

Shared Decision-Making, Decisional Conflict and Regret in Periviable Birth Counseling: A Multicenter Cohort Study in the Context of a Decision Aid

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Abstract

Objective

To describe perceived shared decision-making (SDM), decisional conflict (DC) and decision regret (DR) in prenatal counseling for imminent extreme premature birth, using a decision aid (DA).

Study design

Multicenter, cohort study measuring perceived SDM in parents and physicians, and DC and DR in parents at counseling, 1-, and 3-months post decision-making on palliative comfort care versus early intensive care (scales 0-100). A digital DA was offered before prenatal counseling for birth between 24 and 26 weeks of gestation.

Results

124 participants from 47 prenatal counseling sessions were included (36 pregnant persons, 25 partners, 31 obstetricians, 32 neonatologists). Perceived SDM was high in parents and physicians (SDM-Q-9 and SDM-Q-doc; median 86.7 and 77.8). DC was low (median 20.3), as was DR at 1 and 3 months (median 5 and 10).

Conclusion

Perceived SDM was high, and DC and DR were generally low in periviability counseling using a DA.

Introduction

Prenatal counseling at the limits of viability involves complex and value-laden decisions under conditions of substantial uncertainty. When imminent extreme preterm birth is anticipated, parents are generally counseled about several obstetric and neonatal decisions, including mode of delivery, administration of antenatal corticosteroids, and whether to pursue early intensive care (EIC) or palliative comfort care (PCC)^{1, 2, 3}. There is international variability regarding the upper and lower limits of the gray zone of viability in which these preference-sensitive decisions are made^{4, 5}. These decisions carry significant ethical and emotional implications and are often made under time pressure, with limited and evolving prognostic information.

Shared decision-making (SDM) is widely regarded as the preferred approach in periviability counseling, as it aims to integrate medical information with parents' values and preferences^{2, 3, 6}. However, implementing SDM in clinical settings is challenging, and studies have shown considerable variation in counseling practices and in the extent to which parents feel involved in decision-making^{7, 8, 9}. Patient

decision aids (ptDAs) have been developed to support SDM by providing structured information and facilitating value clarification^{10, 11, 12}. In general, ptDAs have been shown to reduce decisional conflict (DC) and increase knowledge¹³. Though evidence in the context of periviability counseling is scarce, parental knowledge seems to increase, but DC does not appear to decrease^{11, 14, 15, 16}. Moreover, decision-making in this context is known to be burdensome and has been mentioned as a potential source of guilt and decisional regret (DR)^{17, 18}.

We aimed to describe levels of perceived SDM, DC, and DR in prenatal counseling in the context of a digital ptDA supporting counseling in imminent extreme premature birth regarding treatment decisions on EIC versus PCC. Secondly, we explored relationships among SDM, DC, and DR, and explored whether these outcomes varied by treatment decision and/or neonatal outcome.

Methods

Study design and setting

Enrollment for this study took place in 2020 to 2022. During that period, national guidance on perinatal care in extreme prematurity in the Netherlands (2010) defined 24⁺⁰ weeks gestational age (GA) as the earliest point at which EIC may be offered to parents¹⁹. Between 24⁺⁰- and 25⁺⁶-weeks GA, (emphasizing 24⁺⁰-24⁺⁶ GA) the guideline recommended to share decisions with parents after prenatal counseling. National multidisciplinary recommendations for prenatal counseling were made available in 2018, and a Dutch online ptDA to support this was developed and validated afterwards and became freely available online in late 2019^{1, 12}.

This study concerns the part on decision-making of the CODA study (Prenatal Counseling with help of a patient Decision Aid in imminent extreme premature labor; a prospective evaluation of implementation and shared decision making). This multicenter study used validated surveys to assess perceived SDM and DC following prenatal counseling with help of a ptDA for imminent extremely preterm birth and DR at 1 and 3 months later. We included perspectives of both parents (pregnant person and their partner) and clinicians (obstetricians and neonatologists) and explored parental DC and DR. Four academic tertiary perinatal centers in the Netherlands participated.

Study population

Participants were pregnant persons and their partners receiving prenatal counseling for imminent extreme preterm delivery. Counseling could be initiated < 24⁺^{0/7} weeks GA, to allow sufficient time for decision-making, as EIC was offered from 24 + 0 weeks GA in accordance with the Dutch national guideline. Additional inclusion criteria were actual use of the ptDA during counseling (offered before the counseling), age ≥ 18 years, and sufficient Dutch language proficiency. Exclusion criteria included multiple pregnancies, congenital anomalies detected on ultrasound with a significant effect on

prognosis and medically indicated (iatrogenic) preterm birth such as in preeclampsia. Involved obstetricians and neonatologists were also invited to participate.

Enrollment took place between Aug 2020 and Sept 2022. Eligible participants were approached shortly after the prenatal consultation. Written and verbal study information was provided and written informed consent obtained by both the pregnant person and partner. The study was conducted in line with the Declaration of Helsinki. The Medical Research Ethics Committee of the University Medical Center Utrecht granted an exemption from formal review (file 18/400), as the study was not subject to the Dutch Medical Research Involving Human Subjects Act. This was confirmed by local review in the other participating centers.

Data collection

After joint prenatal counseling, ideally conducted by both a neonatologist and an obstetrician, parents were asked to complete two questionnaires within 48 hours after counseling: the SDM-Q-9 (assessing perceived shared decision-making (SDM)) and the Decisional Conflict (DC) scale^{20, 21}. At one and three months post-counseling, parents were contacted by email to complete the Decision Regret (DR) scale, with up to 3 reminders sent if needed²². Clinicians involved in counseling were asked to complete the SDM-Q-9-DOC within 48 hours after counseling²³. Appendix table 1 lists the instruments used.

Demographic and clinical data were either self-reported in the first survey timepoint or extracted from the electronic health records (maternal age, GA at counseling and at birth, parity, marital status, highest education, previous experience with preterm birth, live birth, neonatal mortality, and treatment decision (EIC or PCC)).

The SDM-Q-9 and SDM-Q-9-DOC (translated to Dutch) are validated tools for measuring the perception of SDM by patients and clinicians^{20, 23, 24}. Each contains nine items rated on a 6-point scale from 0 ("completely disagree") to 5 ("completely agree"). Following scoring guidelines, item scores were summed (with up to two missing values imputed using item means), and the total score was multiplied by 20/9 to yield a 0–100 scale, where higher scores indicate a greater degree of perceived SDM. The DC scale assesses perceptions of decisional uncertainty, contributing factors, and perceived decision quality²¹. We used the Dutch version of the standard 16-item scale, with responses rated from 0 ("strongly disagree") to 4 ("strongly agree")^{25, 26}. Scores were summed, divided by 16, and multiplied by 25 to generate a 0–100 scale (higher scores reflect greater DC). Subscales were calculated for uncertainty, feeling informed, values clarity, support, and perceived effective decision-making. The DR scale, designed to assess post-decision distress or remorse, was administered at follow-up at 1 and 3 months^{22, 27}. The Dutch version includes five items rated on a 5-point Likert scale²⁸. Items 2 and 4 were reverse-coded, and item scores were transformed by subtracting 1 and multiplying by 25. A final mean score ranging from 0 (no regret) to 100 (high regret) was calculated.

Data analysis

Data were analyzed using IBM SPSS Statistics version 29.0. At least one completed SDM-Q per case (from the pregnant person, partner, obstetrician, or neonatologist) was required for inclusion in the data analysis. Descriptive statistics (medians and interquartile ranges) were calculated for SDM, DC, and DR scores. Reliability was assessed using Cronbach’s alpha. Associations between scores within counseling sessions (e.g. between the pregnant persona and partner, and between clinicians) and between SDM, DC, and DR were explored using Spearman’s rho. Group differences in scores based on outcome or treatment decisions (EIC or PCC) were explored using Mann–Whitney U or Kruskal Wallis tests.

Results

Demographics

A total of 124 participants from 47 counseling sessions were included, comprising 36 pregnant persons, 25 partners, 31 obstetricians, and 32 neonatologists. Patient demographics per case are presented in Table 1. In most cases, EIC was decided upon (n=40, 85%), and the remainder opted for PCC (n=7, 15%). Remarkably, in 2 out of the total 7 PCC cases, parents reported in the SDM-Q that they had chosen EIC, whereas their physicians reported in the SDM-Q that PCC was the course of action after counseling—consistent with the documentation in the patient records. After counseling, only a minority of pregnant persons (n=8, 17%) actually delivered before 25 weeks GA. Of the 5 cases with neonatal mortality, two died because of a prenatal decision for PCC, and three died later because of prematurity complications despite EIC.

Table 1. Patient characteristics

	N (47 cases total)	% (of all cases) ¹
	Median (IQR) (min max)	
Age in years (pregnant person)	33.3 (30-36) (20-44)	
Para		
• - nulliparous	24	51%
• - multiparous	22	47%
• - unknown	1	2%
GA during counseling		
• - <23 ^{0/7}	1	2%
• - 23 ^{0/7} to 23 ^{6/7}	19	40%
• - 24 ^{0/7} to 24 ^{6/7}	27	57%
Marital status		
• single	1	2%
• relationship / not living together.	4	9%
• relationship / living together.	17	36%
• Married	21	45%
• - unknown	4	9%
Highest education level (pregnant person)		
• lower secondary education	6	13%
• upper secondary education	10	21%
• higher professional education	14	30%
• university degree	10	21%
• - unknown	7	15%
Previous familiarity with preterm birth (n/% yes)		
• explanation of preterm birth in previous pregnancy	3	6%
• explanation of preterm birth in current pregnancy	16	34%
• previous pregnancy <28 weeks GA	2	4%
• Prior use of decision aid for extreme premature birth	0	0%

Treatment decision made²		
• palliative comfort care	7	15%
• early intensive care	40	85%
GA at time of birth		
• <24 ^{0/7}	2	4%
• 24 ^{0/7} to 24 ^{6/7}	6	13%
• 25 ^{0/7} to 25 ^{6/7}	4	9%
• 26 ^{+0/7} to 31 ^{6/7}	12	26%
• 32 ^{+0/7} – above	20	43%
• Unknown due to transfer of care ³	3	6%
Live birth		
• yes	46	98%
• no	0	0%
• unknown	1	2%
Neonatal mortality (first 28 days)		
• yes	5	11%
• no	35	75%
• unknown (intra-uterine transfer to other hospital 24-28 weeks)	2	4%
• unknown (intra-uterine transfer to other hospital >28 weeks)	5	11%
1: Due to rounding, the percentages do not always add up to 100%		
2: Based on what physicians described and confirmed from patient records		
3: One transfer of care (of the pregnant person) to other centers >30 weeks' GA, and two times between 25+0- and 26+0-weeks' GA. No information on delivery date or outcome was available.		

Shared decision making (SDM)

The median overall SDM score for all participants (n=124) was 84.4 (IQR: 73.3–91.1). Detailed subgroup scores are presented in Table 2 and Figure 1. Patients reported a slightly higher SDM score than physicians (p=0.009 Mann Whitney U). Among physicians, the highest scoring SDM item was item #9 (my patient and I reached an agreement on how to proceed, mean 4,6 (scale 0-5)), while for parents it was item #6 (my doctor asked which treatment I prefer, mean 4,7 (scale 0-5)) (see Appendix table 3). Conversely, item #2 (I wanted to know from my patient how he/she wants to be involved in making the decision, mean 3,2 (scale 0-5)) received the lowest scores from physicians, and item #8 (my doctor and I

selected a treatment option together, mean 3,5 (scale 0-5)) from parents. Internal consistency of the SDM measures was good, as indicated by Cronbach's alpha: 0.829 for parents (SDM-Q-9) and 0.828 for physicians (SDM-Q-doc).

Table 2 *Main outcomes per instrument (SDM, DC, DR) and including subscales.*

Instrument (n = total participants (*))	Median (IQR)
SDM-q-9 (n=61)¹	86.7 (76.7 – 97.8)
• Pregnant person (n=36)	84.4 (77.8 – 95.0)
• partner (n=25)	86.7 (75.6 – 95.6)
SDM-q-doc (n=63)¹	77.8 (71.1 – 86.7)
• obstetrician (n=31)	77.8 (73.3 – 86.7)
• neonatologists (n=32)	80.0 (71.1 – 86.7)
DC total score (n=59)	20.3 (6.3 – 29.7)
• Pregnant person (n=35)	23.4 (6.3 – 29.7)
• Partner (n=24)	14.8 (6.6 – 28.1)
- DC subscore uncertainty	25.0 (16.7 – 41.7)
• Pregnant person	25.0 (16.7 – 41.7)
• Partner	20.8 (8.3 – 41.7)
- DC subscore feeling informed	16.7 (8.3 – 25.0)
• Pregnant person	16.7 (0 – 25.0)
• Partner	12.5 (8.3 – 25.0)
- DC subscore values clarity	25.0 (8.3 – 25.0)
• Pregnant person	25.0 (8.3 – 25.0)
• Partner	16.7 (2.1 – 25.0)
- DC subscore support	8.3 (0 – 25.0)
• Pregnant person	8.3 (0 – 25.0)

• Partner	12.5 (0 – 25.0)
- DC subscore effective decision	18.9 (0 – 31.3)
• Pregnant person	25.0 (0 – 25.0)
• Partner	15.6 (0 – 31.3)
DR score 1 month (n=35)	5 (0 – 15)
• Pregnant person (n=19)	5 (0 – 15)
• Partner (n=16)	0 (0 – 27.5)
DR score 3 months (n=37)	10 (0 – 25.0)
• Pregnant person (n=21)	10 (0 – 25.0)
• Partner (n=16)	12.5 (0 – 23.8)
(*) maximum observations would always be 94 per scoring instrument or 47 per respondent type; given a total of 47 cases potentially 94 physicians (obstetricians and neonatologists) or 94 parents (pregnant person and partner) could fill out each instrument.	
1: SDM scores patients versus physicians differ significantly (p 0.009 Mann Whitney U)	
Note: DC, DR 1, and DR 3-month scores did not significantly differ between pregnant person & partner	

Decisional conflict

The median total DC score among all parents (n=59) was 20.3 (IQR: 6.3–29.7); detailed scores are presented in Figure 2 and Table 2. No significant difference was found between the pregnant person and partner. Among the decisional conflict subscores, *uncertainty* had the highest median score (25.0), while *support* had the lowest (8.3). Overall, 33 parents (56%) had a DC score below 25, which is typically associated with readiness to implement a decision²⁶. In contrast, 5 parents (8.5%) had a DC score above 37.5, suggesting decision delay or ambivalence. In this data, internal consistency for the total DC score was excellent, with a Cronbach's alpha of 0.930.

Decision regret (DR)

The median DR score one month after counseling among parents (n=35), was 5 (IQR: 0–15); and at three months (n=37) DR score was 10 (IQR: 0–25). No significant differences were found between the pregnant person and partner. Detailed scores are presented in Figure 3 and Table 2. In this data, internal

consistency of the DR scale was good to questionable, with a Cronbach's alpha of 0.862 and 0.689 at 1 and 3 months, respectively.

Correlations SDM, DC and DR

In this sample of 47 counseling sessions, correlations between perceived SDM, DC, and DR scores were assessed. Due to missing data, sample sizes varied across analyses and several correlations were based on small numbers of sessions, reliable interpretation was limited. SDM-Q-9 scores of the pregnant person and partner showed a moderate to strong positive correlation within counseling sessions (n=20, Spearman's rho correlation coefficient (r) =0.631, p=0.003). No correlation was observed between neonatologists' and obstetricians' SDM-Q-doc scores (n=22 sessions, r=-0.050, p=0.824). For several correlations, small sample sizes were too small to allow reliable interpretation. For example, correlations across all four participants could only be calculated for 4 of the 47 counseling sessions and no conclusion could be drawn. DC scores of the pregnant person and partner were strongly correlated (n=19 sessions, r=0.854, p=0.001). Correlations between the pregnant person and partner on DR scores at 1 and 3 months were low (both n=10 counseling sessions), precluding reliable interpretation.

Higher SDM-Q-9 scores were associated with lower DC scores for both pregnant persons (r=-0.719, p=<0.001) and partners (r=-0.411, p=0.046). SDM-Q-9 scores showed a negative correlation with DR at 1 or 3 months; however, this association reached significance only for the partners at DR 3 months (r=-0.710, p=0.004). DC scores showed a positive correlation with DR, with statistical significance observed only for partners at DR 3 months (r=0.600, p=0.023).

Case characteristics and perceived SDM, DC and DR

Exploratory analysis suggested lower SDM-Q-9 scores, higher DC scores, and a higher DR scores at 1 month in the PCC group compared with the EIC group (Table 3). DR scores were also higher in the cases without neonatal survival. P-values are presented for descriptive purposes; results should be interpreted with caution given the small sample sizes, particularly in the PCC and no-survival groups.

Table 3. Case characteristics and SDM, DC and DR scores among pregnant person and partner

Treatment decisions (Palliative comfort care (PCC) versus Early intensive care (EIC)) *				
		PCC	EIC	P-value (Mann Whitney U)
SDM-Q-9 score, median, (n=61)		76.7 (n=10)	86.7 (n=51)	0.050
DC score, median, (n=59)		28.1 (n=10)	17.2 (n=49)	0.016
DR score, median, 1 month (n=35)		30 (n=4)	0 (n=31)	0.007
DR score, median, 3 months (n=37)		20 (n=5)	7.5 (n=32)	0.213
Outcome (No survival versus survival)				
	No survival	Survival	Unknown	P-value (Kruskal Wallis)
SDM-Q-9 score, median, (n=61)	84.4 (n=6)	86.7 (n=51)	85.6 (n=4)	0.862
DC score, median, (n=59)	24.2 (n=6)	18.8 (n=49)	13.3 (n=4)	0.460
DR score, median, 1 month (n=35)	32.5 (n=4)	5 (n=27)	0 (n=4)	0.004
DR score, median, 3 months (n=37)	30.0 (n=6)	5 (n=29)	10 (n=2)	0.022
<i>Note: the total number of individuals (n) is provided for each cell, as missing data resulted in varying sample sizes across the cells, with participants not completing every questionnaire. All analyses were exploratory. P-values are presented for descriptive purposes only; no corrections for multiple comparisons were applied. Results should be interpreted with caution given small sample sizes.</i>				
<i>*Treatment decision was based upon patient records and physician-reported SDM-Q-doc data like Table 1. In two of seven PCC cases, parents reported having chosen EIC in the SDM-Q-9, whereas physicians reported PCC– consistent with the patient records. When these two cases were excluded from analysis, median scores for the PCC group changed to 75.6 (SDM-Q-9), 28.1 (DC), 30 (DR 1month) and 22.5 (DR 3months), with p-values of 0,100 (SDM-Q-9), 0,055 (DC), 0,008 (DR 1month) and 0,142 (DR 3months).</i>				

Discussion

In this multicenter study evaluating prenatal counseling for imminent extreme premature birth supported by a digital ptDA, we observed generally high levels of perceived SDM among both parents and clinicians, alongside relatively low DC and DR. Higher SDM-scores seemed to be associated with lower DC and DR scores, and higher DC scores with higher DR scores. Decisions for PCC and cases with neonatal non-survival were associated with higher DC and DR, although small sample sizes preclude firm conclusions.

Prior to implementation of the Dutch ptDA, median SDM-Q scores were 84.4 for both parents and clinicians²⁹, compared with 86.7 for parents and 77.8 for clinicians in the present cohort. Median DC decreased from 23.4 in the pre-ptDA cohort to 20.3 in this study, and median DR at one month was lower in the current cohort than previously reported (5 versus 12.5)²⁹. Although these findings are consistent with favorable decisional outcomes in a cohort using the Dutch ptDA, direct attribution to the ptDA is not possible given the historical control design and comparison is limited small sample sizes. Prior studies within the periviability context reported no evident effects of ptDAs on DC: in a randomized study by Guillén et al., in which counseling was standardized and only the additional use of a ptDA was randomized, DC scores were similar between groups (mean 16.3 vs. 16.8)¹¹. Moore et al. observed a substantial reduction from 50 to 0 in DC following counseling that included a ptDA, however, their pre-post design does not allow the effect of the ptDA to be distinguished from the effect of counseling itself³⁰.

Perceived SDM scores were high in both parents and physicians, consistent with our previous cohort²⁹, and comparable to scores reported in other high-stake pediatric counseling sessions³¹ but warrant cautious interpretation. The SDM-Q measures self-perceived SDM, which may reflect general satisfaction with the consultation rather than actual shared deliberation, concordance with observed SDM behavior is known to be limited^{32, 33}. Item-level analysis suggests that while reaching a decision was experienced positively, the more collaborative dimensions of SDM (eliciting how parents wished to be involved and selecting a treatment together) scored relatively lower, similar to Evong et al. studying pediatric surgeries decisions³¹. Finally, the absence of correlation between neonatologists' and obstetricians' SDM-Q-Doc scores within the same sessions could reflect their distinct roles in the conversation but may also highlight that the instrument was not designed for multi-physician settings.

Comparisons with prior studies assessing DC and DR in the periviability context reveal variability. Reported DC scores range from 0 to 50^{11, 29, 30, 34, 35}, while reported DR scores range from 0 to 39^{29, 35, 36, 37}. The association between higher SDM scores and lower DC and DR is consistent with previous findings²⁹. The higher DC and DR observed in families choosing PCC and in cases of neonatal non-survival may not primarily reflect regret about the decision or the quality of counseling itself. Studies examining parental regret in the NICU context suggest that regret is more commonly related to parents' broader experiences of care and communication than to specific end-of-life decisions or the counseling discussions themselves^{38, 39}. This interpretation is consistent with our findings: elevated DR in non-survival cases may reflect outcome-related distress rather than dissatisfaction with the decision-making process. Overall, the literature suggests that opportunities for further optimization lie not only in the use of ptDAs, but also in the quality of prenatal counseling itself. Several studies report more favorable decisional outcomes when parents receive structured counseling compared with no counseling^{11, 30, 37}. Moreover, an active parental role in decision-making and explicit exploration of parental values and preferences are associated with improved decisional experiences^{1, 9, 17, 18, 35, 40, 41}. Building a trusting relationship and personalization of counseling are highly recommended^{1, 42, 43, 44, 45}.

Parents who opted for PCC reported higher DC and DR compared with those who chose EIC. Our previous study also revealed a higher DC score in the PCC group²⁹. Higher DR scores were also observed in cases of neonatal non-survival. These findings should be interpreted with caution, as small sample sizes preclude disentangling the effects of the treatment decision itself from outcome-related distress. Rather than indicating regret about the decision per se, these patterns may reflect the substantial moral weight and emotional burden associated with non-intervention decisions and adverse outcomes, consistent with prior literature showing that end-of-life decisions are generally associated with higher DC than other medical decisions⁴⁶.

Most parents who were counseled for imminent extreme premature birth ultimately delivered at a later GA and did not need to enact the discussed decision, like other cohorts^{11, 29}. Nonetheless, these parents were exposed to the emotional burden of a high-stakes counseling encounter. Such conversations may have impact even when the anticipated scenario does not materialize. In two cases parents and clinicians reported different treatment decisions (PCC versus EIC), despite concordant documentation in the medical record with the treatment decision item of the SDM-Q-doc. No clear explanation related to timing of the SDM-Q-9 or clinical course could be found. Although striking given the magnitude of these decisions, similar discrepancies have been described previously in the periviability counseling literature^{37, 47}. These findings underscore the need for explicit summarization and confirmation of the agreed-upon care plan, for example through structured “read-back” strategies and clear documentation in the medical record. This is particularly important given that counseling content and decisions may evolve over time, and prior studies have shown that clinicians do not always accurately interpret or recall parents’ preferences and decisions^{11, 48}.

The proportion of PCC decisions (15%) is roughly comparable to reports from other studies in the “gray zone of viability”, despite the higher GA thresholds for this gray zone in the Dutch context^{11, 37, 49, 50}. While this study was not designed to assess whether the use of a ptDA altered parents’ treatment preferences, prior studies suggest that counseling may not change initial preferences, which may be already formed and tend to remain stable over time^{11, 30}.

Strengths of this study include the multicenter design, inclusion of both parents and clinicians and the use of validated instruments. However, sample sizes were modest, particularly for subgroup and correlation analyses, limiting the reliability of these estimates. The observational design precludes causal inference. Data collection took place during the COVID-19 pandemic. Missing data and incomplete participation across all four stakeholders reduced the number of fully comparable cases. The cross-sectional design for SDM and DC does not allow assessment of temporal changes, and the study was conducted within a specific national context with established guidelines and a freely available ptDA, which may limit generalizability.

Conclusion

In this cohort, prenatal counseling for imminent extreme premature birth supported by a digital decision aid was associated with high perceived SDM among both parents and physicians, alongside relatively low DC, and DR. SDM scores should be interpreted cautiously, as perceived SDM may not fully capture the collaborative dimensions of shared deliberation. Explicit summarization of the agreed care plan at the end of counseling is recommended, given observed discrepancies in reported treatment decisions. Higher DC and DR were observed in families choosing PCC and in those experiencing neonatal loss; whether additional support in these situations improves decisional outcomes warrants further study.

Declarations

Disclosure: *All authors have indicated they have no potential conflicts of interest to disclose.*

Ethics approval: *This study was conducted according to the principles of the Declaration of Helsinki. Formal exempt from Institutional Review Board approval by the Medical Research Ethics Committee of the University Medical Center in Utrecht (reference number 18/400) was received, as the Committee confirmed that the Dutch Medical Research Involving Human Subjects Act did not apply to this study – which was locally confirmed in the other three centers. Parents signed informed consent after both written and verbal information about the study.*

Availability of data and materials: The dataset is available upon reasonable request through the corresponding author.

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Author Contributions: RG, JFMH, MB, and MH designed and planned the study. JFMH, MB, MH, SM, LD, KK, EvW-K and RG did the data collection. RG did the data analysis, JFMH assisted with data analysis. RG, JFMH and MH interpreted the findings. RG wrote the first version of the manuscript. All authors provided critical feedback and helped shape the research, analysis, and manuscript.

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Figures

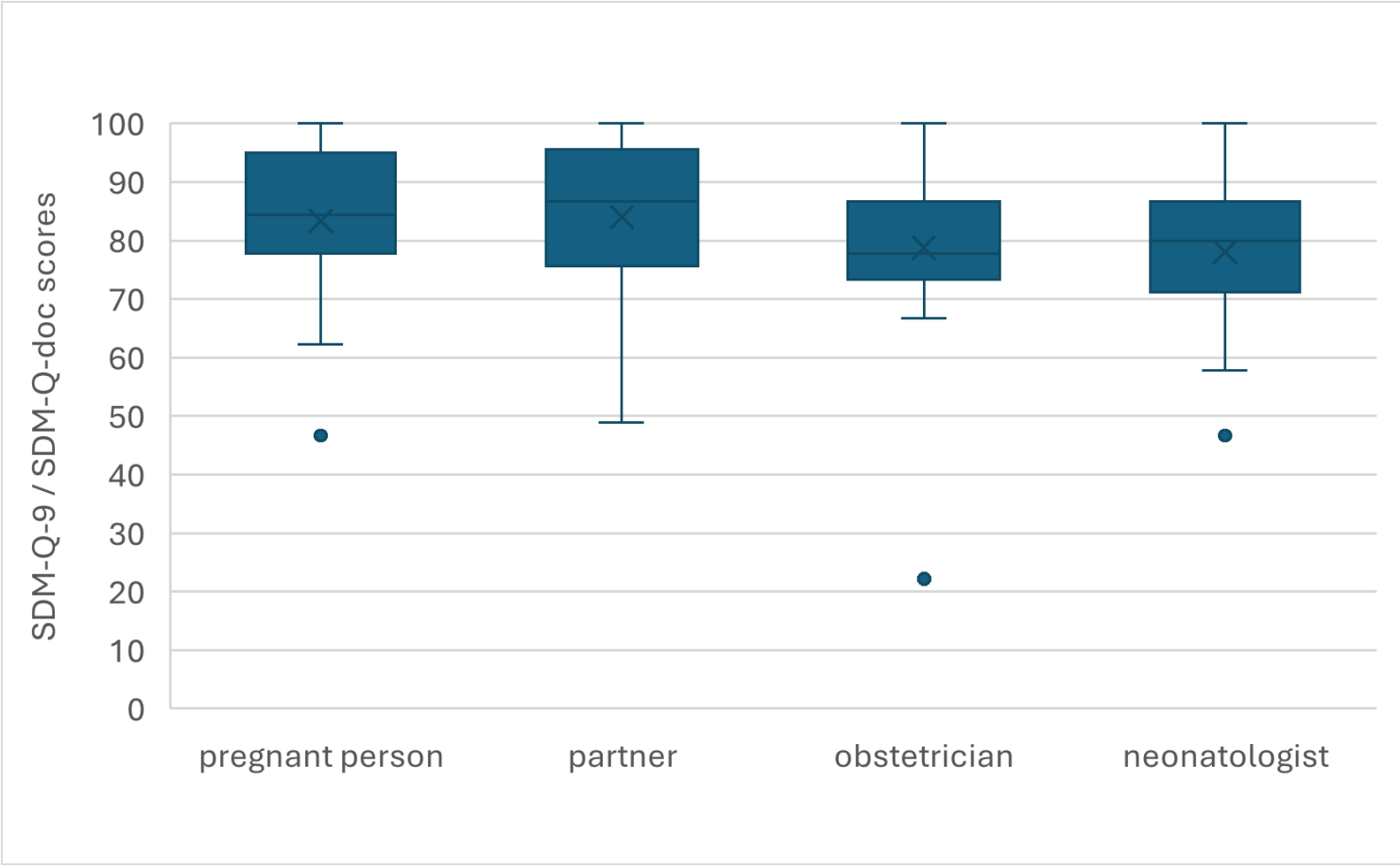


Figure 1

Median SDM-Q scores per participant

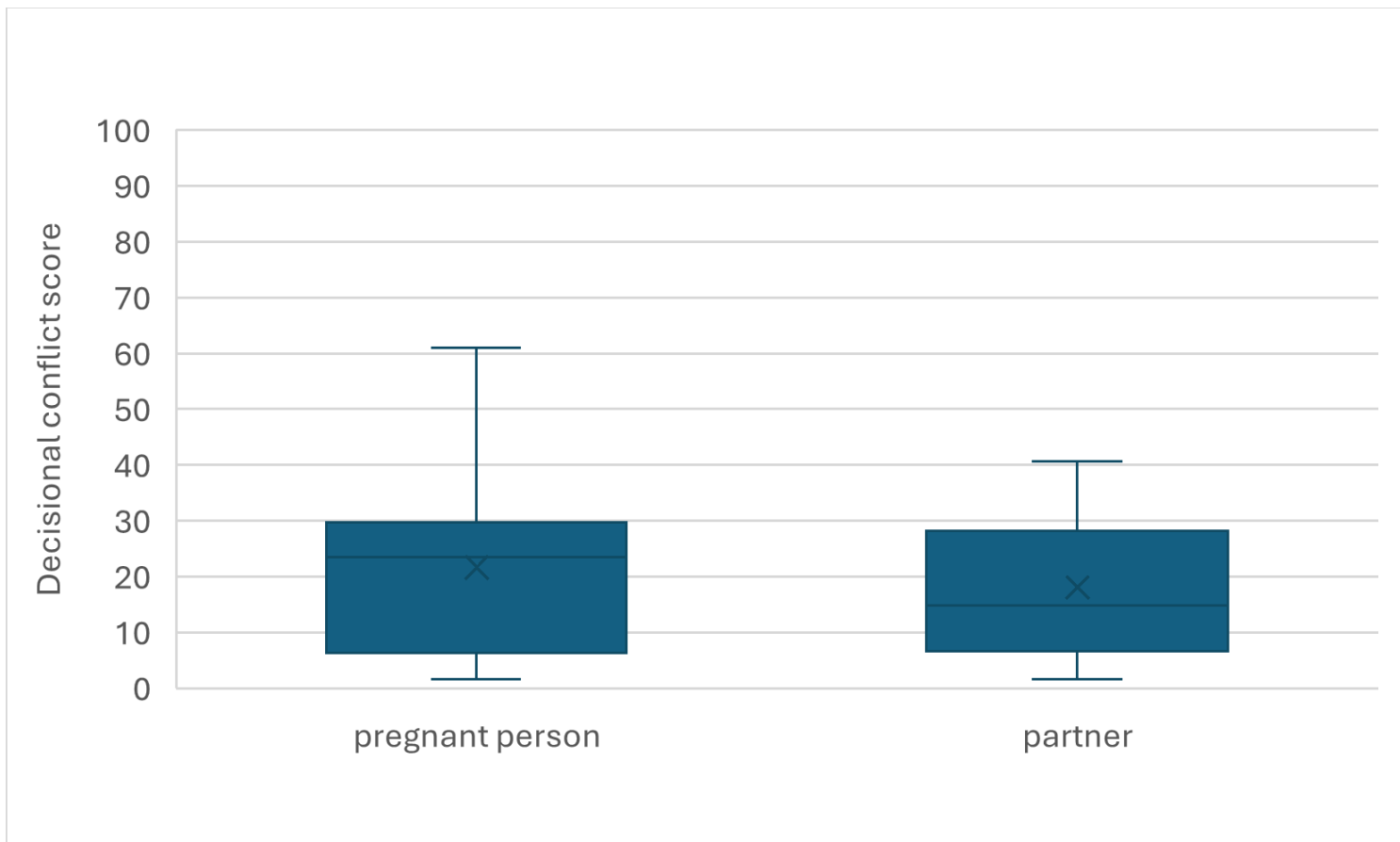


Figure 2

Median DC scores per participant

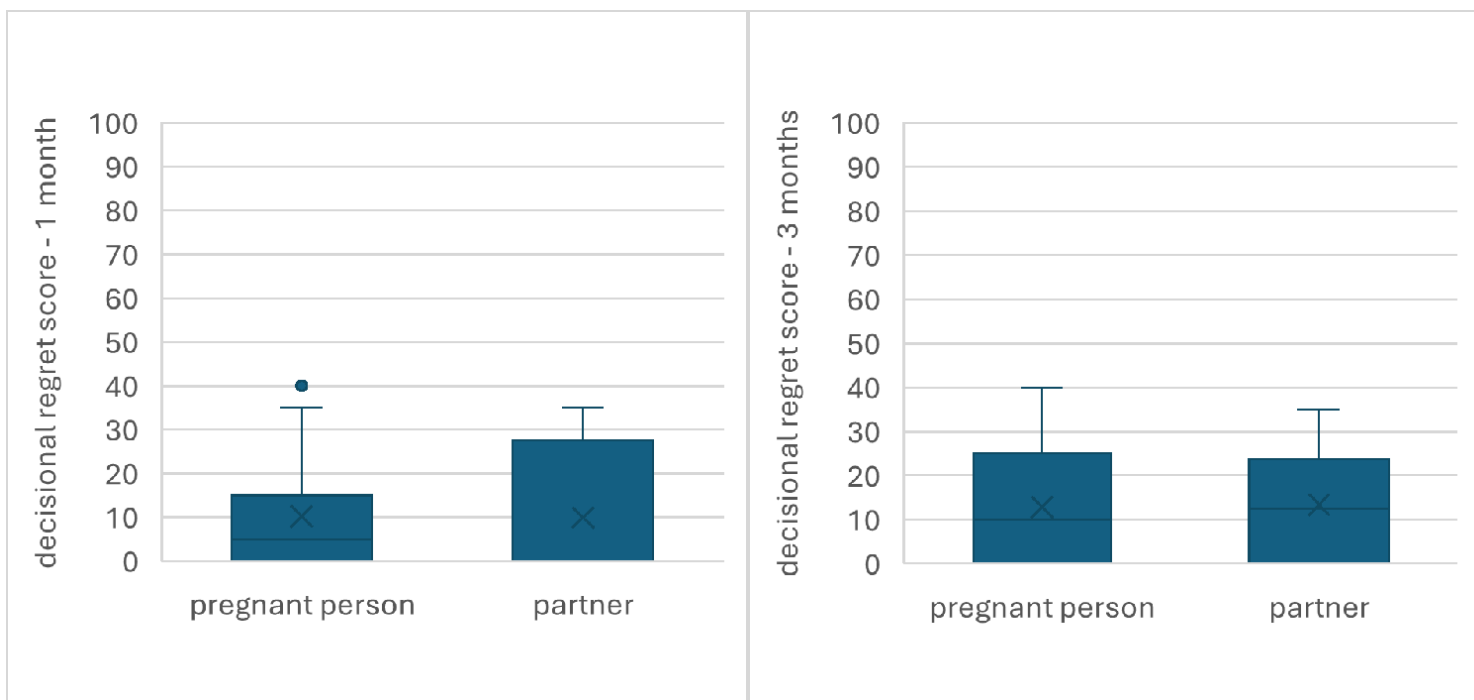


Figure 3

Median DR scores per participant (at 1 and 3 months)

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