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Children's assent within clinical care: A concept analysis

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Abstract

Seeking children's assent has been put forward as a way to foster children's involvement in the healthcare decision-making process. However, the functions of the concept of assent within clinical care are manifold, and methods used to recognize children's capacities and promote their involvement in their care remain debated. We performed an instrumentalist concept analysis of assent, with 58 included articles. Final themes were jointly identified through a deliberative process. Two distinct perspectives of assent were predominant: as an affirmative agreement for a specific decision and as part of a continuous, interactive process of care. Differing standards were provided as to how and when to apply the concept of assent. The concept of dissent was largely omitted from conceptions of assent, especially in situations for which children's refusal would lead to severe health consequences. Ethical implications included fostering autonomy, reducing physical/psychological harm to the child, respecting the child as a human being, and fulfilling the universal rights of the child. There remain important gaps in the theory of assent and its desirable and possible practical implications. Practical standards are largely missing, and evidence supporting the claims made in the literature requires further investigation.

Keywords

Assent, children, concept analysis, health care, patient engagement

Introduction

In research with children, the concept of assent is the current standard to involve children in the consent process (Canadian Institutes of Health Research et al., 2018). This concept allows for children's recognition as agents who can take part in decision-making, while taking into account their legal inability to provide informed consent. Most research on children's assent addresses this

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concept in research ethics. However, within the past 25 years, there has been growing international recognition that the concept of assent has the potential to improve practices when used within clinical care (Katz et al., 2016; Koelch and Fegert, 2010; Olszewski and Goldkind, 2018; Self et al., 2017).

Indeed, pediatric associations have argued that children should participate in their health care (e.g. Committee on Bioethics [CB], 2016), although they disagree in which forms and to what extent (Kurz et al., 2006). Children's involvement in health care has been reported to have several positive ethical impacts (Belitz and Bailey, 2009; Leikin, 1983). Notably, children's engagement in the care process contributes to develop their self-determination (Self et al., 2017). Conversely, if healthcare providers do not include children in the care process, opportunities to develop their decision-making capacities, essential skills to navigate the healthcare system, can be impacted (Deatrick et al., 1990). Explanations of the absence of children's involvement in decision-making include the need to proceed with treatment quickly, healthcare providers' lack of time, and the pressure exercised by parents to have their opinion concerning their child's health prevail (Koshy and Sisti, 2015).

In the United States, criteria recognized by the American Academy of Pediatrics (AAP) have been established for children's involvement in decision-making based on the concept of children's assent (Bartholome, 1995; Committee on Bioethics [CB], 2016). These criteria are presented as allowing for practitioners to adopt more collaborative practices with children and parents (Kurz et al., 2006). However, studies keep highlighting that the concept of assent is often misunderstood, unknown, or used without a defined standard by clinicians (Deatrick et al., 1990; Grootens-Wiegers et al., 2018; Koshy and Sisti, 2015; Pate, 2013; Self et al., 2017). Researchers who have conducted studies related to child assent within clinical care advocate for patient involvement in health care and show the benefits of this collaboration between clinicians, parents, and children, but they do not agree on the meaning or application of child assent (Adams and Levy, 2017; Angst and Deatrick, 1996; Coyne, 2008).

Aim

The primary aim was to analyze the characteristics, meaning, application, and implications of the concept of assent within clinical care (i.e. its functions). The secondary aim was to inquire whether assent could be used in clinical practice as a way to recognize and foster children's capacities as active moral agents and promote their involvement in their care.

Methods

To conduct this analysis, an instrumentalist concept analysis approach was used (Racine et al., 2019). Instrumentalist concept analyses attempt to identify the functions served by a given concept (and surrogate or related concepts) to then enrich the concept based on stakeholder perspectives and subsequently evaluate the impact of that enriched concept (Racine et al., 2019). We report here on the identification of the functions of the concept of children's assent in clinical care, with an emphasis on its ethical functions to foster (or not) children's capacities as active moral agents. The term *function* refers to how the concept is operationalized in practice. The functions include the qualities or features that belong to a concept and make it recognizable (i.e. meaning and characteristics), its goals and its implications within a particular context, as well as what leads to its use

(Racine et al., 2019). Further, we applied an interpretive approach to concept analysis (Rodgers, 2000) to identify the functions of assent as described in the literature.

The term *children* is used here to refer to persons below 18 years old (United Nations Convention of the Rights of the Child, 1989). By *active moral agents*, we refer to the view of children as having the capacity to be fully involved in matters that affect them, including in expressing what they consider as good–bad, right–wrong, and just–unjust (James and Prout, 2015; Montreuil and Carnevale (2016)).

Article sample

Searches were performed using the following terms: child, pediatrics, dissent, patient involvement, professional practice, and patient engagement in MEDLINE and CINAHL (as per CINHAL/MeSH headings) and assent as a keyword since it is not a term listed in these two primary health-related databases. An iterative process was followed in which new terms that came up during article searches and data charting were included to provide a richer understanding of the concept of interest. Therefore, related and surrogate terms were also included in the searches, to take into account other ways children could be included in healthcare decisions and strategies that might be named differently, while sharing similarities with the concept of assent (Rodgers, 2000). We additionally performed ancestry and offspring searches through Google Scholar, including identification of relevant gray literature through this process as well as online searches through Google, using the terms above from database searches.

Article screening

For article screening, duplicates were removed, and articles were screened for relevance using titles and abstracts in the web-based application (Rayyan) (Ouzzani et al., 2016). Screening was based on the following inclusion and exclusion criteria: (1) the article is on children's assent or presents a surrogate or related term that might share the meaning and functions of assent (i.e. pertaining to children's involvement in their care); (2) all years of publication were included, to identify when the concept has emerged and to permit the analysis of historical trends if present; (3) published in English or French; (4) and related to clinical care, services, and/or practices. Two team members independently performed the article screening.

Data charting

At first, full reading of each article was performed. Data from each article were charted in an Excel worksheet, including basic descriptive data about the article and the functions of the concept, including its definition, characteristics, meaning, justifications for its use, context of application, and implications (see Supplementary File 1). Questions were guided by an instrumentalist approach (Racine et al., 2019). A second reading was then performed to refine the initial data collected.

Data analysis

A descriptive analysis was conducted to offer an overview of the included articles based on publication year, countries where the authors were affiliated, and the discipline of their main academic affiliation. An inductive analysis was then performed to identify similarities and differences in given definitions, characteristics, meanings, and functions of the concept based on the

data from the functional analysis section in the Excel table. Two team members independently performed the analysis and then compared the results. Definitions were thematically grouped according to characteristics, meanings, and functions of the concept in different overarching and cohesive perspectives (across themes), which were jointly identified through a deliberative process consistent with an instrumentalist conceptual analysis (Racine et al., 2019). Each perspective was examined to identify contextual or historical trends based on years of publication, authors' country and disciplinary affiliation, context of application, justifications of the use of the concept, and implications of assent for each perspective. However, for the context, justifications, and implications, there were several similarities that cut across the perspectives; these findings are therefore presented for all the included articles as a whole.

Results

In total, 58 articles were included in the analysis (see Figure 1). Nine of the included articles did not indicate explicit characteristics or features of assent; and 14 did not provide a specific definition or referred to an existing definition of assent. These articles however provided other relevant information (e.g. justification for its use or context of application) and were therefore included in the review. We identified the most salient examples to support each point, and included the full list of articles and references in Supplementary File 2.

Descriptive overview

Thirty-nine of the included articles were from the United States, 11 from European countries, 2 from India, 1 from Australia, 1 from Canada, 1 from Israel, and 1 from South Africa. Although all authors had affiliations within the field of child health, some specific disciplines were more prevalent, such as bioethics (13) and nursing (9).

Functional analysis

We first present two predominant perspectives that were identified, followed by the joint analysis of the context of application and clinical/ethical justifications and implications.

Predominant perspectives. Based on the analysis of the definitions, characteristics, meanings, and functions, two cohesive and overarching perspectives on assent coexisting across time were identified: (1) assent as an agreement for a specific decision and (2) assent as part of a continuous, interactive, process of care. We present the two perspectives including results of the application of the concept per perspective. The general recommendation to involve children in their care was present across time—from articles of 1980s to today—with conceptual/theoretical articles emphasizing the lack of clear guidelines as to how to involve children in their care. No historical trends were noted in the analysis as to the evolution of the meaning of the concept.

Assent as an affirmative agreement for a specific decision. The concept of assent was defined as obtaining an affirmative agreement from the child to participate before proceeding to a treatment or procedure in 18 articles (e.g. Beidler and Dickey, 2001; Bricher, 2000; Committee on Bioethics [CB], 2016). This agreement could be expressed in several ways, including a head nod, a formal signature on an assent document, or saying "yes" to a proposed treatment or procedure. It is not

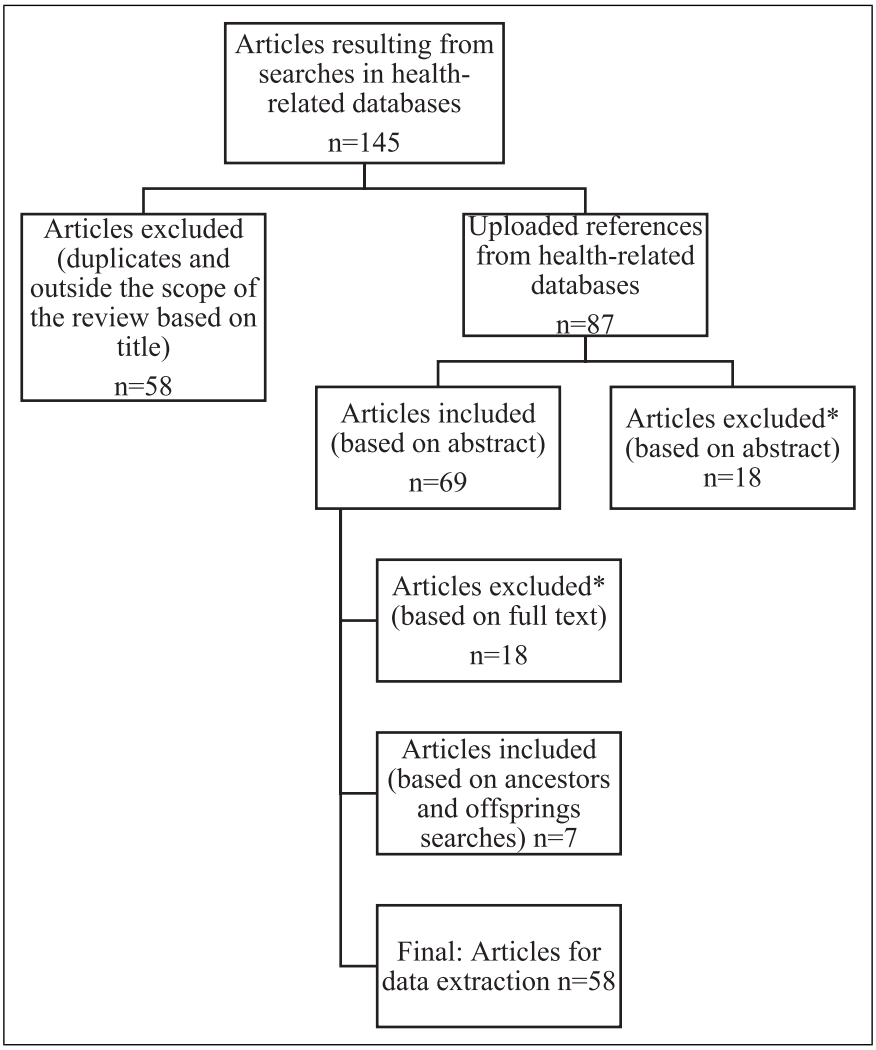

Figure 1. Flow chart. *Note.* Reasons for exclusion (n = 36): assent in research (n = 15), wrong topic (n = 7), duplicate (n = 4), wrong population (n = 3), language other than English or French (n = 2), and article is an abstract only (n = 4).

a binding contract between the child and clinician, but a way to obtain the child's acquiescence or agreement (Pate, 2013).

Certain authors mentioned that assent does not require that the child understand the treatment or what exactly they are being asked. In contrast, other authors considered that enough information should be given to the child so that they can understand what they are being asked, based on their capacity to contribute to decisions about their health. If children express agreement after the information has been shared, it is interpreted as representing assent (Erlen, 1987; Reynolds et al., 2017). This perspective was present in articles from the United States, Australia, India, Sweden, and

Portugal. Eight articles mentioned that school-aged children should be asked for their assent, while the other 10 articles did not specify any age at which to consider assent.

We identified two empirical studies that defined assent as an affirmative agreement, which provide some insight into its actual use in clinical practice. Hallström and Elander (2004) showed that the norm in child health care was largely to exclude children (and parents) from health-related decisions and children and their parents were expected to follow decisions previously made by clinicians. This view aligns with certain authors who posit that children should not be involved in decisions related to their health until they reach the age of majority, as stated by their country's law (e.g. Levy et al., 2003).

The other empirical study sheds light on the discrepancy between the theoretical model of assent proposed by the American Academy of Pediatrics (AAP) and what is seen in medical practice (Lee et al., 2006). The AAP Committee on Bioethics has put forth a guideline for the concept of assent (Committee on Bioethics [CB], 2016). This guideline supports that assent can "help the patient to achieve a developmentally appropriate awareness of the nature of their condition." Clinicians are expected to "tell the patient what they can expect with tests and treatments, make a clinical assessment of the patient's understanding of the situation and the factors influencing how they are responding (including whether there is inappropriate pressure to accept testing or therapy), and solicit an expression of the patient's willingness to accept the proposed care" (Committee on Bioethics [CB], 2016: 2). The study results show that there was a significant lack of knowledge concerning the concept of assent and a reluctance to involve children in the decision-making process, especially among medical specialists (Lee et al., 2006). In 2016, the guideline from the AAP was updated and now includes a statement that children's participation should align with their development and that children "should provide assent to care whenever reasonable" (Committee on Bioethics [CB], 2016: 1). This last aspect includes not asking for the child's assent if a specific decision has already been made by the parents and clinicians. In this case, clinicians should mention to children that this decision has been made and seek children's involvement in certain aspects of care.

Assent as part of a continuous, interactive, process of care. Assent was defined in 14 articles as a continuous, interactive process throughout the child's care, rather than an agreement for specific decisions. In these articles, the child was presented as a stakeholder, in reference to being actively included alongside their parents and the healthcare team in the care process, including decision-making. Assent became an interactive process between the child, family members, and healthcare providers to arrive at decisions together in a continuous manner.

Some of the surrogate terms to "assent," such as "shared-decision making" (Adams and Levy, 2017; Koshy and Sisti, 2015), "collaborative decision-making" (Miller, 2009), and "decision-making involvement" (Angst and Deatrick, 1996; Miller and Harris, 2012), shared the same definition as assent when defined as a continuous, interactive process. In half of these articles, the concept of assent (or surrogate terms) was presented as requiring personalization and adaptation to each individual child's needs. Certain authors highlighted the relationship between the clinician and the child (Adams and Levy, 2017; Koshy and Sisti, 2015), whereas others also included the parents as stakeholders (Angst and Deatrick, 1996; Miller, 2009; Miller and Harris, 2012; Miller and Jawad, 2014). Children were presented as having to be respected, having the right to dissent, and requiring information adapted to their level of understanding (Olszewski and Goldkind, 2018). Different strategies were provided to facilitate children's involvement, such as breaking down the decision-making process into smaller steps, asking simpler questions, and offering options (Miller and Harris, 2012; Olszewski and Goldkind, 2018).

Four empirical studies from the United States were conducted in which assent was described as a continuous process. The results of a study by Angst and Deatrick (1996) showed that children with cystic fibrosis, who receive long-term treatment and hospitalization, felt that they were ignored, had unanswered questions about their health, and that the majority would have preferred to be included more in decisions related to their health. The clinicians' focus was on the negative consequences of shared decision-making and an emphasis was put on the child possibly dying if not assenting to care. In contrast, children with scoliosis, who have a shorter hospital stay and typically one course of treatment, generally felt that they were included and that clinicians focused on positive aspects of shared decision-making. Some implications of children and parents' continuous involvement in their care included having a positive impact on the child's health (Miller, 2009; Miller and Jawad, 2014) and contributing to develop their independence (Miller and Harris, 2012).

Context of application. There was a lack of consensus on when it is appropriate to apply the concept of assent, with no trend identified according to the perspectives. One of the criteria mentioned was the *age of the child*, which varied between articles: some authors claimed that children are able to provide assent by the age of seven (e.g. Erlen, 1987) or nine years (Bartholome, 1989; Beidler and Dickey, 2001; Committee on Bioethics [CB], 2016), whereas others considered it can only be applied to adolescents or those having reached the age of majority (e.g. Belitz and Bailey, 2009). Another criterion is the *child's understanding*, taking into account a child's ability to understand and analyze the consequences of their decisions and express their own choices (e.g. Ruhe et al., 2016). Similarly, the child's cognitive skills were described by certain authors as having to reach a certain threshold based on clinical tools for assent to apply (e.g. Michaud et al., 2015) or for the child to have reached a certain level on Piaget's theory of cognitive development (Beidler and Dickey, 2001; Erlen, 1987; Leikin, 1983). Certain authors mentioned the child's *competence* as a criterion to apply assent, as evaluated by clinicians (Levy et al., 2003). Another criterion mentioned was the child's *decision-making capacity*, which informs the extent to which children can participate in decisions related to their health (Miller, 2009; Olszewski and Goldkind, 2018; Opel, 2017; Ross, 1997).

Justifications and implications. Clinical and ethical justifications, as well as implications of using the concept of assent were explicitly mentioned in certain articles, while inferred in others. In the latter case, we interpreted its implications based on the entirety of the article.

Clinical justifications and implications. The main implication of using assent was on the relationship between the child and clinician, reported in all articles. Using assent was described for instance as contributing to the maintenance of a good relationship and close communication (e.g. Hallström and Elander, 2004; Lee et al., 2006; Olszewski and Goldkind, 2018). Mårtenson and Fägerskiöld mentioned that the purpose of applying assent was to show children that collaboration is desired between them and clinicians (2008). Other authors considered that applying the concept of assent to child health care is intended to give children a voice in their hospitalization (Alderson, 2007; Bricher, 2000).

However, certain challenges were highlighted that prevented its clinical application. For instance, the decision-making skills of the child were questioned and/or minimized when they expressed dissent (e.g. Bartholome, 1989; Koshy and Sisti, 2015). Moreover, the more serious the illness, the more clinicians were reluctant to include the child (e.g. Adams and Levy, 2017; Angst and Deatrick, 1996). The differences in how the concept was defined could also lead to differing interpretations from clinicians and discrepancies in its application (Koshy and Sisti, 2015). It was also a challenge when the decision of the clinician went against that of the family, especially when

there are differences in opinions, values, and understandings (Adams and Levy, 2017; Angst and Deatrick, 1996).

Ethical justifications and implications. Ethical justifications or implications—referring to ethical principles or values that were mentioned in the articles as resulting from the concept of assent—were identified in 43 articles.

The principle of autonomy was mentioned by many authors as being fostered by the application of assent. These authors highlighted that using assent acts as a recognition of children's gradual development into independent, autonomous patients (e.g. Adams and Levy, 2017; Angst and Deatrick, 1996; Ross, 1997). Some authors added that using assent helps children to develop their abilities, which contribute to fulfill the principle of autonomy (e.g. Bray et al., 2018).

In four articles, application of the concept of assent was linked to reductions in physical or psychological harms to the child (Adams and Levy, 2017; Leikin, 1983; Levy et al., 2003; Pate, 2013). Application of this concept may allow a child to feel less psychological pain, which increases well-being (Adams and Levy, 2017), as well as reduces fear (Pate, 2013) or stress (Leikin, 1983). It was described as allowing the child to be prepared for the uncomfortable effects of the treatment or procedure (Leikin, 1983).

Another principle was the respect of the child as a human being in the healthcare context (e.g. Alderson, 2007; Bartholome, 1989). For example, Beidler and Dickey (2001) mentioned that the principle of respect includes taking into consideration the values and preferences of the child, which shows that children are valued by clinicians as human beings (vs objects of care). Other authors described assent as a way to recognize children as moral agents (e.g. Alderson, 2007; Bester et al., 2018).

Ten authors mentioned that the concept of assent contributes to fulfill the legal and universal rights of the child, such as the right to self-determination (Beidler and Dickey, 2001; Erlen, 1987; Levy et al., 2003), to inclusion in decision-making (Committee on Bioethics [CB], 2016), and the authority to express their opinion without limits (Coyne, 2008).

Related terms. Certain terms including *competence* and *decision-making capacity* were closely related to assent, but required that the children have sufficient autonomy to fully understand the situation at hand and make their own health-related decisions. These terms often inferred the capacity to consent.

Dissent was a contrary term to assent. Dissent refers to situations in which the child temporarily refuses or withholds from any kind of treatment or procedure (Bartholome, 1989) or when the child, parents, and clinicians disagree on a course of action (Erlen, 1987). In certain articles, the concept of dissent was not included in the concept of assent: for these authors, children have the ability to agree with treatment or care but not to disagree (e.g. Hallström and Elander, 2004).

Discussion

Our main aim was to clarify the characteristics, meaning, application, and implications of the concept of assent within clinical care. The clinical application of the concept of assent has been discussed in the literature for almost 40 years, with different perspectives on its definition and use in practice. The two predominant perspectives identified—assent as an agreement and assent as an interactive, continuous process—reflect differences in its conceptualization and clinical application and currently coexist in the literature. Conversely, the definition of assent in research shows more

consistency and clarity in its application, even if some discrepancies persist (Crane and Broome, 2017).

The concept of assent appears to serve the intended function within research of allowing the child to agree or refuse to participate. Dissent or objection is a part of the assent process within research (Canadian Institutes of Health Research et al., 2018) but appeared problematic in the clinical context. This is perhaps due to the much more optional nature of research participation in contrast to clinical care which is intended to benefit the child directly and for important health reasons. The concept of dissent was largely omitted from conceptions of assent within clinical care, as what was sought was more agreement with a preestablished decision, especially in situations for which children's refusal would lead to severe health consequences. The definition of assent therefore differed from the one used in research to allow for a form of protection in cases in which a particular treatment or procedure would be deemed in the child's best interest by the healthcare team.

The two perspectives identified reflected differing outlooks on children and childhood. For instance, the perspective of assent as an agreement largely referred to developmental psychology as a framework to identify children's level of involvement in the decision-making process. There was often a certain age at which children were considered as having the ability to fully participate to decisions. In contrast, in the perspective of assent as a continuous process, authors tended to view children as active participants irrespective of their age. Children were then included throughout the decision-making process, to a different extent depending on the level of severity of the illness (instead of on their age). This difference in outlooks related to children reflects current debates within childhood studies, ranging from authors viewing children as incomplete beings who cannot actively take part in matters that affect them, to a view of children as active agents who should be continuously involved (James and Prout, 2015; Montreuil and Carnevale, 2016; Spencer, 2000). Adopting the latter view of children as active agents leads to a conceptualization of assent as a continuous process in which children are involved throughout the decision-making process.

Assent in clinical practice

Our secondary objective was to inquire whether assent could be used in clinical practice as a way to recognize and foster children's capacities as active moral agents and promote their involvement in their care. Independent of the perspective, about half of the articles mentioned beneficial outcomes resulting from the concept of assent's clinical use. The different clinical and ethical implications reported could also be affected by the outlook adopted in relation to children and clinicians' values. For example, collaboration between children and clinicians has been reported as resulting from the application of assent, as well as the recognition of children as full human beings. This outlook could therefore become both a criterion preceding and resulting from the use of assent. Further research would however be required to investigate the implications of the concept of assent from children's perspective, as is done in research (Crane and Broome, 2017).

Many of the authors who viewed children as active agents also used other terms to refer to assent, such as shared decision-making. This concept could be used as a surrogate term for assent, in reference to a continuous involvement of children within the decision-making process. It could also be used as a related term, as it emphasized the involvement of other stakeholders, primarily parents, which the concept of assent did not always capture. Within research, assent is more specific to the child and refers to an affirmative agreement (or disagreement) (Canadian Institutes of Health Research et al., 2018). Parents can play a role in the assent process, for example, to explain a study or assist the child in making a decision, but assent rests with the child (Sibley et al., 2016). As seen in

the results above, within clinical practice, assent is not always sought when children are considered as too young or when their condition is severe.

In light of our results, the term shared decision-making might better capture the shared nature of the decision-making process within clinical care, especially for the perspective of assent as a continuous, interactive process. The term shared decision-making is increasingly used with adults (Bomhof-Roordink et al., 2019) and recently began to be used with children (Boland et al., 2019; Coyne and Harder, 2011; Wyatt et al., 2015). Studying the use of this term in child health care could be pertinent to clinicians who seek a collaborative partnership in contrast to an agreement to a preestablished decision. Asking children directly would be especially informative to understand how they perceive their involvement.

Limitations

Very few empirical studies have been conducted on the concept of assent's application; most reported implications were anecdotally shared by the authors or inferred, thus hindering our ability to extract this information from the articles. Both conceptual/theoretical articles and empirical studies were therefore included; however, dissertations and books were excluded. Accordingly, a quality appraisal tool was not used for this review. Searches were performed in two databases related to health research, which could have prevented the identification of articles from other fields addressing this concept. Moreover, the information related to the concept of assent's meaning was not always elaborated on by the authors, which prevented a detailed analysis. More research on clinicians' perspectives and experiences related to children's assent could help to address this limitation of the current literature.

Implications for practice

Applying the concept of assent to clinical practice could contribute to recognize children's capacity as active moral agents. However, this analysis shows that there are different perspectives as to how to apply this concept: one of which perceives assent as an affirmative agreement from the child (in which case children's involvement in decision-making is limited and their agency might not be fully recognized) and the other in which assent is seen as a continuous, interactive process wherein children are actively included alongside their parents and the healthcare team in the care process, including decision-making. This inclusion of children in the decision-making process has the potential to foster children's autonomy, reduce physical and psychological harm, acknowledge children as human beings (in contrast to objects of care), and uphold children's rights.

Not all the authors perceived dissent as being part of the concept of assent, but dissent appears important to fulfill the function of fostering children's inclusion (from their perspective). For healthcare providers, this could imply to conceptualize assent differently—that is, as more than acquiescence or agreement for a preestablished decision—to allow for an interaction or a dialogue between children (their parents) and healthcare providers in which dissent could be addressed.

Conclusion

Through this concept analysis of 58 articles, the concept of assent was analyzed within clinical care to highlight its characteristics, meaning, application, and implications, as well as discuss how it can

foster (or not) children's involvement in their care. Assent appears to have the potential to foster children's involvement and is considered as leading to different beneficial outcomes for children and the care process. However, there remain important gaps in assent's theory and its desirable and possible practical implications. Practical standards are largely missing, and evidence supporting many claims made in the literature would require further investigation in real-world use.

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Supplemental material

Supplemental material for this article is available online.

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