid. Also apparent in **Figures 2-5**, most participants agreed that the decision aid and coaching were very helpful, and they would recommend it to others. From these results, it may be concluded that the decision aid and coaching are effective in helping parents come to a decision regarding their unborn EPI and the implementation of these decision aids may be beneficial for future patients.

References & Acknowledgements

All data for this study (including the numbers presented in this poster) was analyzed by methodologist Salwa Akiki.

I would like to thank...

- The Undergraduate Research Opportunity Program at the University of Ottawa for this chance to experience research first hand.
- Dr. Gregory Moore (gmoore@cheo.on.ca); academic neonatologist and assistant professor at the University of Ottawa for this amazing opportunity and learning experience.
- Ms. Salwa Akiki; methodologist at CHEO's Clinical Research Unit for training me to use the REDCap database.
- The additional investigators of the Decision Aid project