

Shared Decision-Making in Children with Cleft: A Parent Perspective

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ABSTRACT

Purpose: To assess whether there are differences in caregiver perception of the shared decision-making process during treatment discussions for the child with cleft lip and/or palate (CLP).

Methods: A questionnaire was administered to caregivers of children with CLP. The questionnaire consisted of 39 items regarding demographics, treatment, and satisfaction. Caregivers were asked to recall a recent consultation and indicate their level of agreement with the implementation of the different steps of the SDM process.

Results: A total of 110 caregivers completed the survey. The average age was 36.1 years. Over half of the sample identified as Hispanic (52%), 35% as White, 6% Black and 7% Asian. When asked about the SDM process, the average level of agreement was higher for the steps of SDM that assess understanding and expectations (90%), risks and benefits (87%) and arrange for follow-up (87%). The average level of agreement was lower for the initial and latter steps. Individual factors showed significant differences in acceptance of the various steps of the process. A higher level of agreement with disclosure was reported by caregivers whose children recently underwent surgeries including premaxillary set back, ear tube placement, eye surgery, stoma closure, and dental rehabilitation (94%), compared to those who underwent secondary lip surgery (58%) and alveolar bone graft (76%). A lower level of agreement with discussion of risks and benefits was reported by caregivers working full time (85%) compared to those who did not report working full time (90%). A higher level of agreement during negotiation was reported by caregivers with shorter appointments (94%) compared to caregivers with appointments lasting between 60-90 minutes (68%). Lower levels of agreement when arriving to a shared decision were seen among those reporting annual incomes of less than \$25,000 (64%) compared to those reporting annual incomes of greater than \$51,000 (93%). Ninety-one percent indicated a high level of satisfaction with overall treatment, 7% reported it could be better and 1% each reported average satisfaction and no satisfaction.

Conclusions: Our data shows a wide range in acceptance of the individual steps of SDM, but a high level of satisfaction with overall treatment. This suggests that high levels of parental participation in the decision-making process is not a pre-requisite for satisfaction.

BACKGROUND

- Treatment for CLP requires comprehensive care and a high level of parental engagement to navigate the health care system and ensure optimal outcomes.
- Historically, approaches to medical decision-making have ranged from paternalistic to more patient centered.
- The emergence of shared decision-making (SDM) has become the preferred approach to clinical counseling because it allows for the alignment of values, preferences and goals.

METHODS

- Participants were recruited from the patient population of the Texas Cleft-Craniofacial Center and the UT Pediatric Dentistry Clinic and invited to complete a 39-item questionnaire.
- Caregivers were asked to recall a recent consultation and indicate their level of agreement with the implementation of the different steps of the SDM process.
- SDM was assessed using the Shared Decision-Making 9-item Questionnaire (SDM-Q9) in Visual Analog Scale (VAS) format.
- Differences between the average level of agreement and independent factors were determined using the Kruskal-Wallis test.
- Pairwise comparisons to determine differences between levels of the independent factors were completed using the Tukey-Kramer-Nemeyi test.

RESULTS and CONCLUSIONS

- A total of 110 caregivers completed the survey.
- The average age was 36.1 years.
- 52% identified as Hispanic, 35% as White, 5% as Black, and 7% as Asian.
- Higher levels of agreement were seen in the steps of SDM that assess understanding and expectations (90%), risks and benefits (87%) and arrange for follow-up (87%).
- The following variables played a significant role in predicting level of agreement with the individual steps of SDM:
 - Recent surgical procedure during disclosure that a decision needs to be made
 - Full-time employment during discussion of benefits and risks of the treatment options
 - Appointment length during negotiation
 - Family income during reaching a shared decision
- 91% of caregivers reported a high level of satisfaction with treatment, 7% reported it could be better, and 1% each reported average satisfaction and no satisfaction.

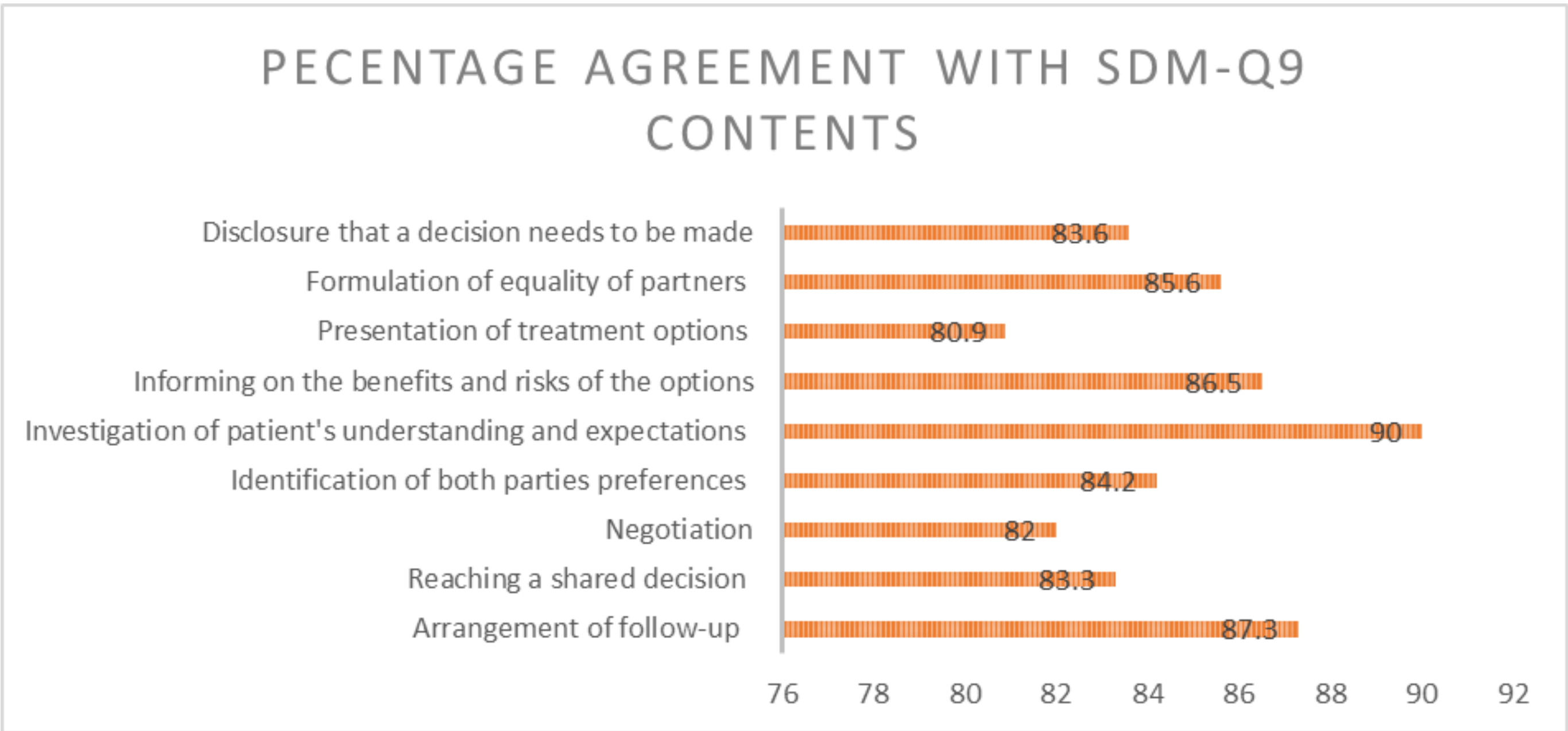


Figure 1. Percentage agreement with SDM-Q9 contents as reported by caregivers of children with CLP.

TREATMENT SATISFACTION

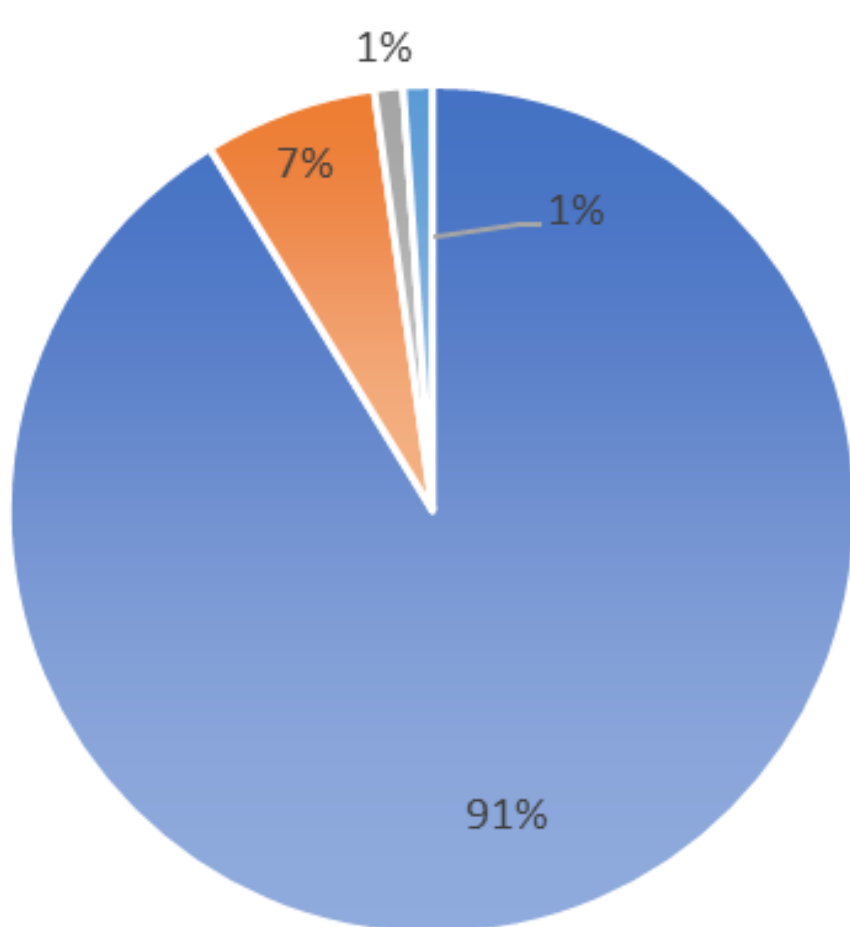


Figure 2. Treatment satisfaction.
91% reported a high level of satisfaction.
7% reported treatment could be better.
1% reported average satisfaction.
1% reported no satisfaction.
None reported being overall unhappy with treatment outcomes.

STEPS CORRESPONDING TO SDM-Q-9 ITEMS	VARIABLE OF SIGNIFICANCE	PERCENT AGREEMENT	KRUSKAL-WALLIS P-VALUE	PAIRWISE COMPARISON P-VALUE
DISCLOSURE THAT A DECISION NEEDS TO BE MADE	Recent surgical procedure		0.042	(1:2) 0.99
	(1) Lip surgery	86%		(1:3) 0.261
	(2) Palate surgery	86%		(1:5) 1.0
	(2) Secondary lip	58%		(1:7) 0.670
	(3) Bone graft	76%		(2:3) 0.168
INFORMING ON THE BENEFITS AND RISKS OF THE OPTIONS	(4) Other	94%		(2:5) 1.0
	Employment		0.01	(2:7) 0.745
	(1) Yes	85%		(3:5) 0.290
	(2) No	90%		(3:7) 0.029
				(5:7) 0.802
NEGOTIATION			0.04	(1:2) 0.018
	Appointment length (mins)			(1:3) 0.054
	(1) <30	94%		(1:4) 0.305
	(2) 30-60	84%		(2:3) 0.472
	(3) 60-90	68%		(2:4) 0.845
REACHING A SHARED DECISION	(4) > 90	74%		(3:4) 0.999
	Income		0.01	(1:2) 0.067
	(1) 0-25k	64%		(1:3) 0.023
	(2) 26k-50k	94%		(1:4) 0.386
	(3) 51k-100k	93%		(2:3) 0.975
	(4) >100k	85%		(2:4) 0.778
				(3:4) 0.516

Table 1. Content analysis of SDM steps and explanatory variables of significance.

The process of shared decision-making is complex. It may be useful to consider the process as independent steps in order to foster an environment of shared decision making that is tailored to each individual patient.

Future research should investigate the preferred level of involvement of the various stakeholders during medical decision-making for the cleft population.