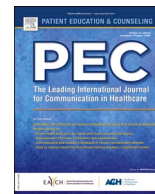


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Perceived shared decision making and satisfaction with care among children and adolescents with special healthcare needs and their parents: Cross-sectional evidence from the PART-CHILD Study

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ABSTRACT

Objectives: To compare shared decision making (SDM) and satisfaction with care (SWC), an indicator of care quality, between children with special healthcare needs (CSHCN) and parents and to assess the association between SDM and SWC in both groups.

Methods: We recruited CSHCN ≥ 7 years and parents from 15 outpatient facilities that completed a paper questionnaire assessing SDM (highest vs. lower levels of SDM) and SWC. Differences in SDM and SWC were assessed with McNemar and paired t-tests. We used adjusted linear mixed models to investigate cross-sectional associations between SDM and SWC.

Results: Based on data from 275 CSHCN and 858 parents, 39% and 64% of CSHCN and parents reported the highest level of SDM ($p < 0.0001$). No difference in SWC was observed ($p = 0.36$). Perceived SDM was associated with SWC in both groups (both $p < 0.0001$).

Conclusion: Associations between SDM and SWC reinforce the role of SDM for care quality. Large proportions of CSHCN and parents reporting suboptimal levels of SDM highlight the need for effective programs to promote SDM in the target population.

Practice implications: Until effective programs become available, healthcare professionals can use existing opportunities to involve CSHCN and parents in consultations (e.g., provide sufficient opportunities to ask questions).

1. Introduction

Adapting the seminal definition by Elwyn et al. to triadic encounters, defined here as encounters involving patients, parents and providers, often observed in pediatric healthcare, shared decision making (SDM) with children and adolescents (hereinafter *children* to avoid redundancy) with special healthcare needs (CSHCN) and their parents comprises three core elements: (1) provision of information on health issues and treatment options by healthcare professionals, (2) elicitation of patient and parent preferences and (3) integration of these preferences into

healthcare decisions [1,2]. SDM contributes to patient-centered care and has the potential to improve the quality of service provision for both CSHCN and their parents. Prior work suggests that SDM with CSHCN is associated with reduced worries [3] and an increased understanding of procedures [4,5]. SDM with parents has the potential to reduce decisional conflict [6] and to increase knowledge about health conditions [7] and satisfaction with care (SWC), an important indicator of high-quality healthcare services [8].

While in most countries ethical considerations and legal regulations limit participation of minors in health-related decision making without

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the involvement of consenting legal guardians, there is a growing awareness that many children with medical experience due to chronic illnesses can be involved in decision making [9,10] by, inter alia, voicing their preferences regarding participation goals and care plans. Despite this and accumulating evidence that children want to be involved in healthcare consultations [11,12] and SDM [13], both the contribution of CSHCN to the overall speaking time during patient-parent-provider encounters (4–14%) and their involvement in SDM are limited [14, 15]. In addition, prior work suggests that parents of CSHCN wish for more involvement in medical decisions regarding their children and highlight opportunities to achieve this including the provision of sufficient opportunities to ask questions and considering parents as essential pillar of the treatment team [16,17]. This highlights the need to involve both CSHCN and their parents in SDM in age-appropriate and needs-based ways to confer SDM-related benefits and to improve quality of care.

Despite the importance of SDM for patient-centered care, to our knowledge no study has previously assessed the association between SDM and SWC, an important dimension of care quality. Studies investigating the association between characteristics of provider communication more broadly, rather than SDM specifically, and SWC showed mixed results [18,19]. Moreover, prior work on provider communication was mostly based on direct observations of triadic encounters and qualitative research approaches [14,15] with only limited quantitative evidence on subjective accounts of patient-parent-provider communication [18,20]. Using validated patient- and parent-reported experience measures to investigate perceived SDM among CSHCN and their parents would complement the substantial body of evidence from qualitative studies and direct observations and thus substantiate calls for strengthening SDM in pediatric healthcare [8,21]. In this study, we therefore compared the extent of perceived SDM and SWC between CSHCN and their parents and assessed the association between both factors in a large multi-site sample in Germany.

2. Methods

We used baseline data from the stepped wedge cluster randomized PART-CHILD trial conducted between 2018 and 2020 in 15 German multidisciplinary outpatient facilities providing diagnostic services and treatment for CSHCN aged 0–18 years, with a wide spectrum of predominantly neurological, neurodevelopmental and behavioral health conditions [22]. The trial evaluated a complex intervention to strengthen participation-centered care for CSHCN. We recruited CSHCN aged seven years or older who were able to complete a paper-based questionnaire and parents, regardless of their child's participation in the study. CSHCN below the age of seven were excluded, given limited reading and writing competencies of preschoolers that preclude the completion of self-report questionnaires. CSHCN and parents completed separate paper-and-pencil surveys. We assessed perceived SDM using the validated German CollaborATE^{pediatric} scales for CSHCN and parents comprised of three items on (1) provision of information by healthcare professionals, (2) elicitation of patient and parent preferences and (3) integration of these preferences into healthcare decisions [23,24], respectively (response range: 0–9, with sum scores of 27 and <27 indicating the highest and lower levels of perceived SDM, respectively) [23]. SWC was investigated using the YHC-SUN-SF for CSHCN and the CHC-SUN-SF for parents, validated scales showing excellent psychometric properties in the target population (six items per scale; range of mean scores: 1–5; high mean scores equivalent to high SWC) [25].

We used McNemar and paired t-tests to assess differences in perceived SDM and SWC between CSHCN and their parents, respectively. The cross-sectional association between perceived SDM and SWC was investigated by adjusted linear mixed models comprising a random effect for study site and controlling for parent-reported potential confounders (sex and age of CSHCN, type of impairment, appointment and healthcare professional present at appointment). Variances explained by

SDM were assessed with η^2 that relates the sum of residual and between-cluster variance of a model with confounders to the same sum of variances of a model that included confounders and SDM. In sensitivity analyses, we investigated the association between SDM and SWC among parents with CSHCN aged 7 years or older. $P < 0.05$ for two-sided tests were considered statistically significant. Statistical analyses, limited to complete cases, were performed in 2022 using SAS version 9.4.

The study was approved by the Medical Ethics Review Board of the Medical Faculty Mannheim at Heidelberg University (2018–529N-MA) and the Ethics Review Boards of all study sites. Data collection was exempt from written informed consent as only anonymous data were collected. Reporting in this short communication is based on the STROBE reporting guideline [26].

3. Results

We included 275 CSHCN and 858 parents in the analyses (Table 1). A lower proportion of CSHCN reported the highest level of SDM compared with their parents (39% vs. 64%, $n = 200$, $p < 0.0001$). Concerning SWC, there was no difference between the two groups (mean=4.34 vs. 4.30, $n = 200$, $p = 0.36$). In the adjusted linear mixed model, we observed strong associations between perceived SDM and SWC for both CSHCN and parents, with standardized mean differences of 0.84 and 1.13, respectively (Table 2). In the two models, SDM explained 18% and 24% of the variance, respectively. When restricting the dataset to parents of CSHCN aged 7 years or older in sensitivity analyses, we observed a standardized mean difference for the association between perceived SDM and SWC of 1.18 ($n = 394$; $\beta = 0.68$; 95% CI: 0.57–0.80; $p < 0.0001$; $\eta^2=0.24$), comparable to the results that were based on all participating parents.

4. Discussion and conclusion

4.1. Discussion

In this study, a lower proportion of CSHCN reported the highest level of perceived SDM compared with their parents, extending limited prior work on suboptimal, i.e. lower than preferred, levels of SDM among children [18,20] and limited observed child participation in patient-parent-provider communication more broadly [14,15]. Aligned with prior work [16,17], more than one third of parents reported suboptimal levels of SDM in this study. Taken together, these results highlight the importance of developing age-appropriate and needs-based programs to involve both CSHCN and their parents in health-related decision making processes and to provide environments in which both groups can contribute to SDM in meaningful ways. Recent work identified several leverage points that could be addressed when developing programs to strengthen SDM with CSHCN and parents in pediatric healthcare settings including poor quality information about available options, limited SDM skills among healthcare providers, poor continuity of care due to high staff turnover and clinical workflows limiting SDM (e.g., restricted integration of SDM into care pathways) [21].

In contrast to limited prior research suggesting differences in SWC among CSHCN and their parents [27,28], both groups reported similar levels of SWC in this study. According to a recent review, differences between CSHCN and their parents are not limited to levels of SWC but also encompass aspects of healthcare organization and delivery that matter for the two groups, reinforcing the importance of measuring and understanding SWC among CSHCN and parents separately [29]. Based on this evidence, future work in Germany should seize opportunities to assess SWC among CSHCN and their parents in a more diverse set of healthcare settings, including primary care practices, hospital-affiliated outpatient services, inpatient departments and rehabilitation clinics, to investigate whether similar levels of SWC can be replicated across settings, potentially signaling that pediatric healthcare in Germany addresses antecedents of SWC among CSHCN and their parents equally

Table 1
Sample characteristics.

	Parents		CSHCN ^a		
	Eligible sample	Analysis sample	Eligible sample	Analysis sample	
Sample size	1,120	858	352	275	
Satisfaction with care, mean (SD)	4.20 (0.68)	4.21 (0.67)	4.32 (0.67)	4.31 (0.68)	
Perceived shared decision making, No. (%)	Missing	-	33	-	
	Highest level of perceived SDM	626 (58)	511 (60)	119 (36)	102 (37)
	Lower levels of perceived SDM	451 (42)	347 (40)	209 (64)	173 (63)
	Missing	43	-	24	-
Personal potential confounders					
Sex of CSHCN, No. (%)	Male	750 (68)	585 (68)	237 (68)	190 (69)
	Female	361 (32)	273 (32)	114 (32)	85 (31)
	Missing	9	-	1	-
Age of CSHCN, No. (%)	0 - 2 years	148 (13)	110 (13)	-	-
	3 - 6 years	449 (40)	354 (41)	-	-
	≥ 7 years	519 (47)	394 (46)	352 (100)	275 (100)
	Missing	4	-	-	-
Type of impairment ^b , No. (%)	Physical impairment	453 (43)	394 (46)	108 (33)	95 (35)
	Cognitive impairment	386 (37)	327 (38)	83 (25)	73 (27)
	Other impairment	482 (46)	370 (43)	189 (57)	151 (55)
	Missing	72	-	20	-
Care-related potential confounders					
Type of appointment ^b , No. (%)	Diagnostic	503 (45)	411 (48)	166 (47)	129 (47)
	Therapeutic	466 (42)	393 (46)	150 (43)	124 (45)
	Counseling	561 (50)	451 (53)	191 (54)	155 (56)
	Missing	-	-	-	-
Type of healthcare professional present at appointment ^b , No. (%)	Physician or psychologist	725 (69)	582 (68)	271 (80)	225 (82)
	Allied health professional ^c	376 (36)	314 (37)	84 (25)	67 (24)
	Educator	67 (6)	51 (6)	14 (4)	11 (4)
	Other health professional	58 (6)	53 (6)	16 (5)	16 (6)
	Missing	72	-	15	-

^a Self-report data on satisfaction with care and perceived shared decision making was only available for patients aged 7 years and older who were able to complete the survey despite their chronic illness.

^b Based on tick all that apply-questions, the numbers and percentages do not add up to the sample size and 100%, respectively.

^c Allied health professionals included physiotherapists, speech and occupational therapists. Analysis samples included complete cases only. CSHCN, children with special healthcare needs; SD, standard deviation; SDM, shared decision making.

Table 2
Association between perceived shared decision making and satisfaction with care among children with special healthcare needs and their parents.

Independent variable: Perceived SDM (Ref.: lower levels of SDM)	Association between perceived shared decision making and satisfaction with care ^b			
	β (95% CI)	SMD	p-value	η^2
CSHCN aged 7 or older (n = 275) ^a	0.53 (0.38; 0.67)	0.84	< 0.0001	0.18
Parents of CSHCN (n = 858)	0.65 (0.57; 0.73)	1.13	< 0.0001	0.24

^a Self-report data on SWC and perceived SDM was only available for patients aged 7 years and older who were able to complete the survey despite their chronic illness.

^b Adjusted for age group and sex of CSHCN, type of impairment, appointment and healthcare professional present at appointment. η^2 relates the variance explained by SDM to the total variance after partializing out the variance due to potential confounders. β , regression coefficient interpretable as adjusted mean difference between participants with optimal and lower levels of SDM; CI, confidence interval; CSHCN, children with special healthcare needs; ref, reference group; SDM, shared decision making; SMD, standardized mean difference, defined as the adjusted mean difference β divided by the square root of the total unexplained variance of the outcome.

well.

In line with limited prior work on provider communication and SWC among parents [19], we observed a strong association between SDM and SWC in this group. In contrast to a pilot study on patient-parent-provider communication in pediatric gastroenterology [18], SDM was also associated with SWC among CSHCN in the current study. Taken together, these findings highlight the promotion of SDM among CSHCN and their parents as a promising way to improve SWC, an important marker for high-quality healthcare services [8], in this target population. In addition, the association between perceived SDM and SWC, comparable levels of SWC in CSHCN and parents (as opposed to differences in SDM) and moderate η^2 in the adjusted model suggest that SWC may represent a broad concept potentially influenced by a wide range of factors other than SDM not investigated in this study. We thus anticipate that exploring complementary factors to promote SWC in future studies would provide additional guidance for developing a multipronged approach to further improve the quality of pediatric healthcare services.

Cross-sectional analyses, a sample mostly comprised of patients with

neurological and behavioral health conditions and limited demographic and health data restrict the interpretation of our findings. Future studies may complement the available evidence by including children with other chronic illnesses such as asthma, diabetes and inflammatory bowel disease, gathering comprehensive demographic and health data to better characterize study populations and using intervention designs to assess the causal effect of SDM on SWC.

4.2. Conclusions

Despite numerous calls to strengthen SDM with CSHCN and their parents [7,30,31], two thirds of CSHCN and one third of parents reported suboptimal levels of SDM, respectively. These findings highlight the need for developing effective programs to promote SDM in this target population. Strong associations between perceived SDM and SWC among both groups reinforce the important role of SDM for quality of care.

4.3. Implications for practice

Until effective programs to strengthen SDM for CSHCN and their parents become available [7], our results call on healthcare professionals to seize existing opportunities to involve CSHCN and their parents in child-parent-provider consultations more broadly [14]. For example, healthcare professionals can deliberately use facilitative behaviors such as asking children questions (also separately from parents), encouraging clarifications and using equidistant seating arrangements during consultations to increase participation of CSHCN in consultations in general and the development of participation goals and care plans more specifically [10,22,18]. Health professionals should be aware of and ensure the provision of pauses children need to formulate answers [14]. To increase the involvement of parents, service providers should provide sufficient opportunities for parents to ask questions and contribute to child-parent-provider consultations in meaningful ways, based on a shared understanding that parents are an essential pillar of the treatment team [16,17].

Moreover, albeit not explicitly developed in the context of SDM, healthcare professionals may use other established communication techniques including motivational interviewing to engage CSHCN and their parents at their desired level [32].

CRedit authorship contribution statement

Nisius Katja: Writing – review & editing, Writing – original draft, Visualization, Formal analysis. **Krug Katja:** Writing – review & editing. **Georg Sabine:** Writing – review & editing, Project administration, Methodology, Data curation, Conceptualization. **Görig Tatiana:** Writing – review & editing, Project administration, Methodology, Data curation, Conceptualization. **Hoffmann Dorle:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Eichinger Michael:** Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Data curation, Conceptualization. **De Bock Freia:** Writing – review & editing, Project administration, Methodology, Funding acquisition, Conceptualization.

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Declaration of Competing Interest

None.

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