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Decision-making capacity in childbirth as a gatekeeper for self-determination? A scoping review of its conceptualisations

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ABSTRACT

Legally, as any other adult person in the medical context, a person giving birth is presumed to have decision-making capacity. Yet, one reason for mistreatment in birth can be found in the apparent uncertainties and misconceptions regarding the conceptualisation, operationalisation and assessment of decision-making capacity in birth. The widespread notion of birthing people lacking decision-making capacity has detrimental effects on the way they are treated. We carried out a scoping review of international literature (N=121). The primary research question was: How is decision-making capacity in birth conceptualised?

The vast majority of studies came from high-income countries (n=115) and were ethical/philosophical (n=48) or legal analyses (n=36). We inductively developed the following categories: (1) default assumptions, (2) criteria, (3) limiting and enhancing factors, (4) assessment, (5) population-specific conceptualisations, (6) meta-conceptualisations and (7) mistaken or questioned criteria. At a conceptual level, no universally shared consensus regarding decision-making capacity in birth exists, and, at a practical level, this ties in with various injustices experienced by birthing people. Since conceptualising decision-making capacity is a question of power and birthing people by virtue of their position in research and medicine are unlikely to be part of the respective knowledge-producing communities, for the time being it is crucial to insist that decision-making capacity in birth is legally presumed until proven otherwise, and to critically reflect on the prevailing (mis)conceptions about birthing people. In conclusion, establishing epistemic justice throughout the process of conceptualising decision-making capacity in birth is a prerequisite for advancing reproductive rights and improving birth experiences.

INTRODUCTION

In sharp contrast to its widespread occurrence,[1–14] ethical and medical associations widely condemn autonomy violations in birth and any coercive measures being imposed on birthing people with decision-making capacity (DMC). This upholds the bioethical principles of respect for autonomy, non-maleficence and beneficence as well as the deduced principle of informed consent (IC), thereby codifying the recognition of birthing people's reproductive rights.[15–18] A person with DMC holds the ethical and legal authority to consent to or refuse medically indicated treatment.[19–21] Valid and meaningful IC has to be provided voluntarily and knowingly, which requires a person to have DMC. Thus, DMC is a prerequisite for IC to medical treatment (ie, transforming a choice into a legally binding decision of a competent patient) and, as such, a gatekeeper for a patient's autonomy. Accordingly, any medical intervention performed without IC on a person with DMC constitutes an unlawful violation of the constitutional rights to personal freedom, privacy and bodily integrity. Hence, it qualifies as a legally significant bodily injury and human rights violation.[18 22–25] However, ensuring rights-based care during birth is not only an ethicolegal imperative but also translates into better birth outcomes. Negative birth experiences are well-documented to have a causal relationship with adverse psychological outcomes among birthing people, such as postpartum depression and postpartum post-traumatic stress disorder.[5 26 27] Such adverse outcomes, in turn, negatively affect early initiation of breastfeeding,[28] mother-child-bonding and child development,[29 30] parental self-efficacy,[31] parental couple relationships[32 33] and parenting stress.[34] Furthermore, they influence future reproductive decisions and health behaviour, for example, they decrease the likelihood of subsequent birth[35 36] and deter individuals from seeking care in birthing facilities again.[37 38]

Legally, as any other adult person in the medical context, a person giving birth is presumed to have DMC.[17 21 39–41] DMC is presumed unless, in reasonable doubt concerning the birthing person's mental condition, the contrary is proven and documented through a thorough evaluation

by a qualified provider (in Switzerland, this includes physicians and midwives).[17 39] While DMC is binary, it is neither rigid nor static: with it being both specific with regard to time and decision, it can be understood as dynamic, depending on the decision to be made and the circumstances. The legal presumption of capacity and burden of proof of incapacity imply that coercion during birth is only permissible under certain rarely occurring circumstances. One of which is when thorough assessment asserts a lack of DMC, which has to be documented, and the decision cannot be transferred to a legally authorised representative.[42] In such cases, however, the decision must still correspond to the presumed will of the person and not merely to a physician's preference. However, international studies indicate that in practice providers often suspend the presumption of DMC during the intrapartum period, which then leads to autonomy violations.[43–46] The standards for DMC during birth appear to be set differently than in other areas of medicine, frequently justified by the reference to the exceptional physical and emotional states birthing people are in (eg, pain, hormonal influences), or birthing people are generally simply deemed to lack DMC. This suggests that one reason for the numerous cases of mistreatment and autonomy violations can be found in the apparent uncertainties and misconceptions regarding the conceptualisation, operationalisation and assessment of DMC in the context of birth. Ultimately, the widespread notion of birthing people lacking DMC has detrimental effects on the way they are treated in birth. It encourages professional and institutional attitudes resulting in medical interventions without or against IC and regularly leading to mistreatment and reproductive rights violations in birth.[39]

While DMC and competence are often used interchangeably and their meanings are inverted in some legal settings (eg, UK),[47] the former usually represents a clinical assessment of a person's cognitive abilities. But the concept is also used in a legal context to determine if a person can make legally valid decisions, in general or with regard to specific acts.[48 49] Assessment instruments in clinical practice are most often based on the four criteria set out by Appelbaum and Grisso: (a) understanding relevant information, (b) appreciating the situation and its consequences, (c) manipulating information rationally and (d) communicating a choice.[50] The respective tests align with the so-called procedural account of DMC, according to which DMC should be assessed based on the process by which a decision is reached, disregarding the apparent reasonableness of the outcome.[51] This account conceptualises DMC as a purely mental ability residing within a person closely tied to notions of rationality.[19 52] However, this cognitivist conceptualisation has garnered much criticism.[53] Particularly feminist scholars argued that it neglects a person's interdependence as well as the social and political structures underlying and permeating decision-making.[54 55] Scholars working on mental health-related issues caution that these accounts risk discriminating against persons diagnosed with mental disorders.[53 56] In light of this, it has been proposed to broaden the conceptualisation by so-called substantive factors such as beliefs and values informing a decision (ie, substantive account of DMC)[51] and by desires, emotions or relational aspects.[19 49 57] Lastly, in response to these conceptual questions, some authors have suggested treating DMC as an essentially contested concept.[58 59] Such concepts are inherently open to dispute, not merely because of inconsistent use or practical disagreements, but because they embody conflicts of values that cannot be conclusively resolved through rational argument. This idea captures a concept's inherent potential to evoke disputes that cannot be conclusively resolved using rational arguments, since the concept's contestability is not only practical in nature (eg, inconsistent use, disagreements, equivocation) but mainly stems from a conflict of values embodied within the concept and hence is normative in nature.[58–61]

Despite the sketched conceptual controversies and the clear ethicolegal and health-related significance of DMC in birth, no literature review has yet synthesised and analysed the existing conceptualisations. A thorough understanding of DMC is imperative to fully appreciate what the principle of autonomy entails at a conceptual level and how it operates in specific instances such as birth.[19] To fill this gap, this scoping review provides a comprehensive synthesis and analysis of the conceptual dimensions of birthing people's DMC. The scoping review informs both clinical practice and ethicolegal standards.

METHODS

Unlike systematic reviews' focus on precise and clinically relevant research questions, scoping reviews apply less restrictive inclusion criteria and draw on data from studies irrespective of study design or study quality.[62] They are an approach to evidence synthesis to determine the scope and volume of existing literature on a specific topic. Particularly, they are a tool to map and identify a body of evidence on a topic for which more specific questions have yet to be defined.[62] As such, the method is well suited for comprehensively mapping the conceptual landscape of DMC in birth.

Research question and objective

The primary research question of this scoping review is: How is the concept of DMC in birth conceptualised in the literature? Given the current lack of a literature synthesis on this topic, the main objective is to unravel and consolidate existing—and oftentimes conflicting—conceptualisations of DMC in birth, thereby addressing a critical research gap with direct implications for birthing people's reproductive rights and health. Beyond synthesis, this review seeks to excavate a more comprehensive (ie, broadened understanding), more context-sensitive (ie, responsive to the particular circumstances of birthing), and inclusive (ie, attentive to marginalised

Table 1 Search results

Block	Matches					
	Medline	Scopus	PsycINFO	Web of Science	CINAHL	Philosopher's Index
1	604.294	3.556.967	378.739	2.806.453	307.076	47.386
2	10.694	26.652	8.131	6.772	1.584	1.515
1 and 2	133	1.922	528	126	47	329
Total: 3.085, after deduplication: 2.486						
Date of search: 6 June 2024.						

populations disproportionately at risk to be excluded from decision-making in birth based on assumptions about their DMC) conceptualisation of DMC in birth. Furthermore, efforts are made to identify and critically assess widely held misconceptions surrounding birthing people's DMC. For the purpose of this review, we define misconceptions of DMC in birth as those deviating from the ethicolegal standards as outlined in the second paragraph of the introduction section (ie, strong ethicolegal presumption of DMC in birth). Ultimately, the aim is to inform both perinatal care and the revision of ethicolegal standards.

Search strategy and information sources

To frame the review, Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) were followed.[63 64] In addition to the authors' prior knowledge about DMC in birth, search terms were identified by, first, preliminarily searching databases and analysing keywords, titles, and abstracts, second, consultation with experts, and, third, targeted internet searches. We structured the search strategy around two main blocks: 'birth' (ie, context of interest) and 'DMC' (ie, concept of interest); see table 1 for search results and online supplemental table 1 for detailed search strings. We applied Arksey and O'Malley's multistaged framework for scoping reviews: identification of research question; identification of relevant studies; selection of studies; charting of data and collating, summarising and reporting results.[65] We searched six databases and employed Boolean logic (table 1).

Eligibility criteria

To be included, studies had to (a) address the conceptualisation of DMC (b) in birth and (c) have an abstract written in English, German, French or Spanish. No criteria were applied to study methodology, population, study quality, geographical region or publication date. To capture a comprehensive census of relevant literature, we deliberately included a wide range of conceptual angles, such as: what is DMC in birth, who has DMC in birth, when DMC in birth is present, which factors limit or enhance DMC in birth, which aspects of DMC in birth should be scrutinised, and what theoretical foundations underlie the concept(ualisation) of DMC in birth.

Selection process and search results

We conducted the searches on 6 June 2024. The database search resulted in 3085 records. After de-duplication, 2486 records remained, which were screened for eligibility based on a critical examination of titles and abstracts. This step resulted in 245 reports, out of which 218 could be retrieved. Full-text screening of these articles resulted in 56 included studies. In addition, we identified 294 records through other methods: 100 through Google, 104 through Google Books, 68 through screening of references of studies included from databases, and 22 through own knowledge (figure 1). Out of these, we included an additional 67 suppstudies in the review. Hence, 121 studies comprised the final set of included studies (see online supplemental table 2, figure 1). For the purpose of selecting studies, we used Covidence software. All records were screened by two reviewers. Disagreements were solved through discussions among the research team members involved in screening (MR, PS, FH and JE).

Data analysis

To extract general study characteristics, we developed a 17-item data extraction framework (eg, title, authors, year of publication, country, information on background of authors, type of literature, study design). We inductively coded conceptualisations of DMC in birth, using analysis software MAXQDA.[66] In this step, we preliminarily grouped the specific instances of conceptualising DMC in birth based on commonalities. Subsequently, we developed superordinate and subordinate themes. In a next step, we combined these themes into main themes. Lastly, we rediscussed, refined and named main themes, to build a coherent framework of DMC conceptualisations.

RESULTS

We included a total of 121 studies in the review. The vast majority came from high-income countries (n=115, 95.0%; UK: n=38, 31.4%, USA n=35, 28.9%), three from upper-middle-income countries (China, Turkey, Colombia), two from lower-middle-income countries (India, Nigeria) and one from a low-income country (Uganda).[67] Most studies were ethical/philosophical analyses (n=48, 39.7%), legal analyses (n=36, 29.8%), empirical analyses (n=15, 12.4%; n=9 qualitative, n=6 quantitative) and medical-ethical recommendations (n=9, 7.4%).

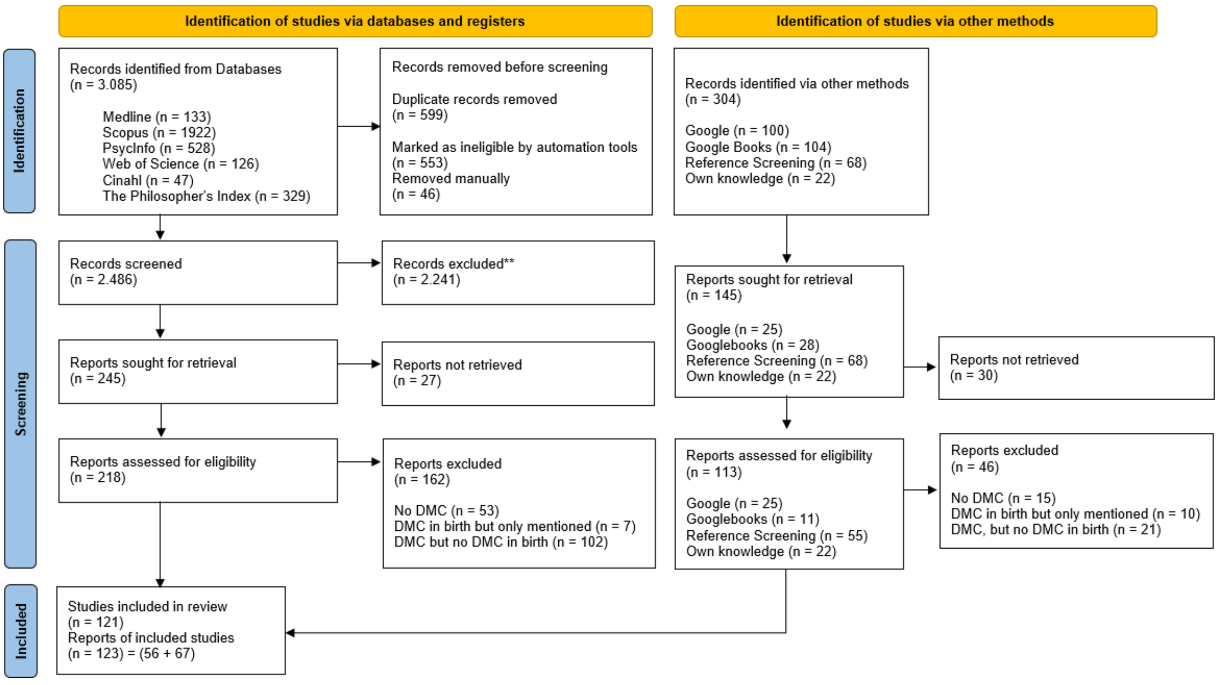

Figure 1 PRISMA flow chart for inclusion of studies. DMC, decision-making capacity; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

With respect to publication date, 30 studies (24.8%) were published between 2020 and 2024, 44 between 2010 and 2019 (36.4%), 24 between 2000 and 2009 (19.8%), and 21 before 2000 (17.4%; earliest publication from 1982, n=3 from 1980s). This indicates an increase in publications over the past decades. Notably, 35 studies (29.0%) addressed DMC in birth in relation to C-sections, among which 28 (80.0%) dealt with a few cases of court-ordered emergency C-sections. Further details on characteristics of included studies are presented in online supplemental table 2. Based on the included literature, we inductively developed the following seven categories regarding the conceptualisation of DMC in birth, which will be presented in more detail in the below sections: (1) default assumptions of DMC, (2) criteria of DMC, (3) limiting and enhancing factors of DMC, (4) assessment of DMC, (5) population-specific conceptualisations, (6) meta-conceptualisations of DMC and (7) mistaken or questioned criteria of DMC (as explicitly stated by the authors of included literature) (figure 2).

It has to be noted that, in the following reporting of results, the identification of a study with certain remarks on the conceptualisation of DMC in birth—unless stated otherwise—does not necessarily mean that the authors of the respective study held this view. Instead, besides authors arguing for a certain position themselves, studies can contain a certain position for various reasons, for example, as part of an argument, as part of a historical perspective, as part of a brief review of positions, as a quote from study participants (eg, interviews, surveys), or to scrutinise the respective position. However, since the primary aim of our scoping review was to comprehensively

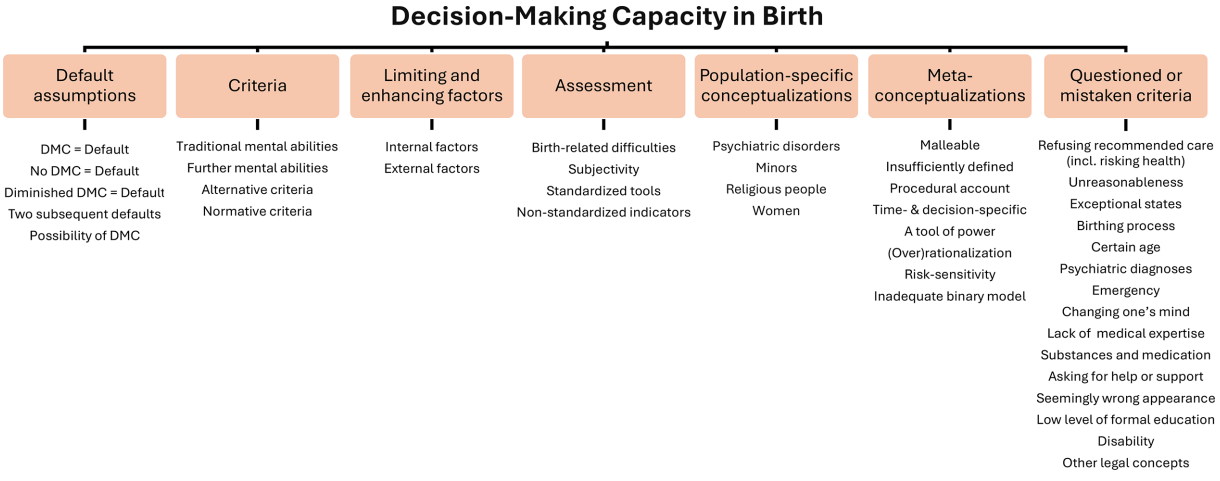

Figure 2 Main categories of conceptualisations of DMC in birth. DMC, decision-making capacity.

map the landscape of conceptualisations of DMC in birth (and not to identify every existing position with a respective author, nor to quantify them), we attempted to capture and report all positions, and only identified a position with studies, if relevant for the results. Hence, to facilitate readability of reported results (ie, identifying all positions with the respective authors would blow it out of proportion and result in an improperly long results section) and to allow the reader to find and familiarise with a certain position, we cited the study in which the respective position can be found and only flagged the latter as stemming from the authors' if relevant. Lastly, in line with our attempt to facilitate readability, in the main text we only cite a maximum of five exemplary studies for each finding. We provide a separate version of the results section that contains more citations pertinent to a specific finding in online supplemental appendix 3 to enable readers to access a more comprehensive list of references. The number of references to a specific conceptualisation does not reflect a degree of consensus regarding the latter; instead, a conceptualisation, for example, could have been cited and discussed numerous times specifically because it is a highly controversial one.

Default assumptions of DMC

The are five default assumptions regarding birthing people's DMC: (1) DMC, (2) no DMC, (3) continuously increasing incapacitation, (4) first DMC, then no DMC and (5) a mere possibility of DMC. First, the majority of studies considered birthing people having DMC by default, including two medical-ethical recommendations from Swiss and British national Obstetrics and Gynecology associations.[68–70] Second, contrary to the default assumption of having DMC, a proportion of studies either shared[71 72] or critically referenced[39 73–76] the view that the default assumption for birthing people is not having DMC or having diminished DMC, respectively. Third, a few studies either argued[77–80] or critically referenced[74 81] that, in almost every birth, the further labour advances the more incapacitated birthing people become (ie, continuous incapacitation not necessarily reaching the level of incapacity). Lastly, a few studies explicitly described two distinct and subsequent default assumptions for the intrapartum period in general (ie, sequential incapacitation always leading to level of incapacity): first birthing people are deemed to have DMC, but at some point during labour all birthing people do become incapacitated and thus the default changes.[77 82 83] Fifth, a few studies, including a US medical-ethical recommendation,[84] did not directly claim that birthing people generally possess DMC, but rather describe cases of birthing people with DMC. They used expressions containing capacity and the birthing person such as 'adult patient with DMC during labour'[84–87] or conditional sentences such as 'if a woman is competent'.[88] Consequently, these studies merely articulated the possibility of DMC in birth, without explicitly articulating that DMC in birth is the default. Related to this, despite acknowledging the default assumption of DMC in birth, a small number of studies still emphasised the need to assess whether DMC is actually maintained during birth on an individual basis.[80 89]

Criteria of DMC

DMC criteria can be grouped into four categories: (1) traditional four mental abilities based on Appelbaum and Grisso's landmark publication,[50] (2) further mental criteria going beyond Appelbaum and Grisso's abilities, (3) alternative non-cognitive mental criteria and (4) normative criteria. First, the four criteria stipulated by Appelbaum and Grisso in 1988 (ie, understanding relevant information, appreciating the situation and its consequences, manipulating information rationally, communicating a choice) were by far the most frequently discussed.[50] The majority of studies referred to these abilities when predicating DMC in birth on certain criteria.[90–94] Examples for references to the four abilities are: absorbing information, recognising facts, retaining information, comprehending information, understanding own diagnosis (ie, understanding relevant information); comparing choices to alternatives, appreciating medical decision, appreciating how information relates to one's own circumstances, questioning (ie, appreciating the situation and its consequences); weighing pros and cons, defending one's own standpoint, making sound inferences, possessing values, reasoning (ie, manipulating information rationally); expressing values, preferences, choices and decisions (ie, communicating a choice).

Second, a minority of studies highlighted mental abilities that are likely to be related to or underlying Appelbaum and Grisso's four abilities, but which could not easily be assigned to one of the latter. Most of these studies explicitly cited 'rationality' and 'reason'.[81 95–98] Other studies referred to rather global cognition-related assessments such as 'thinking straightforwardly and logically',[99] 'sound mind',[89] 'cognitive functioning',[100] 'being lucid'[101] or 'optimal concentration'.[102] Furthermore, both legal[89 103–105] and developmental maturity[103] were mentioned as criteria for DMC in birth. Similarly, a few studies only vaguely defined the respective global ability, merely referring to 'understanding' or 'assessing a situation'.[80 106–108] Third, various studies brought forward criteria which are less closely related to cognition and rationality and can thus be categorised as alternative criteria for DMC in birth, for example, 'experiential' aspects,[109 110] a correct 'perception of reality',[101 111 112] 'embodied knowledge',[45] 'somatic intuition',[110] 'emotions'[74] or 'relational' aspects.[110 113]

Lastly, numerous studies quoted normative criteria primarily based on value judgements and hence spanning beyond actual abilities. The most frequent criterion was merely disagreeing with medical recommendations, consequently refusing recommended care, and ultimately risking own or fetal health (as determined by providers).[101 114–117] Having DMC, in turn, would have required agreeing to recommended care, being

able to prioritise one's own or fetal short-term physical health under all circumstances, and not risking one's own or fetal health and life. Notably, one text explicitly construed having DMC as prioritising fetal health over one's own health,[101] and a few studies listed the 'ability to believe information' as a criterion for DMC in birth.[103 114 118 119] Furthermore, a proportion of studies described obstetric expertise,[104 120 121] making choices that others might make in similar situations,[98 113] and the 'ability to make objective decisions' [81] as criteria for DMC. One study showed that historically the 'ability to endure pregnancy without any complaint' was seen as a criterion for DMC in birth.[98]

Limiting and enhancing factors of DMC

Studies frequently mentioned limiting and enhancing factors of DMC in birth, both internal factors residing within the birthing person and external factors. Internal factors possibly limiting DMC in birth were: (1) pain[44 122–125]; (2) stress, distress, emotions and emotional stress[77 81 120 126 127]; (3) the clinical and physical condition (eg, nausea, delirium, emergency birth, 'uterine influence', brain damage, unconsciousness, effects of hormones)[106 128–130]; (4) the influence of medication[73 131–134]; (5) fear and anxiety[44 90 116 135 136]; (6) exhaustion, fatigue and tiredness[73–75 137 138]; (7) vaguely defined (aspects of) the mere process of birthing and labour (eg, limbic functions, contractions, progress of birth, labour intensity)[139–144]; (8) psychiatric conditions (eg, delusional thinking, denial of pregnancy, unreasonable fear of the fetus, auditory hallucinations, learning difficulties)[83 91 96 145 146] and (9) other non-psychiatric mental conditions (eg, confusion, flat affect, euphoria, information overload, attention focused on birthing)[21 147–150]; and (not further specified) shock.[119 125 147 151 152] Furthermore, a few studies alluded to a lack of medical expertise,[105 126 148] and biographical events and personal circumstances (eg, age, origin and cultural tradition, particular mental history, negative birth experiences)[77 97 108 114 153] on the part of birthing people. Apart from internal limiting factors, several studies referred to external factors possibly limiting DMC in birth, such as being in a vulnerable position, missing interpreter services, pressures and duress, and a loud and busy labour ward.[87 132 136 154 155]

In addition, a small number of studies explicitly touched on factors possibly enhancing DMC. An internal factor possibly enhancing DMC was birth preparedness through birth preparation and birth education (ie, education about intrapartum management or clinical issues; educational interventions).[97 120 156 157] External factors possibly enhancing DMC were: communication (eg, open and empathetic),[16 156–158] medication (eg, treating mental disorders, alleviating pain)[104 116 148 157 159] and decision-making tools (eg, visualisations, reminding birthing people through Ulysses contracts of their earlier preferences).[120 157]

Assessment of DMC

Studies on the assessment of DMC in birth revealed various statements on the underlying conceptualisation of DMC. These statements revolved around four main points: (1) birth-related difficulties, (2) inherent subjectivity, (3) standardised assessment tools and (4) non-standardised indicators. First, discussing the assessment of DMC, a few studies argued that the assessment of DMC during birth is difficult due to birth-related factors like time pressure, pain, medication, stress,[153 160] while other studies emphasised that birthing is a natural, irrational process and hence the assessment of DMC is only of limited applicability in birth.[161] Second, some studies further highlighted that determining the required level of DMC is inherently subjective, which can lead to inconsistencies.[103] Third, many studies reported a variety of standardised global assessments of DMC in birth, both in general (eg, Appelbaum and Grisso's assessment, RCAT) and for particular situations (eg, CURVES for emergency situations, Gillick test for minors).[16 69 138 152 156] Fourth, beyond standardised global tools, numerous studies proposed single non-standardised intrapartum indicators to facilitate DMC assessment. These indicators could either be assessed through direct interaction between providers and the birthing person (eg, asking a person to summarise or repeat, exploring their perspective through dialogue and communication)[89 100 105 106 162] or by considering only the birthing person (eg, evaluating a person's judgement against the relevant expertise, holistically looking at a person's circumstances).[77 103 162]

Population-specific conceptualisations

Numerous studies expanded on the conceptualisation of DMC in birth for specific populations, namely (1) people diagnosed with psychiatric disorders, (2) minors, (3) religious people and (4) women. First, for people diagnosed with psychiatric disorders studies either discussed the latter either in general or specifically for certain disorders such as depression, psychosis and schizophrenia or phobias. These studies suggested that psychiatric disorders cause fluctuating levels of DMC and affect various mental abilities required for DMC. For psychiatric disorders in general, mentioned impaired abilities were, for example, to fully consider risks of a treatment; to evaluate whether consequences are desirable; to appreciate the impact of consequences for oneself; to cognitively understand and reason from present events to their consequences; to absorb and retain information; or to pay attention.[83 163–165] According to one study, labour and the associated pain can exacerbate the underlying issues of intellectual disability or serious mental illness.[99] Most studies on the impact of psychiatric disorders addressed psychosis and schizophrenia. Mentioned impairments included the ability to consider the effects of one's behaviour on pregnancy; to process information (ie, absorb, retain and recall information); to be emotionally stable; to acknowledge one's pregnancy; to cooperate; to make a voluntary decision; to explain a decision; and to exhibit

evaluative understanding (eg, seeing fetus as a frightening entity that needs to be expelled, assuming that providers intend to harm).[156 165–168] For depression, mentioned impairments included the ability to appreciate positive aspects of the future (which impairs evaluative understanding); to turn attention to what providers say; and to exhibit maternal behaviour.[148 169] For people diagnosed with intellectual disabilities or severe cognitive impairments, all but one study[170] deemed this population to lack or to have limited DMC.[99 132 148] Lastly, a small number of studies addressed phobias, particularly needle phobia (many of them referring to the same case from the UK). Here, mentioned impaired abilities were, for example, to perceive reality accurately; to focus on anything else but the phobia evoking stimulus; to weigh treatment information; and to make a decision.[111 115 123 133 160] One study presented the case of a woman diagnosed with agoraphobia, who refused to give birth in a hospital and, as a consequence, was deemed to lack DMC.[171] Further populations specifically discussed in the literature, although to a significantly smaller extent, were minors, religious people and women as such.

Second, for minors, while a few studies explicitly argued that minors under some circumstances (eg, being emancipated as indicated by being married or in the army, being 16 years of age or more, having sufficient understanding) can have DMC,[89 104 107] other studies mentioned impaired abilities such as making fully informed choices (due to lack of experience and judgement), processing information (due to selective perception), and appreciating risks.[89 100 104 132] Third, for religious people, DMC was questioned because of religious beliefs leading to refusal of care (eg, C-sections, blood products).[171 172] Finally, a few studies described that women as such are deemed to lack DMC due to so-called, for example, 'female instability' or 'uterine influence' during pregnancy,[98 101 114 155 173] which can be traced back to gendered, patriarchal misconceptions regarding (pregnant and labouring) women.[127 173]

Meta-conceptualisations of DMC

Many studies elaborated on the nature of the concept of DMC in birth itself, rather than focusing on specific parts of the conceptualisation. They transcended the mere question of how to conceptualise DMC, allowing a broader understanding of the concept. The main meta-conceptual perspectives addressed DMC's (1) malleability, (2) definition (insufficient definition, procedural accounts, time-specificity and decision-specificity), (3) usage as a tool of power, (4) overemphasis on rationality, (5) risk-sensitivity and (6) binary framework. First, studies apostrophised DMC in birth as malleable (ie, in light of fluctuating levels of DMC it is possible to restore DMC).[105 173–175] Second, studies acknowledged that the meaning of DMC remains unsolved and that DMC is embedded in an insufficiently defined autonomy framework[71 151]; underscored that DMC is not predicated on outcome but on ability (ie, DMC requires to be able to, not to actually make reasonable decisions)[82 107 108 171 172]; and that DMC has to be understood and assessed in light of a specific situation (ie, time-specific and decision-specific).[21 80 93 152 174]

Third, a few studies critically examined the instrumental use of DMC as a tool of (bio-)political, legal and medical power oppressing birthing people. For example, they referred to the utilisation of DMC by judges or providers to protect birthing people's or fetal short-term physical health and to override the former's autonomy. These studies also highlighted concerns about those people not precisely defining the criteria for DMC, and instead applying circular reasoning to disempower birthing people (ie, a person lacks capacity if they have a mental disability which makes them unable to decide; a patient who is unable to decide has a mental disability, which renders them lacking DMC).[16 112 123 151 175]

Fourth, other studies focused on the (over-)rationalisation of DMC in birth. These studies emphasised that rationality-based criteria should be applied consistently, raised questions about who determines the threshold between rationality and irrationality, and argued that rationality requirements may easily be set too high. They further criticised DMC's overemphasis on cognitive aspects and called for a widened, alternative understanding of rationality in birth.[110 127 161 171 174] Fifth, some studies sketched the debate surrounding possibly setting higher DMC thresholds in cases of high risk[99 103 118 147 151]; for example, distinguishing between substantive risk-sensitivity (ie, higher risk raises the DMC threshold) and epistemic risk-sensitivity (ie, higher risk raises the requirement for evidence of intact DMC).[113]

A last meta-conceptual issue concerns the (in)adequacy of the existing binary framework for DMC in birth, which renders DMC an all-or-nothing concept. Various studies challenged this binary idea.[104 162 173] While DMC has evolved from the demands of IC in healthcare, the concept of competence had been developed earlier in the legal context.[162] Moreover, while DMC fluctuates and hence is a dynamic concept, competence is a static binary concept.[99 102 105 162 173] Consequently, the two concepts are misaligned.[162] Especially for birthing people, who not always can be assigned to one side of the binaries, the binary legal framework may not be suitable and in-between spaces exist.[99] Finally, various studies suggested that DMC should rather be construed as a continuum.[78 82 102 113 164]

Questioned or mistaken criteria of DMC

Contrary to category (2) 'Criteria of DMC', where authors presented supposedly valid criteria for DMC, a plethora of studies explicitly flagged various criteria for DMC in birth as either questionable or mistaken. From an ethical and legal perspective, it is clear that the following criteria do not eo ipso translate into a lack of DMC on the part of a birthing person. Nevertheless, these criteria are prevalent in the literature, prompting several authors to refute the respective claims.

As such, the mere presence of one of the following instances does not mean a person lacks DMC: refusal of recommended care (including risking own or fetal health)[117 145 176–178]; perceived unreasonableness (eg, unpredictability, irrationality, making unwise decisions, indecisiveness, making a decision based on irrational or no apparent reason, religious motivations, foolishness)[90 96 133 177 179]; exceptional states during birth (eg, pain, emotional stress, fear, panic, fatigue)[44 126 147 174 180]; the birthing process as such[109 161 168 181 182]; a certain age[79 89 153 180 183]; psychiatric diagnoses[131 153 164 172 183]; emergency situations[77 108 158 170 184]; changing one's mind during the course of birth (eg, regarding pain relief or mode of delivery)[89 108 170 175]; a lack of medical expertise[45 105 121 126 153]; the use of substances and medication (eg, opioids, alcohol, sedatives, drugs)[104 113 170 180 183]; seeking assistance or support (eg, finding a decision hard to make, consulting others, making special requests)[130 180]; a perceived inappropriate appearance or behaviour (eg, expressions of anger or high body mass index)[183 185]; a low level of formal education[77 104 180]; disability[105 183] or other legal concepts (eg, capacity to conclude contracts).[45 79]

DISCUSSION

To date, no literature synthesis has addressed the conceptualisation of DMC in the specific context of birth. Spanning seven categories, this scoping review provides a comprehensive synthesis of conceptual perspectives on DMC in birth. In particular, it revealed the existing default assumptions regarding DMC in birth, criteria for its assessment, limiting and enhancing factors of DMC in birth, as well as population-specific and meta-conceptualisations. The review not only demonstrates that there are conceptual inconsistencies, but also suggests that these are likely to translate into clinical practice. In the following discussion of our main findings, we first address general characteristics of the final set of included studies, before we set on to discuss our findings through the lens of epistemic injustice. We then address various areas of controversy regarding the conceptualisation of DMC in birth, and show how the latter abet disenfranchising care and negative birth experiences. Lastly, we touch on the question of DMC as a culturally bound concept.

General characteristics of included studies

The final set of 121 included studies originated predominantly from Western high-income countries, which could point to—besides language-related selection effects and more resources allocated to research in these countries—DMC being primarily a Western concept. Also, most studies were ethical/philosophical analyses, legal analyses, or medical-ethical recommendations, hinting to the nature of the concept of DMC as an empirical-normative hybrid.[58] Both our review findings[127] and additional empirical evidence[44] indicate that rights violations in birth often stem from widely held misconceptions about birthing people's DMC in general. In light of this, a disproportionately high number of studies in our review focused on specific cases in which DMC is questioned (eg, C-sections, court-ordered C-sections, psychiatric disorders). This misalignment risks diverting attention from a general conceptual discussion of DMC in birth, which is largely absent, or, to put it the other way around, risks falsely suggesting that DMC in birth is uncontroversial. In fact, it has been argued that birthing people are in an altered psycho-physical state during birth, so-called birthing consciousness.[121 186] Surprisingly, our review indicates that the question of what birthing consciousness means for the operationalisation and assessment of DMC in birth and what normative implications follow from it has not been addressed, let alone solved. Yet, irrespective of these conceptual shortcomings, there is a strong legal presumption for DMC in general. Therefore, also for birthing people, DMC is legally presumed until the opposite is proven and documented. The burden of proof lies with the provider. However, our scoping review reveals a gap between this rather favourable and protective legal framework (with a strong presumption of DMC) in many countries and empirical findings reported in the literature.

Through the lens of epistemic injustice

Not only persons, institutions or collective agents, but also theoretical concepts can be legitimately described as epistemically unjust.[187 188] As revealed by our review, current conceptualisations of DMC in birth represent various forms of epistemic injustice. For example, most studies build on a limited range of hermeneutical resources when conceptualising DMC,[105 108 118 151] which privileges certain dimensions (such as cognitive aspects, rationality and reasoning) mostly from the biomedical sciences and individualistic cognitivist understandings of autonomy. This tendency simultaneously disregards alternative dimensions (such as embodied knowledge, intuition and relationality) often developed outside biomedical frameworks and informed by feminist perspectives on autonomy.[187 189] Moreover, birthing people—particularly, historically marginalised populations such as people diagnosed with psychiatric diseases who were most frequently discussed in the literature[162 164 173 175]—are vulnerable to harms arising from epistemically unjust conceptualisation of DMC in birth. These conceptualisations contribute to the pervasive assumption that birthing people lack DMC, a presumption that legitimises unjust practices and contributes to the routine violation of reproductive rights during birth.[44 187]

Applying Jordan's idea of authoritative knowledge further illuminates these dynamics: In the context of DMC in birth, certain knowledge systems appear to be authoritative, meaning that despite the existence of other legitimate, parallel knowledge systems they are accorded greater epistemic weight and carry a stronger power base.[190 191] These dominant knowledge systems are mainly structured and produced by disciplines traditionally shaped by a male gaze on—primarily—women's

bodies (eg, medicine, philosophy, law). Correspondingly, our review identified numerous mistaken and misapplied criteria for DMC in birth which oppress and constrain birthing people—for example, interpreting the mere refusal of recommended care or a (seemingly) unreasonable choice as evidence of incapacity.[114 159 172 173] The underlying patriarchal expectations of conformity and associated provider attempts to justify coercive measures through the ascription of incapacity are specifically directed towards the birthing person and highly prevalent in the perinatal context.[171 192] Against the described background of epistemic obstacles, gender-based misconceptions, and medical authority, the current conceptualisation of DMC must be regarded as a structural injustice. In an otherwise identical situation, it would be considerably more difficult to imagine that a birth companion or provider would be deemed to lack DMC merely for disagreeing with recommended care or making a perceived 'unreasonable choice.'

Conceptual controversies in need of clarification

The included literature highlights various areas of controversy for which a clarification or reconceptualisation should be considered to do more justice to birthing people's DMC. Most prominently, this concerns the question of a possible broadening of DMC in birth to extend the conceptualisation beyond cognition and reasoning by including alternative aspects, such as embodied knowledge, intuition, relational aspects, somatic aspects, emotions and experiential aspects.[101 110–113] Such reconceptualisations have been proposed in other areas, for example in the paediatric setting, for which Ruhe and colleagues proposed relational DMC.[49] Relational DMC shifts away the focus from the individual to include significant social others. Such an approach would be in line with relational understandings of autonomy articulated by feminist scholars (ie, relational autonomy).[42 189] However, unlike most legislations that deem children to lack DMC, birthing people are presumed to possess it. Any potential broadening or reconceptualisation of DMC thus requires careful scrutiny to avoid reinforcing misconceptions of birthing people generally lacking DMC or to prevent the premature transfer of decision-making authority to designated representatives.

Furthermore, a frequently discussed point of debate of current DMC conceptualisations lies in their applicability to real world healthcare settings, especially the birth context. Here, it is argued that DMC actually fluctuates and that there are in-between spaces.[99 162 173] Hence, in the included literature, the binary conceptualisation of DMC is questioned,[104 162 173] and a continuum model is proposed.[82 103 162] At the same time, while possibly being more adequate for birthing people, such a reconceptualisation would conflict with the prevailing binary framework for legal competence, which also is an all-or-nothing concept.[99 162 173] Again, the binary nature of legal competence should not obscure the general presumption of DMC: 'all' and 'nothing' are not equally likely, but the former is the case most often and the latter occurs very rarely. Moreover, our review identified internal and, to a smaller extent, external factors determining DMC. This raises the question whether the concept of DMC encompasses external circumstances.[193] The inclusion of external limiting factors—such as the absence of interpreter services or a loud and hectic labour ward—into the conceptualisation of DMC should, however, be critically examined. While such factors could provide substantial leverage and responsibility for institutional and structural improvements to enable birthing people to have DMC, it could conversely also be misused as a means of rendering birthing people as 'more incapable'. In the literature, another controversially discussed aspect of current DMC conceptualisations is the issue of risk-sensitivity, namely, whether higher-risk situations warrant higher DMC[99 103 118] and, if so, whether this raises the DMC threshold (ie, substantive risk-sensitivity) or the requirement for evidence of DMC (ie, epistemic risk-sensitivity).[113]

Lastly, the synthesised literature was also inconclusive regarding the so-called procedural account of DMC.[51] While most positions endorsed this account, according to which assessment of DMC should be based on the process by which a decision is reached and should disregard a decision's reasonableness as a criterion, various studies, as well as many provided insights into clinical practice demonstrated that reasonableness as perceived by providers is in fact a widely applied criterion. In a similar vein, so-called substantive accounts of DMC do not predicate DMC on mental abilities determining decision-making but on values and beliefs informing the decision.[51] In an attempt to reconcile both procedural and substantive accounts, Banner proposes 'recognisable reasons' as a practical way of incorporating both procedural and substantive elements of decision-making into assessments of DMC.[51] It could be worthwhile to evaluate the applicability of this approach to birthing people, especially in light of the difficulties of assessing DMC in birth due to the above-mentioned conceptual controversies as well as due to numerous birth-related factors. For those birthing people who are in fact at the margin of DMC, the approach of supported decision-making could be employed to safeguard autonomy to the greatest possible extent.[194]

Disenfranchising care as a result of conceptual controversies

DMC is legally presumed and burden of proof of incapacity lies on the provider. For these rare instances of DMC assessment, DMC has to be empirically observable and criteria have to be defined to invalidate the presumption of DMC and to prove that a person does not have DMC. While some extent of subjectivity is still inherent to any clinical assessment of DMC, those criteria ideally ensure sufficiently reliable interassessor-agreement minimising the risk of discrimination. Yet, the operationalisation and criteria-based assessment of DMC has not only direct legal consequences for the birthing person but

also conceptual antecedents with normative implications. That is, before its application in clinical practice someone had to define these criteria: thereby, at least in cases of binary conceptualisations, inevitably drawing a demarcation line between DMC and no DMC. The latter questions are questions of power. The conceptual inconsistencies and controversies excavated by our review, however, are likely to translate into an inconsistent application and assessment in clinical practice, ultimately harming and disenfranchising birthing people. As indicated by the identified mistaken or questioned criteria, this situation opens the door for a gendered and discriminatory use of DMC in birth, particularly towards, for example, birthing people diagnosed with mental disorders or intellectual disabilities, impoverished birthing people or racialised birthing people or those disagreeing with the care path recommended by providers. Applying DMC discriminatorily in birth raises additional legal questions related to anti-discrimination law, equal protection principles or the Convention on the Elimination of All Forms of Discrimination Against Women.[23] To conclude, DMC can be and is being used as a tool of power oppressing birthing people, particularly if there is conceptual incoherence (that leads to inconsistent assessments and an unjust application in practice) and particularly towards historically marginalised populations (that are—mistakenly—deemed to lack DMC). DMC is not a 'soft' concept that can be applied on providers' discretion and, if deemed necessary by the latter, to (unjustly) assert recommended care. In contrast, from an ethicolegal perspective, DMC determines competence with DMC as the default assumption. The legal concept competence, in turn, is a rigid and binary model supposed to function as a gatekeeper—not a stumbling block—for birthing people's autonomy.[195] Related to this, it is paramount that professional guidelines and legal standards clarify how DMC has to be assessed and what has to be documented.

There seems to be a contradiction between, on the one hand, the expectation that birthing people should be prepared for birth, ask questions and make informed choices, and, on the other hand, the likelihood of such behaviour to be interpreted as a refusal of recommended care—then, as shown by our findings—resulting in disenfranchising care and an instrumental ascription of incapacity in birth. Such contradictory experiences may result in feelings of ambivalence, negative and sometimes even traumatic birth experiences.[27 110] In fact, over the last decade, mistreatment in birth has gained global attention. In response, the WHO explicitly advocates for a human rights-based approach.[22] Yet, numerous studies bear witness to persistent mistreatment, violence and abuse in birth, disproportionately affecting historically marginalised groups (eg, racialised people, immigrants, people with high BMI, those with low economic or educational status, LGBTQ+ people).[1 2 7] The latter oftentimes are related to widely held misconceptions about birthing people's DMC in general.[44 127] Our review identified normative as well as various mistaken or questioned criteria of DMC in birth. This demonstrates that DMC indeed is a normative concept,[58] frequently being used as a tool of medical, political and cultural power,[171 192] which often results in rights violations and negative birth experiences.

DMC as a culturally bound concept

Lastly, geographical distribution of included studies' countries of origin suggests that DMC in birth is a culturally bound concept. The great majority of studies came from Western countries (95%; other origins: Turkey, India, Uganda, Nigeria, China, Colombia). In fact, individual autonomy is seen as a key principle in contemporary Western bioethics.[196 197] Other cultures, for example Turkey's, were shown to place less value on individual autonomy and instead to be more community-oriented.[198] Similarly, Chinese bioethics is characterised by an emphasis on family-oriented autonomy, which means families not individual patients mainly give IC.[199] These examples illustrate that, if the overarching principle of respect for individual autonomy is not as emphatically shared as in Western countries, associated principles (eg, IC) and concepts (eg, DMC) are not as significant either. On the contrary, in other cultures, notions of family-based or community-based autonomy are applied and hence DMC as an inherently individualist concept is rendered obsolete. Still, a few studies included in our review[110 113] and other authors have proposed to reconceptualise DMC by including relational aspects.[19 49 57] Along the same lines, Tömmel pleads for a relationship-based implementation of self-determination in birth through assisted decision-making by a person of one's own choice.[200] Also, numerous studies in our review described external factors determining DMC,[89 99 127] possibly including familial and community-related factors. It should be examined to what extent such a broadened understanding of DMC and external factors impacting on DMC could facilitate the integration of ideas of individual autonomy and of family-autonomy. However, none of the included studies has generally questioned or denied the concept of DMC in light of cross-cultural analyses. Lastly, jurisdictional boundaries and diversities need to be acknowledged. DMC conceptualisations including DMC thresholds, burden of proof regarding DMC or default assumptions may differ across jurisdictions.

Limitations

Language restrictions might have limited the results of our search, possibly causing us to miss relevant literature written in other languages. Hence, the transferability of our results to other contexts needs to be examined with caution. Moreover, the fact that DMC is primarily a Western concept in and of itself is a limitation in light of global bioethics initiatives and attempts to decolonise bioethics. Nevertheless, our findings can serve as starting points for dialogue between and integration of diverse bioethical traditions.

CONCLUSIONS

Our findings show that, in spite of various factors rendering the intrapartum period a unique decision-making context, only a very limited number of studies take on the task of conceptualising DMC specifically for birth. Moreover, at a conceptual level, no universally shared consensus regarding DMC in birth exists, and, at a practical level, this ties in with various forms of injustices experienced by birthing people. Since conceptualising DMC is a question of power and birthing people by virtue of their position in research and medicine are unlikely to be part of the respective knowledge-producing communities, for the time being it is crucial to insist that DMC of birthing people is legally presumed until proven and documented otherwise, and to critically reflect on the prevailing (mis)conceptions about birthing people. In conclusion, establishing epistemic justice throughout the process of conceptualising DMC in birth is a prerequisite for advancing reproductive rights and improving birth experiences.

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