

# The Concept of Child-Centred Care in Healthcare

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The position of children in healthcare reflects their changing and evolving positioning in society more broadly. The concept of child-centred care orientates children to a more central position within children's healthcare, where the child is at the centre of thinking and practice. However, a clear definition of child-centred care and clarity around the concept is yet to be achieved.

Keywords: child-centred care ; agency ; participation ; decision making ; communication

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## 1. Introduction

The position of children in healthcare reflects their changing and evolving positioning in society more broadly <sup>[1]</sup>. The concept of child-centred care orientates children to a more central position within children's healthcare, where the child is at the centre of thinking and practice <sup>[1][2][3]</sup>.

The concept of child-centred care adds to the different notions or concepts of centredness used to describe the focus of healthcare in general as well as healthcare for children and young people <sup>[4]</sup>. Other facets of centredness in healthcare include person-centred (and patient-centred) care, family-centred care (FCC) and various (and perhaps confounding) combinations of these. The precise meanings of each are subject to confusion and misunderstanding as well as uncertainties. Reactions or responses to societal shifts can be seen as the drivers for these different concepts.

The term 'person-centred care' (PCC) evolved from the term 'patient-centred care' and is a loosely defined term <sup>[5][6]</sup> but typical definitions present it as a holistic approach to care that is respectful and individualised, that includes negotiation of care, choice and where persons receiving care are empowered to be involved in health decisions at the level they choose <sup>[4][7]</sup>. PCC was described in the mid-20th century when there was a call to understand the patient as a whole person. Key attributes of PCC are that patients should be treated as individuals and with respect and dignity and that their needs, wants and preferences are included in care planning <sup>[8]</sup>. In PCC, the focus is on the individual—an adult with autonomy <sup>[4]</sup>. PCC has been seen to typically, or traditionally, refer to adults rather than children, with a strong representation within the mental healthcare, older person and dementia care literature <sup>[4]</sup>.

In the context of children's healthcare, FCC recognises that children need to be cared for in the context of their family, that families are the constant in the child's life and the family's values and priorities should be central in the plan of care for the child <sup>[9]</sup>. The theoretical origins of FCC came from the understanding of child attachment theories and recommendations from the Platt Report <sup>[10]</sup>, which also had a significant influence on changes to care of children in hospitals. Where parents were largely excluded from children's hospital wards in the 19th and the first part of the 20th century, there have been incremental changes towards acceptance of parents, their presence and building partnerships <sup>[11][12][13]</sup>.

In FCC, the family is the unit of care <sup>[14]</sup> and involves healthcare providers working in partnership with families, and the care of the child is in the context of their family <sup>[3]</sup>. In FCC, the focus is on adults—the parents and health professionals rather than the child. In FCC, parents and health professionals are the recognised active members and children and young people are allocated a more passive and less prominent role <sup>[1][15]</sup>. FCC is described as having been a preferred approach to children's healthcare for some decades; however, complex issues have been identified that compromise the effectiveness and implementation of this model including relationship, attitudinal and resource factors <sup>[2][14]</sup>.

Current constructions of childhood that lie within an emancipatory, rights-based, citizenship-oriented and participatory paradigm <sup>[16]</sup> have been major drivers in the development of the concept of child-centred care <sup>[17][18]</sup>. Child-centred care in healthcare reflects the broader societal view of children's rights that is framed by the UN Convention on the Rights of the Child <sup>[19]</sup>. The approach recognises children as social actors both in their own right and as active participants in their care, with its theoretical origins in the new sociology of childhood <sup>[20]</sup>.

Rather than a model that provides a method or recipe for achieving child centredness, child-centred care is seen as an approach or philosophy that underpins and informs children's healthcare. The approach places children at the centre of healthcare practice and, where able, children and young people are included as active participants in their care and decision making [2][4]. Child-centred approaches recognise that children and young people experience illness and disability differently than adults and that their healthcare needs are different than those of adults [2]. The premise that the best interests of the child should be the paramount consideration underpins the approach [2]. In child-centred care, the central role of parents and families in relationships and interactions continues to be acknowledged [2][4].

The difference between child-centred care and FCC is one of emphasis based on the extent to which children's interests are highlighted or prioritised in the planning and delivery of care [21][22]. In child-centred care, the focus is on the child in the context of their family. Child-centred care acknowledges the need to specifically focus on children and young people. It also recognises that their views and concerns are not necessarily the same as those of parents/carers or healthcare providers [2][15][23].

PCC and child-centred care have more similar attributes than child-centred care and FCC [4]. These commonalities include competence, values, own needs and active participation [4].

Although the concept of child-centred care is increasingly referred to in the healthcare literature, particularly within the nursing literature, a clear definition of child-centred care and clarity around the concept is yet to be achieved and further work is needed in developing the definition [15][24].

## **2. The Concept of Child-Centred Care in Healthcare**

### **2.1. What Constitutes the Concept of Child-Centred Care in Healthcare?**

There is no clear consensus across the papers about what constitutes child-centred care, suggesting that it is an emerging, ambiguous and poorly defined concept. However, four interconnected concepts—agency, participation, decision making and communication—were identified or discussed to some degree in many but not all papers. These concepts are ones that typically appear in the contemporary literature about children's positioning within society, healthcare and children's health literacy and it would be hard to argue that any of these are unimportant. However, even when these concepts were present in the reviewed papers, they were often simply referred to rather than clearly defined, perhaps reflecting the complexity of such concepts and the fact that definitions are contested. For the most part, the papers neither state the depth or degree to which agency, participation, decision making and communication should be present nor how they can be enacted authentically to ensure that child-centred care ensues. The belief that child-centred care is important is evident in the reviewed papers and this aligns with other work that proposes that the importance of child-centred approaches to care is key to good quality care (see, for example [25]).

In the review, the agency was mostly discussed in terms of children's rights [1][3][25] and their positioning in society, and closely linked with participation [3][4][26]. Agency is argued to result from relationships between human beings and their environment [27], which is a continuum characterised by interdependence [28]. Agency is clearly important as it requires adults to acknowledge the inherent wisdom and skills of children and young people [29], perceiving them as citizens [16]. Healthcare professionals who wish to work in child-centred care ways need to accept that children are already beings with agency who can reflect on and co-construct their worlds [30]. This means that child-centred care requires healthcare professionals and organisations to ensure that they reduce barriers to children acting agentically, and create opportunities for children to actively participate and enact their agency, such as, for example, through shared decision making [31] and participation in clinical encounters [32] and during periods of hospitalisation [33], as well as interventions focusing on health and well being [34]. However, as seen in the review, e.g. [3][35][36][37], research that specifically focuses on children's participation in medical encounters reveals that their participation is typically marginal [38][39].

Agency and participation require the acknowledgment that children and health professionals are actors within what has been described as a networked system [40]. In a networked system, everything affects everything else, meaning that factors are contingent on each other and competing agendas and, ultimately, interdependent [28]. Child health literacy is a field with growing momentum, and closely mirrors the core concepts of participation, agency, decision making and communication identified. The current global attention being given to health literacy in general, as well as to child health literacy, may well be a driver towards achieving child-centred care.

Communication was perceived to be a core element of child-centredness and that this involved creating a space for communication [35] and supporting children to be able to express their views and engage in dialogue and conversation [41][42][43][44]. Recent work addressing child-centred communication strategies aligns with findings from the review and

proposes core steps (greet, engage, involve and share) upon which good communication, even in time-limited encounters, can be built [45]. Other work, albeit not expressed as overtly child centred, supports the need to actively promote communication with all children [46][47], respect children's expertise [48] and address health literacy issues [49]. This shift toward more child-centred communication practices can be seen in the endorsement of using resources co-developed with children and young people to support communication [50].

Decision making was another aspect of child centredness that was identified (see for example [25][35][44]). However, there is robust evidence that shared decision making is not consistently implemented, often resulting from barriers such as healthcare professionals having insufficient time, the presence of power imbalances and healthcare professionals not having the requisite skills for shared decision making [51]. To overcome such issues, strategies to promote shared decision making include the use of decision-support tools to facilitate the participation of children. The tension between whether the views of parents should supersede the views of children in decision making [11][23]. The ethics of whose voice (child or parent) should hold sway and in what circumstances is complex and contextual. Yet, until children can be active participants in communication that concerns them, engagement in decision making is not possible. Research shows that children are often marginalised in triadic (child–parent–healthcare professional) clinical encounters [39] and that dialogue is often dyadic (parents–professionals) [38], resulting in exclusion of children's perspectives.

Lacking of evidence for the impact of child-centred care and how children benefit from child-centred care. This is perhaps unsurprising considering that the more firmly embedded concept of FCC in children's healthcare is still reported to lack robust impact evidence [15][26][52][53]. No clearly defined consensus measures to determine the impact of child-centred care were evident within the review, reflecting the lack of attention to developing measures and/or measuring the impact of child-centred care in the literature. This is somewhat at odds with what is seen in the much larger field of (primarily adult) patient-centred care, which is now widely recognised internationally as a means of delivering high-quality healthcare. A meta-narrative review of patient-centred care [54] identified 50 measurement instruments being used, albeit only 10 of these were directly measuring patient-centred care. If child-centred care is to be a sustainable and convincing model to guide practice and be able to compete with other models or frameworks of care, it needs to establish robust evidence of its effectiveness. Other facets of child health practice that are child centred, if not completely embodying child-centred care, include child-centred outcome measures and child-centred experience measures. Scott et al. [55] argue that using person-centred outcome measures in "routine paediatric care is key to child-centred quality care" (p42) but they note that implementation of and adherence to such measures is not simple and barriers exist.

Evidence from different countries with different health systems shows that the lack of a systematic approach, at all levels in an organisation, can impede the well-integrated adoption of person-centred care [56]. Successful adoption requires the use of evidence-based knowledge, guidelines and national regulations [56]. The lack of a clear evidence base for impact and benefit, as well as a lack of guidelines and regulations, perhaps provides a rationale for why child-centred care has not, so far, been effectively adopted across healthcare systems.

## **2.2. How Has the Concept of Child-Centred Care Developed?**

It is difficult to identify whether or if child-centred care has developed over the period covered, as the term has been used loosely; a lack of definitional sources lies at the root of this challenge. What is clearer is the tension between child-centred care and FCC [26]. Previously, there was no seeming questioning of the relationship between the two forms of care [26]. Now, there is greater evidence of a realisation that, while the two forms of care can be mutually supportive, they can also be at odds with each other, and the rights of children (for instance, a child's right to be involved in decision making) might be "trumped" by parental rights [23]. There is an overlap between child-centred care and person-centred care. However, work relating to person-centred care typically focuses on adults [57] and there is the potential that person-centred approaches miss the particularities, uniqueness and changing dynamic of providing care for children. A future development proposed is melding the concept of child-centred care with FCC to become child and family-centred care (CFCC) [26], although this is likely to just blur the distinction between the two concepts and may not necessarily advance the position of children's agency, participation and decision making.

## **2.3. What Is the Applicability of Child-Centred Care and What Are Its Limitations?**

The applicability of child-centred care lies in its potential to create a better balance in terms of power [23], empowerment [58] agency [26][44], participation [25][35][36][43] and respect for the child [3]. In many circumstances, the evidence shows that family-centred care has essentially become parent oriented and often primarily oriented to maternal involvement [3]. Although not always talked of in terms of child-centred care, there is evidence in the other literature, that aligns with child-centred care values, such as dealing with the rights of the child and the importance of listening to the voice of the child and responding to their expressed needs [46][59][60][61]. However, ensuring that care genuinely becomes child-centred

means that their voices and wishes should be given primacy wherever possible. The limitations of child-centred care are twofold: firstly, the legal rights for decision making lie with the parents <sup>[61]</sup>, and secondly, the assumptions about the capacity of the child to be involved in decisions about their care, rather than be a passive receiver of care.

## 2.4. How Does the Concept of Child-Centred Care Benefit and Inform Children's Healthcare?

A child-centred care approach has the potential, if implemented effectively, to acknowledge and reaffirm the rights of the child outlined in the United Nations Convention on the Rights of the Child (UNCRC) <sup>[19]</sup>. The approach recognises children's rights to participate in healthcare matters and decisions about their care. The concept of child-centred care positions children in a more central orientation within healthcare, so that the focus is on the child in the context of the family rather than the other way around (where the child's perspectives are secondary).

Considering the evidence from the person-centred care literature where benefits are considered in the wider context such as impacts on patient safety <sup>[62]</sup>, rationales proposed for child-centred care need to extend to debates about wider contextual issues rather than being inwardly focused.

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