

Shared decision-making for children with medical complexity in community health services: a scoping review

Sonja Jacobs ¹, Nathan Davies,² Katherine L Butterick,¹ Jane L Oswell,¹ Konstantina Siapka,¹ Christina H Smith³

To cite: Jacobs S, Davies N, Butterick KL, *et al*. Shared decision-making for children with medical complexity in community health services: a scoping review. *BMJ Paediatrics Open* 2023;**7**:e001866. doi:10.1136/bmjpo-2023-001866

Received 16 January 2023
Accepted 2 March 2023

ABSTRACT

Background Children with medical complexity is an increasing population whose parents and healthcare providers face multiple decisions. Shared decision-making is a process where patients, their families and healthcare providers collaborate to make decisions based on clinical evidence and informed preferences of the family. Shared decision-making has benefits for the child, family and healthcare providers, including improved parental understanding of the child's difficulties, increased participation, improved coping skills and more efficient healthcare use. It is, however, poorly implemented.

Aims and methods A scoping review was conducted to explore shared decision-making for children with medical complexity in community health services, including how shared decision-making is defined in research, how it is implemented, including barriers and facilitators and recommendations for research. Six databases were systematically searched for papers published in English up to May 2022: Medline, CINAHL, EMBASE, PsycINFO, PubMed, Cochrane Database of Systematic Reviews and sources of grey literature. The review is reported according to the Preferred Reporting Items for Scoping Reviews.

Results Thirty sources met the inclusion criteria. Most factors can either be a facilitator or barrier to shared decision-making depending on the context. Two significant barriers to shared decision-making in this population include uncertainty about the child's diagnosis, prognosis, and treatment options and the presence of hierarchy and power imbalance during clinical encounters with healthcare providers. Further influencing factors include continuity of care, the availability of accurate, accessible, adequate, and balanced information and the interpersonal and communication skills of parents and healthcare providers.

Conclusion Uncertainty about diagnosis, prognosis and treatment outcomes for children with medical complexity are additional challenges to the known barriers and facilitators to shared decision-making in community health services. Effective implementation of shared decision-making requires advancement of the evidence base for children with medical complexity, reducing power imbalance in clinical encounters, improving continuity of care, and improving the availability and accessibility of information resources.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Shared decision-making is an evidence-based approach with known benefits to children with medical complexity, their families and the healthcare system, it is, however, poorly implemented.

WHAT THIS STUDY ADDS

⇒ This study highlights the impact of uncertainty of diagnosis, prognosis and treatment outcomes for children with medical complexity on shared decision-making. It highlights how healthcare providers can improve the implementation of shared decision-making by addressing the power imbalance in clinical encounters, improving continuity of care, improving communication and interpersonal skills, and making information more accessible to parents from diverse backgrounds.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This review can guide a research strategy in the field of shared decision-making for children with medical complexity in community health services support healthcare professionals to consider their influence on the decision-making process in everyday practice.

INTRODUCTION

Children with medical complexity (CMC) have needs in four domains, namely (1) substantial family-identified healthcare and special educational needs, (2) one or more severe and potentially lifelong chronic conditions, (3) limitations to body structure and function, performance of activities and participation that may require technological assistance such as feeding tubes and (4) high projected healthcare use including the involvement of multiple subspecialties.¹ These children are increasing in number.^{1 2} Parents and healthcare providers (HCPs) for CMC face multiple, complex decisions throughout their childhood including decisions about tube feeding, mechanical ventilation, medications and surgery.^{1 3 4}



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY. Published by BMJ.

¹Community Children's Therapies, Barts Health NHS Trust, London, UK

²Research Department of Primary Care & Population Health, University College London, London, UK

³Division of Psychology and Language Sciences, University College London, London, UK

Correspondence to

Dr Christina H Smith; christina.smith@ucl.ac.uk

Mrs Sonja Jacobs; sonja.jacobs@nhs.net

Table 1 Eligibility criteria

	Included	Excluded
Population	Parents and/or caregivers of children under 18 with medical complexity	Adult patients
	Children with specific medical diagnoses if they meet criteria for medical complexity	Children with behavioural, emotional or mental health conditions (eg, autism, depression, attention deficit hyperactivity disorder)
	Healthcare providers for children with medical complexity	
Concept	Shared decision-making in the paediatric clinical context	Decisions about vaccinations or public health issues
		Pregnancy, perinatal or viability decision-making
		Decision about participating in research
Context	Outpatients or tertiary care settings	Inpatient hospital settings
	Children's community health services	Primary care settings
	Contexts spanning multiple settings if they address paediatric community healthcare delivery	Settings outside healthcare (ie, education)
		Universal health service
		Prevention programmes

Shared decision-making (SDM) is an evidence-based approach that is an essential part of patient-centred care.^{5–7} It is a process where parents, as surrogate decision-makers for their child, and HCPs work in partnership to make decisions based on clinical evidence and family preferences.^{7–10} This approach is supported by policy makers and regulatory bodies nationally and internationally.^{5–10} The benefits for patients, families and HCPs include improved patient or carer knowledge and understanding, reduced decisional conflict, increased participation and engagement in care, improved coping skills, and efficient use of healthcare resources.^{5 6 8 10} SDM is, however, poorly defined due to

the interpretive nature of what is meant by 'shared',^{6 11} with fundamental differences in how patients, carers and HCPs understand the purpose of and their role in SDM.^{6 8 12–14}

The difference between parental and HCP approaches to decision-making often result in poor implementation of SDM. HCPs base their decisions on clinical and empirical evidence,⁸ which is often lacking for CMC.^{1 15} Parents consider the social, emotional and psychological impact of decisions on their child, their family and cultural and religious beliefs in addition to potential clinical outcomes.^{8 11 13} Parental decisions about what is 'good enough' for their child with medical complexity are often more intensely scrutinised by HCPs than for non-medically complex children, with a lack of awareness or importance given to the impact of decisions on the family.^{8 11 13–16} Clinical uncertainty combined with complex family dynamics require HCPs to swap traditional hierarchical and paternalistic approaches to decision-making, where decisions are made based on clinical information and empirical evidence,^{5 8 11 12 15 17} for an approach that allows parental collaboration and discretion in decision-making.^{11 15}

The personal and healthcare cost of poor implementation of SDM is amplified in the CMC population due to their significant healthcare use. Understanding factors impacting SDM for CMC will help to improve medical and developmental outcomes, quality of life of children and families and effective use of healthcare resources.^{5 8 10}

This scoping review aimed to explore the landscape of SDM for CMC in community health services.

The objectives for this review were to:

1. Explore how SDM is defined in research.
2. Understand to what extent SDM is implemented for CMC in community health services.

Table 2 Text words, index terms and subject heading identified for full search

Key concept	Text words/index terms/MeSH terms (Medical Subject Headings)—combined using Boolean operators AND/OR
Children	child; child, preschool; adolescent; infant, extremely premature; infant; infant, newborn; paediatric
Medical complexity	medical complexity; special healthcare needs; disabilities; assistive technology; disabled children; developmental delay; chronic disease/th (therapy); nervous system diseases/th (therapy); medical fragility
Shared decision-making	Parental decision-making; shared decision-making; parent perspective; decision-making; patient participation; family-centred care; patient-centred care; professional-family relationship; parental discretion; bioethical issues

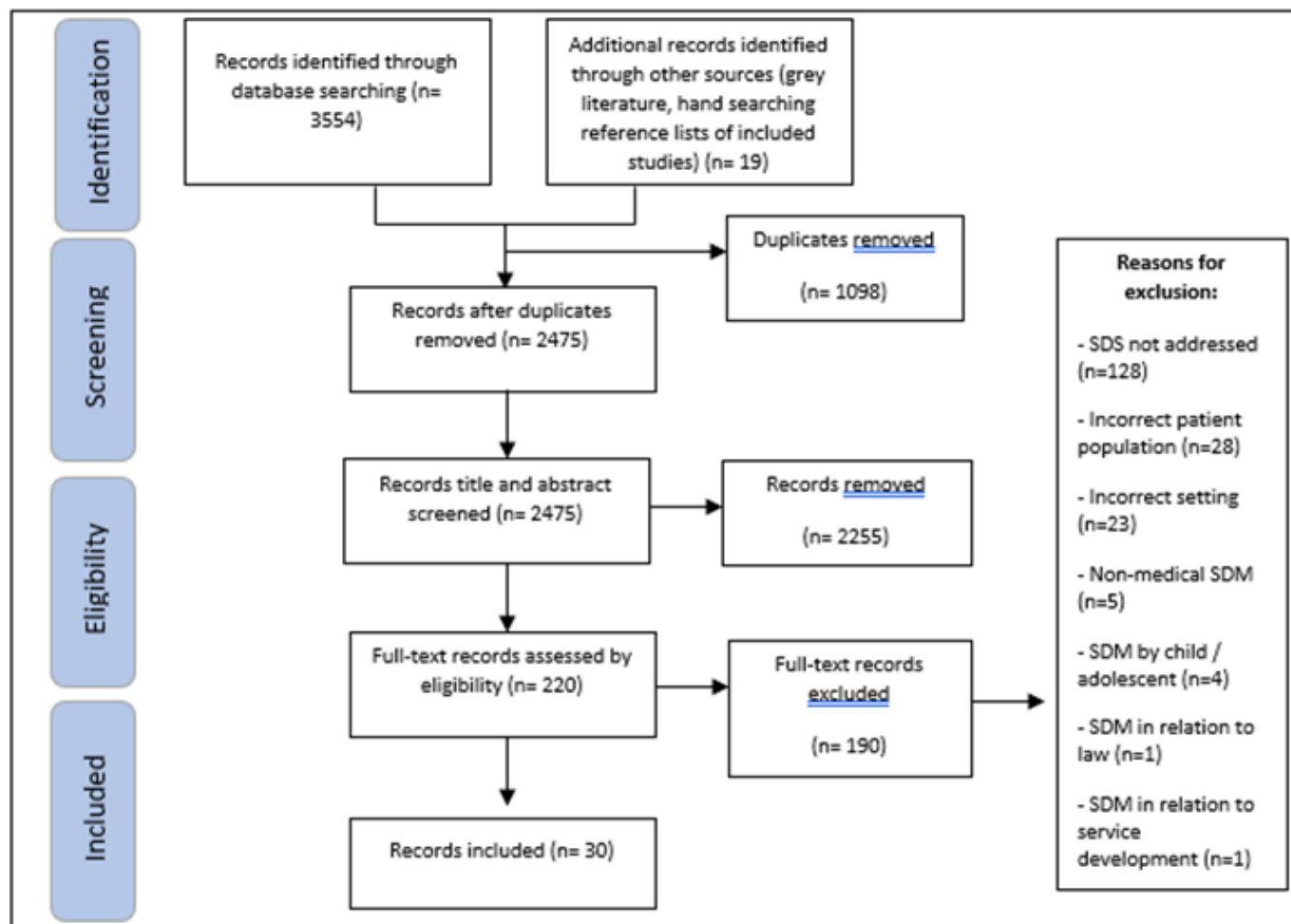


Figure 1 PRISMA flow chart. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SDM, shared decision-making.

3. Consider the differences in SDM between ethnic groups.
4. Identify the barriers and facilitators to SDM for CMC.
5. Provide recommendations for future research.

METHODS

A scoping review was conducted following the Joanna Briggs Institute (JBI) manual for evidence synthesis^{18–20} and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews.²¹

Protocol and registration

A scoping review protocol was registered on Open Science Framework on 19 May 2022.¹⁶

Eligibility criteria

Eligibility criteria are outlined in [table 1](#). SDM included any process involving parents or caregivers in medical decision-making with HCPs¹⁰ and included family-centred practices. Sources reporting on multiple populations or settings were included if results were reported separately or if at least 50% of the results related to the eligible population or setting. Primary research using any

methodology, secondary research including systematic reviews, literature, and scoping reviews and editorial or opinion pieces were included.

Information sources

The search included literature published from 1982 when SDM was first mentioned in scientific literature.⁹ Only articles published in English were included due to the time and cost of transcription. A three-step search strategy was followed.¹⁸ An initial search of Medline and CINAHL identified text words and index terms to develop a full search strategy ([table 2](#)). This search strategy was reviewed by a librarian using the Peer Review of Electronic Search Strategies 2015 guideline²² and was used to search databases including Medline, CINAHL, EMBASE, AMED, PsycINFO, PubMed, Cochrane Database of Systematic Reviews and sources of grey literature including Open Grey, NICE guidelines and CanChild website. The reference lists of included sources were screened for additional sources. The final search was completed on the 26 May 2022.

Selection of evidence

Identified sources were uploaded to Covidence systematic review software and duplicates removed. Titles

Table 3 Description of sources—qualitative studies (ordered from earliest publication date)

Lead author	Title	Country	Date	Aim
Brotherson ²⁵	Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities	USA	1995	To explore the issues families face in deciding whether to place a feeding tube
Katz ²⁶	A cultural interpretation of early intervention teams and the IFSP: parent and professional perceptions of roles and responsibilities	USA	1995	To understand how members of an early intervention team involve families in developing of individual family service plans (IFSP).
Blue-Banning ²⁷	Dimensions of family and professional partnerships: constructive guidelines for collaboration	USA	2004	To identify indicators of professional behaviour indicative of collaborative partnerships.
Brotherton ^{28 29}	Mothers' process of decision-making for gastrostomy placement	UK	2012	To explore mothers' constructions of decision-making in gastrostomy feeding
Stille ²⁹	Parent partnerships in communication and decision-making about subspecialty referrals for children with special needs	Canada	2013	To describe factors influencing parent–clinician partnerships in SDM when children with special healthcare needs are referred to subspecialists.
Zaal-Schuller ³⁰	How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities	The Netherlands	2016	To compare experiences of parents and physicians involved in the end-of-life decision process
Buchanan ³¹	What makes difficult decisions so difficult?: An activity theory analysis of decision-making for physicians treating children with medical complexity	Canada	2020	To first understand the complexity of the activity of decision-making
Lin ³²	Parent perspectives in SDM for CMC	USA	2020	To identify components of SDM unique to the care of CMC from the perspective of parents.
Jabre ³³	Parent perspectives on facilitating decision-making around paediatric home ventilation	USA	2021	To understand parent perspectives about how clinicians can better facilitate decision-making around home ventilation
Reeder ³⁴	Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care?	UK	2021	To explore the important themes of dis/empowerment and the influence of the therapeutic relationship
Buchanan ⁴	Decision-making for parents of children with medical complexities: activity theory analysis	Canada	2022	To explore decision-making of parents of CMC as an activity within the context of a process shared between clinician and parent

CMC, children with medical complexity; SDM, shared decision-making.

and abstracts were screened against criteria by the first author and 33% was screened by second authors. Full texts of potentially relevant sources were assessed against inclusion criteria by the first author and 33% by second authors. Reasons for exclusion of sources at full text were recorded. Disagreements between the reviewers were resolved through discussion and a third reviewer if needed. The result of the search is outlined in a PRISMA flow chart (figure 1).

Data charting process

The JBI source of evidence template¹⁸ was modified for extraction of details about the author, publication year, country, participants, aim, context, study methods and findings relevant to the review questions. The first author completed data extraction and 10% were checked for consistency by second authors. Discrepancy in extraction were resolved through discussion. The extraction tool

Table 4 Description of sources—quantitative and mixed-methods studies (ordered from earliest publication date)

Lead author	Title	Country	Date	Aim
Guerriere ³⁹	Mothers' decisions about gastrostomy tube insertion in children: factors contributing to uncertainty	Canada	2003	To explore mothers' perceptions of decision uncertainty.
Denboba ³⁵	Achieving family and provider partnerships for children with special healthcare needs	USA	2006	To assess whether families feel like partners in decision-making by their doctors
Pickering ⁴⁰	Disabled children's services: how do we measure family-centred care?	UK	2010	To evaluate staff and parental views of family-centred care in organisations providing services to young disabled children in Wales
Smalley ³⁶	Family perceptions of shared decision-making with healthcare providers: results of the National Survey of Children With Special Healthcare Needs, 2009–2010	USA	2014	To use data from a national survey to determine families' perceptions of SDM and determine the sociodemographic correlates
Lin ³	Shared Decision-Making among Children with Medical Complexity: Results from a Population-Based Survey	Canada	2018	To compare the rates of SDM reported by parents of CMC with the rates of SDM reported by parents of non-complex children with special healthcare needs
Jolles ³⁸	Shared decision-making and parental experiences with health services to meet their child's special healthcare needs: Racial and ethnic disparities	USA	2018	To test the relationship between SDM and parental report of frustration with efforts to get services for their child and to assess SDM's influence on minority parents' service experiences
An ³⁷	Effects of a Collaborative Intervention Process on Parent-Therapist Interaction: A Randomised Controlled Trial	South Korea	2019	To determine whether collaborative intervention impacted interactions between parents of children with physical disabilities and physical therapists

CMC, children with medical complexity; SDM, shared decision-making.

was iterative and was updated as the researchers became more familiar with the evidence.

Synthesis of results

Data were analysed by quantifying text, conducting basic qualitative content analysis and frequency counts.²³ Barriers and facilitators were ordered according to themes and mapped onto the ecological model of health behaviour (EMHB).^{23–24} The EMHB emphasises the multiple layers of influence on healthcare behaviour and can guide the development of interventions by ensuring consideration of all factors impacting implementation.²⁴ Four ecological levels were used (1) individual level including factors related to the child's needs, (2) family level relating to knowledge, attitudes and skills of parents, (3) interpersonal level focused on interactions between HCPs and parents, and (4) organisational level considering institutional and HCP practices.

Patient and public involvement statement

No patients were involved in conducting this scoping review.

RESULTS

Description of included sources

Thirty articles were included in this review, 18 were primary studies, 11 used qualitative^{4 25–34} (table 3), 5 quantitative^{3 35–38} and 2 mixed methods^{39 40} (table 4). Eight articles were theoretical or opinion pieces^{41–48} (table 5) and four literature reviews^{49–52} (table 6). Twelve of the primary studies included parent participants, one included HCPs and five included parents and HCPs. Seventeen sources originated in the USA, seven in Canada, four in the UK, two in the Netherlands and one in South Korea. Research interest in SDM for CMC is increasing with 23 articles published in the last 10 years of which 15 were published in the last 5 years.

Definition of SDM for CMC

Eighteen articles defined or described SDM (figure 2). A collaborative approach and equal partnership between parents and HCPs were most frequently noted as key elements of SDM. Most other elements offered guidance on how to achieve this partnership. Three sources

Table 5 Description of sources—reviews (ordered from earliest publication date)

Lead author	Title	Country	Date	Aim
Kruijsen-Terpstra ⁴⁹	Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review	The Netherlands	2013	To review literature on the experiences of parents of children with cerebral palsy with the physical and/or occupational therapy of their child.
Popejoy ⁵⁰	Decision-making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis	UK	2017	To synthesise findings from qualitative research about decision-making and future planning for children with life-limiting conditions.
Jonas ⁵¹	Parental Decision-Making for Children With Medical Complexity: An Integrated Literature Review	USA	2022	To consolidate existing literature on parental experience of medical decision-making for CMC.
LeGrow ⁵²	Relational Aspects of Parent and Home Healthcare Provider Care Practices for Children With Complex Care Needs Receiving Healthcare Services in the Home: A Narrative Review	Canada	2022	To review literature on relational aspects of parent and home healthcare provider care practices for children with complex healthcare needs.

CMC, children with medical complexity.

referenced the impact of uncertainty of prognosis and treatment outcomes for CMC on this collaborative process.

Implementation of SDM for CMC in community health services

Two qualitative^{26 34} and two quantitative^{3 36} studies reported on the implementation of SDM with CMC in

Table 6 Description of sources—theoretical or opinion (ordered from earliest publication date)

Lead author	Title	Country	Date	Aim
Bazyk ⁴¹	Changes in Attitudes and Beliefs Regarding Parent Participation and Home Programmes: An Update	USA	1989	To discuss traditional and current attitudes and practices regarding parent participation.
Arvedson ⁴¹	Ethical and legal challenges in feeding and swallowing intervention for infants and children	USA	2007	To outline current state of evidence-based decision-making with feeding and swallowing.
An ⁴³	Family-professional collaboration in paediatric rehabilitation: a practice model.	USA	2014	To describe a practice model of family-professional collaboration for paediatric rehabilitation.
Austin ⁴⁴	Improving Partnerships to Make Family-Centred Care Work for Children with Special Healthcare Needs.	USA	2014	Explaining the importance of partnership working from a parental perspective
Adams ⁴⁵	Shared Decision-Making and Children with Disabilities: Pathways to Consensus.	USA	2017	To provide a basis for a systematic approach to implementation of SDM.
Madrigal ⁴⁶	Supporting Family Decision-making for a Child Who Is Seriously Ill: Creating Synchrony and Connection	USA	2018	To discuss the process of supporting families facing chronic and serious illness during decision-making.
Mahant ⁴⁷	Decision-making around gastrostomy tube feeding in children with neurologic impairment: Engaging effectively with families	Canada	2018	To review evidence and conceptual frameworks and provide recommendations to support decisions about gastrostomies.
Lee ⁴⁸	Decision-Making for Children with Medical Complexity: The Role of the Primary Care Paediatrician.	USA	2020	Discussion of influences on decision-making from a paediatrician's perspective.

SDM, shared decision-making.

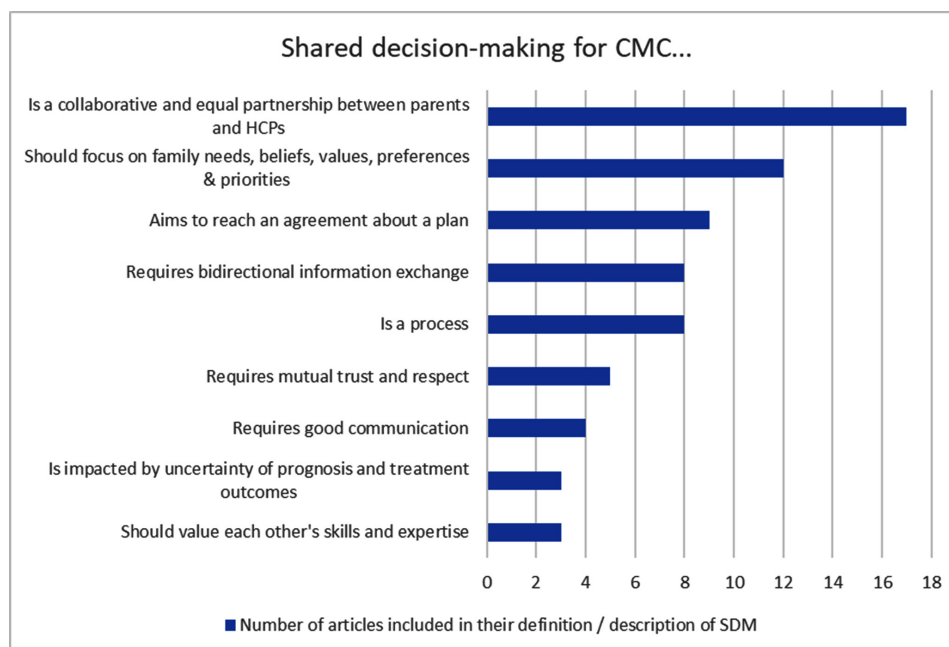


Figure 2 Elements of shared decision-making (SDM) for children with medical complexity. CMC, children with medical complexity; SDM, shared decision-making.

community settings. The two qualitative studies were conducted 26 years apart (ethnographic study in 1995²⁶ and interview-based study in 2021³⁴), in both parents perceived a power imbalance between them and HCPs with decision-making situated with HCPs. Two quantitative studies analysed the same dataset from a national survey in the USA^{3 36} and found that although 85% of parents felt like partners with their child's doctor, there was a negative association with minority ethnic and low socioeconomic status³⁶ and children with greater complexity.³ This was attributed to multidisciplinary support needs, frequent hospital admissions, clinical uncertainty and social difficulties often experienced by parents of CMC.

Differences in SDM in different communities

Eight of the 18 primary studies reported on participant ethnicity but only three USA studies reported on differences in SDM among participants from a black, Hispanic and white background.^{35 36 38} These studies found that families from minority ethnic backgrounds, those with lower educational backgrounds and lower income levels experienced less coordinated care and less SDM.

Barriers and facilitators to SDM for CMC

Twenty-eight articles mentioned at least one barrier or facilitator to SDM. The most cited barriers related to clinical uncertainty of CMC, power imbalance between parents and HCPs and the lack of continuity of care (table 7).

The most cited facilitators to SDM for CMC included sharing of accessible, adequate, accurate and balanced information about all treatment options including knowing about uncertainty. Several facilitators related to the way HCPs viewed and engaged parents as active team

members, service accessibility and attributes relating to the family (table 8).

Research recommendations

Nineteen articles concluded with research recommendations, most related to discovering how to involve families and develop collaborative relationships, particularly families from diverse backgrounds (table 9).

DISCUSSION

This scoping review explored the landscape of SDM for CMC in community health services. SDM is important in this population due to the complex long-term nature of their health conditions and high healthcare use. Like previous reviews,^{6 10} this review found no unifying definition for SDM in the literature. All sources highlighted the importance of SDM; however, few studies explored the effectiveness of SDM for CMC, especially in community health settings. This might in part be due to the varying nature of service delivery models in different countries. The lack of implementation research is a shortcoming in paediatric research generally¹⁰ with evidence mainly pertaining to adult care.^{5 17} Limited research exists about SDM for CMC who are from a minority ethnic or disadvantaged background. Three studies showed poorer implementation in black and Hispanic communities in the USA.^{35 36 38} This is congruent with evidence from a systematic review that included studies from 15 countries, showing that adults from minority ethnic or disadvantaged backgrounds experience more barriers to SDM.⁵³ Research shows that SDM interventions can significantly improve the outcomes for disadvantaged adult patients, including increased knowledge and participation in

Table 7 Barriers to SDM for CMC mapped to the ecological model

Individual (child) level—theme: uncertainty	
Uncertainty about diagnosis or clinical management options	3 28 29 31 32 36 45 47 48 50
Lack of evidence and uncertain illness trajectories	3 25 31 32 45 47 50
Limited or conflicting information	25 29 30 39
Uncertainty about child's comfort and quality of life	36 50
Family level	
Language barriers	29 36 38 40 45
Poor general and health literacy	25 28 45 50
Lack of parental understanding of child's diagnosis and prognosis	29 40 45
Lack of trust in HCPs	27 34 50
Parents not feeling heard	34 44 50
Poverty, Black or minority ethnic background	35 36
Parental physical and emotional exhaustion and strong emotions	32 50
Interpersonal level—theme: power imbalance	
Hierarchy and power imbalance, coercive conversations by HCP, failure to explain options fully or withholding information and labelling parents as non-compliant if they disagree with HCPs	3 4 26 28–30 32 34 36 44 45 48 50
Using medical jargon and providing too detailed information	4 27 33 40 43 45 51
HCPs not valuing parental opinion and experience	30 32 34 45
Organisational level—theme: lack of continuity of care	
Involvement of multiple subspecialties, lack of continuity of care	3 4 32 40 44 45 48 50
Healthcare systems that dictate treatment options	4 31 32 50
Lack of time in consultations	3 43 45
Lack of professional understanding and valuing of SDM	31 45
Limited access to the right person to answer questions	4 50
HCPs, healthcare providers; SDM, shared decision-making.	

decision-making.⁵⁴ It is, therefore, not surprising that exploring SDM in diverse communities was one of the most cited research recommendations.

Many influencing factors could either be barriers or facilitators to SDM depending on the context.^{5 7 53} Most factors identified in this review are situated in the organisational level where HCPs can influence change. This includes organisational and personal understanding of and commitment to SDM, interpersonal skills that build trust and respect, active listening, cultural sensitivity, empowerment of families to be active team members and to share their values, opinions and fears, continuity of care, access to the right HCPs and enough time in consultations. Previous studies found that the top patient-reported barriers to SDM include disorganised healthcare systems and the quality of interactions with HCPs,⁵³ whereas the main barriers identified by HCPs are lack of time and motivation to pursue SDM and a perception that patients do not want to engage in decision-making.^{5 7} There is, however, an awareness among HCPs that good communication and coordination of care can improve SDM.² To improve implementation of SDM it should be viewed as a culture within organisations and a way of interacting with every service user rather than another clinical tool.^{2 10}

Another significant patient-identified barrier is hierarchy and power imbalance still prevalent in traditional approaches, where HCPs are the main decision-makers.⁸ Even when espousing SDM, HCPs often provide biased information in order to achieve a specific decisional outcome, for instance by only providing information about their preferred treatment option.⁷ This review found that HCPs often fail to explain all available options, withhold information and use jargon. In some instances, HCPs provide too much and too detailed information, also negatively impacting the decision-making process. Effective information exchange is an important step in the decision-making process⁵⁵ and can either decrease or increase the power balance in the relationship.

This power imbalance is compounded by clinical information being held by HCPs who can influence the accuracy, clarity, tailoring and sharing of that information.^{7 13 53} This review identified accessible, adequate, accurate and balanced information as one of the most significant contributors to successful SDM and conversely, the lack of evidence and information as a barrier to SDM. Providing information that outlines options, risks and uncertainties can improve SDM^{7 8} and if presented in an

Table 8 Facilitators to SDM for CMC

Individual (child) level	
Valuing the personhood of the child	27 33 51
Family level	
Parental comfort with decision-making	28 32 38 50 52
Knowledge of the healthcare system	4 50 51
Parental educational level	31 50
Parental understanding of the child's diagnosis and prognosis	34 50
Interpersonal level	
Mutual trust and respect	4 27 29 35 46 48 49
Actively empowering families to express their opinions, fears and hopes	27 28 40 46 47 49
Reciprocal good interpersonal skills	27 30 31 40 50
Reciprocal active listening	27 34 35 40 46
Regarding parents as experts on their child	29 40 49–51
Having shared goals	27 44 46 48
Sensitivity to cultural differences	27 33 40 50
Showing dedication to the family	27 33 51
Professional awareness of parental decision-making preferences	46 47
Respecting family decisions	26 31
Organisational level—theme: information and access	
Having accessible, sufficient, accurate and balanced information about all treatment options including knowing about uncertainty	4 25–27 30 32 33 46 47 51
Access to peer-to-peer support	25 29 33 36 38 47 50
Having sufficient time to consider information and knowing the time-horizon for decision-making	30 32 33 47 50 51
Access to information from non-professional sources such as social media	31 32 39 47 50
Including parents as members of the team	27 36 40
Continuity of care	33 40 51
Access to interpreters if needed	29 40
Access to the right healthcare professionals to answer questions	4 29
HCP seeking advice from the wider team in the face of uncertainty	31 51
Having access to written information	29 30
CMC, children with medical complexity; HCP, healthcare provider; SDM, shared decision-making.	

accessible and culturally sensitive format, can help overcome language and socioeconomic barriers such as poor literacy.⁵³

A complicating factor in SDM for CMC is, however, the lack of clinical and empirical evidence and information due to the unique illness trajectory of CMC, leading to high levels of uncertainty. The presence of uncertainty was the most striking barrier to SDM for CMC found in this review and sets CMC apart from many other patient populations. A high level of uncertainty is not a typical feature of SDM for children⁷ or adults⁵³ but has been cited in areas such as neonatal intensive care,¹⁵ paediatric end-of-life care^{15 56} and dementia end-of-life care.⁵⁵ The similarities with these clinical areas underscore the high-stress nature of decision-making for CMC.^{13 14}

This review highlights the need for further research to increase the evidence base relating to diagnosis, prognosis and treatment options for CMC and to address the implementation of SDM for CMC, specifically focussing on families from diverse backgrounds who often experience less SDM.

Strengths and limitations

This review contributes to the limited evidence base concerning SDM for CMC and highlights themes around uncertainty, power imbalance and information sharing on implementation of SDM. The risk of missing sources due to the number of synonymous terms for SDM⁶ and CMC¹ used in the literature was mitigated by developing a comprehensive list of search terms and conducting a systematic search using a range of databases. Results were strengthened by

Table 9 Research recommendations

Discover how to involve families and develop collaborative relationships in SDM	26 27 30 31 34 49 50 52
Explore SDM within diverse communities, including diversity in family structure, culture and ethnicity, education level and healthcare setting	30 32 36–38 49 51 52
Explore family and healthcare professional's beliefs, perspectives and experiences of SDM	30–32 43 51 52
Develop guidelines for SDM	27 36 46 50
Evaluate the effect of professional training on SDM	27 34 37
Evaluate proposed models of SDM	36 43
Develop outcomes measures for SDM	45
Develop support technologies for SDM	45
Investigate information needs for effective SDM	25
SDM, shared decision-making.	

having second reviewers at all screening stages. Healthcare organisation and configuration vary across and within countries. It can range from mainly hospital-based services to services delivered in various hospital and community settings, services can be offered free at the point of contact or require payment by insurers or service users. This variation could have impacted the identification of and comparability of studies. Most sources originated in the USA and Canada where barriers might be different to the UK and other parts of the world. The studies that included minority ethnic groups were conducted in the USA and do not represent the UK population. The review only included sources published in English, which might have resulted in the exclusion of potentially valuable papers.

CONCLUSION

This scoping review revealed that uncertainty about diagnosis, prognosis and treatment outcomes for CMC has a significant impact on SDM, in addition to barriers and facilitators identified in other paediatric and adult populations, highlighting the need to advance the clinical evidence base for this population. Furthermore, many factors impacting SDM fall within the organisational level where HCPs can influence change, including pursuing a power balance and equal partnership, improving continuity of care and improving information resources to meet the needs of parents of CMC, including those from diverse backgrounds. Focusing on these factors can potentially improve medical and developmental outcomes, quality of life of children and families and more effective use of healthcare resources. This review can be used to guide a research strategy in the field of SDM for CMC in community health services.

Twitter Sonja Jacobs @SttSonja

Contributors SJ, ND and CHS planned the study. SJ is the guarantor and took the lead in performing the scoping literature search and data analysis and writing the manuscript. KB, JLO and KS were second reviewers for source selection and extraction and reviewed the manuscript. ND and CS supervised the study and reviewed the manuscript. All authors critically reviewed the final draft of the manuscript.

Funding SJ is an ICA Pre-doctoral Clinical Academic Fellow supported by Health Education England and the National Institute for Health Research, grant number: NIHR301944.

Disclaimer The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health and Social Care.

Competing interests No, there are no competing interests.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 Unported (CC BY 4.0) license, which permits others to copy, redistribute, remix, transform and build upon this work for any purpose, provided the original work is properly cited, a link to the licence is given, and indication of whether changes were made. See: <https://creativecommons.org/licenses/by/4.0/>.

ORCID iD

Sonja Jacobs <http://orcid.org/0000-0001-5021-0119>

REFERENCES

- Cohen E, Kuo DZ, Agrawal R, *et al.* Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* 2011;127:529–38.
- Birchley G, Thomas-Unsworth S, Mellor C, *et al.* Factors affecting decision-making in children with complex care needs: a consensus approach to develop best practice in a UK children's Hospital. *BMJ Paediatr Open* 2022;6:e001589.
- Lin JL, Cohen E, Sanders LM. Shared decision making among children with medical complexity: results from a population-based survey. *J Pediatr* 2018;192:216–22.
- Buchanan F, Lai C, Cohen E, *et al.* Decision-Making for parents of children with medical complexities: activity theory analysis. *J Particip Med* 2022;14:e31699.
- Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16.
- Park ES, Cho IY. Shared decision-making in the paediatric field: a literature review and concept analysis. *Scand J Caring Sci* 2018;32:478–89.
- Boland L, Graham ID, Légaré F, *et al.* Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci* 2019;14:7.
- Angela C, Collins A. King's fund centre (london). making shared decision-making a reality: no decision about me, without me. *King's Fund* 2011. Available: <https://www.kingsfund.org.uk/publications/making-shared-decision-making-reality>
- Mulley AG, Chris T, Glyn E. Patients' preferences matter: stop the silent misdiagnosis. *King's Fund* 2012. Available: <https://www.kingsfund.org.uk/publications/patients-preferences-matter>
- Wyatt KD, List B, Brinkman WB, *et al.* Shared decision making in pediatrics: a systematic review and meta-analysis. *Acad Pediatr* 2015;15:573–83.
- Vemuri S, Hynson J, Williams K, *et al.* Decision-Making approaches for children with life-limiting conditions: results from a qualitative phenomenological study. *BMC Med Ethics* 2022;23:52.
- Fiks AG, Hughes CC, Gafen A, *et al.* Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics* 2011;127:e188–96.
- Dias BC, Marcon SS, Reis PD, *et al.* Family dynamics and social network of families of children with special needs for complex/continuous cares. *Rev Gaucha Enferm* 2020;41.

- 14 Woodgate RL, Edwards M, Ripat JD, *et al.* Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatr* 2015;15:197.
- 15 Krick JA, Hogue JS, Reese TR, *et al.* Uncertainty: an uncomfortable companion to decision-making for infants. *Pediatrics* 2020;146(Suppl 1):S13–7.
- 16 Jacobs S, Davies N, Smith CH. Shared decision-making for children with medical complexity in community health services – scoping review protocol. *Open Science Framework Published Online First* 2022.
- 17 Joseph-Williams N, Lloyd A, Edwards A, *et al.* Implementing shared decision making in the NHS: lessons from the magic programme. *BMJ* 2017;357:j1744.
- 18 Peters MDJ, Marnie C, Tricco AC, *et al.* Updated methodological guidance for the conduct of scoping reviews. *JBIM Evid Synth* 2020;18:2119–26.
- 19 Peters MDJ, Godfrey C, Mclnerney P, *et al.* Best practice guidance and reporting items for the development of scoping review protocols. *JBIM Evid Synth* 2022;20:953–68.
- 20 Jordan PZ. *JBIM manual for evidence synthesis*. 2020.
- 21 Tricco AC, Lillie E, Zarin W, *et al.* PRISMA extension for scoping reviews (PRISMA-scr): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
- 22 McGowan J, Sampson M, Salzweid DM, *et al.* PRESS peer review of electronic search strategies: 2015 guideline statement. *J Clin Epidemiol* 2016;75:40–6.
- 23 Pollock D, Peters MDJ, Khalil H, *et al.* Recommendations for the extraction, analysis, and presentation of results in scoping reviews. *JBIM Evidence Synthesis* 2023;21:520–32.
- 24 Sallis JF, Owen N, Fisher E. Ecological models of health behavior. In: Glanz K, Rimer BK, Viswanath K, eds. *Health Behavior and Health Education: Theory, Research and Practice*. Jossey-Bass, 2008: 465–86. Available: <https://www.researchgate.net/publication/43508113> [accessed 28 Nov 2022].
- 25 Brotherson MJ, Oakland MJ, Secrist-Mertz C, *et al.* Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities. *Journal of the Association for Persons with Severe Handicaps* 1995;20:202–12.
- 26 Katz L, Scarpati S. A cultural interpretation of early intervention teams and the IFSP: parent and professional perceptions of roles and responsibilities. *Infant-Toddler Intervention: The Transdisciplinary Journal* 1995;5:177–91. Available: <https://www.researchgate.net/publication/234649683>
- 27 Blue-Banning M, Summers JA, Frankland HC, *et al.* Dimensions of family and professional partnerships: constructive guidelines for collaboration. *Exceptional Children* 2004;70:167–84.
- 28 Brotherton A, Abbott J. Mothers' process of decision making for gastrostomy placement. *Qual Health Res* 2012;22:587–94.
- 29 Stille CJ, Fischer SH, La Pelle N, *et al.* Parent partnerships in communication and decision making about subspecialty referrals for children with special needs. *Acad Pediatr* 2013;13:122–32.
- 30 Zaal-Schuller IH, Willems DL, Ewals F, *et al.* How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Res Dev Disabil* 2016;59:283–93.
- 31 Buchanan F, Cohen E, Milo-Manson G, *et al.* What makes difficult decisions so difficult?: an activity theory analysis of decision making for physicians treating children with medical complexity. *Patient Educ Couns* 2020;103:2260–8.
- 32 Lin JL, Clark CL, Halpern-Felsher B, *et al.* Parent perspectives in shared decision-making for children with medical complexity. *Acad Pediatr* 2020;20:1101–8.
- 33 Jabre NA, Raisanen JC, Shipman KJ, *et al.* Parent perspectives on facilitating decision-making around pediatric home ventilation. *Pediatr Pulmonol* 2022;57:567–75.
- 34 Reeder J, Morris J. Becoming an empowered parent. how do parents successfully take up their role as a collaborative partner in their child's specialist care? *J Child Health Care* 2021;25:110–25.
- 35 Denboba D, McPherson MG, Kenney MK, *et al.* Achieving family and provider partnerships for children with special health care needs. *Pediatrics* 2006;118:1607–15.
- 36 Smalley LP, Kenney MK, Denboba D, *et al.* Family perceptions of shared decision-making with health care providers: results of the National survey of children with special health care needs, 2009–2010. *Matern Child Health J* 2014;18:1316–27.
- 37 An M, Palisano RJ, Yi C-H, *et al.* Effects of a collaborative intervention process on parent-therapist interaction: a randomized controlled trial. *Phys Occup Ther Pediatr* 2019;39:259–75.
- 38 Jolles MP, Lee PJ, Javier JR. Shared decision-making and parental experiences with health services to meet their child's special health care needs: racial and ethnic disparities. *Patient Educ Couns* 2018;101:1753–60.
- 39 Guerriere DN, McKeever P, Llewellyn-Thomas H, *et al.* Mothers' decisions about gastrostomy tube insertion in children: factors contributing to uncertainty. *Dev Med Child Neurol* 2003;45:470–6.
- 40 Pickering D, Busse M. Disabled children's services: how do we measure family-centred care? *J Child Health Care* 2010;14:200–7.
- 41 Arvedson JC, Lefton-Greif MA. Ethical and legal challenges in feeding and swallowing intervention for infants and children. *Semin Speech Lang* 2007;28:232–8.
- 42 Bazyk S. Changes in attitudes and beliefs regarding parent participation and home programs: an update. *Am J Occup Ther* 1989;43:723–8.
- 43 An M, Palisano RJ. Family-professional collaboration in pediatric rehabilitation: a practice model. *Disabil Rehabil* 2014;36:434–40.
- 44 Austin D. Improving partnerships to make family-centered care work for children with special health care needs. *Science of Caring* 2014;1. Available: <https://scienceofcaring.ucsf.edu/community/improving-partnerships-make-family-centered-care-work-children-special-health-care-needs>
- 45 Adams RC, Levy SE, COUNCIL ON CHILDREN WITH DISABILITIES. Shared decision-making and children with disabilities: pathways to consensus. *Pediatrics* 2017;139:1–9. 10.1542/peds.2017-0956 Available: <https://doi.org/10.1542/peds.2017-0956>
- 46 Madrigal VN, Kelly KP. Supporting family decision-making for a child who is seriously ill: creating synchrony and connection. *Pediatrics* 2018;142(Suppl 3):S170–7.
- 47 Mahant S, Cohen E, Nelson KE, *et al.* Decision-Making around gastrostomy tube feeding in children with neurologic impairment: engaging effectively with families. *Paediatr Child Health* 2018;23:209–13.
- 48 Lee KJ, Hill DL, Feudtner C. Decision-Making for children with medical complexity: the role of the primary care pediatrician. *Pediatr Ann* 2020;49:e473–7.
- 49 Kruijsen-Terpstra AJA, Ketelaar M, Boeije H, *et al.* Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review. *Child Care Health Dev* 2014;40:787–96.
- 50 Popejoy E, Pollock K, Almack K, *et al.* Decision-Making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child Care Health Dev* 2017;43:627–44.
- 51 Jonas D, Scanlon C, Bogetz JF. Parental decision-making for children with medical complexity: an integrated literature review. *J Pain Symptom Manage* 2022;63:e111–23.
- 52 LeGrow K, Cohen E, Espin S. Relational aspects of parent and home health care provider care practices for children with complex care needs receiving health care services in the home: a narrative review. *Acad Pediatr* 2022;22:196–202.
- 53 Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014;94:291–309.
- 54 Durand M-A, Carpenter L, Dolan H, *et al.* Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS One* 2014;9:e94670.
- 55 Davies N, De Souza T, Rait G, *et al.* Developing an applied model for making decisions towards the end of life about care for someone with dementia. *PLoS One* 2021;16:e0252464.
- 56 Richards CA, Starks H, O'Connor MR, *et al.* Physicians perceptions of shared decision-making in neonatal and pediatric critical care. *Am J Hosp Palliat Care* 2018;35:669–76.