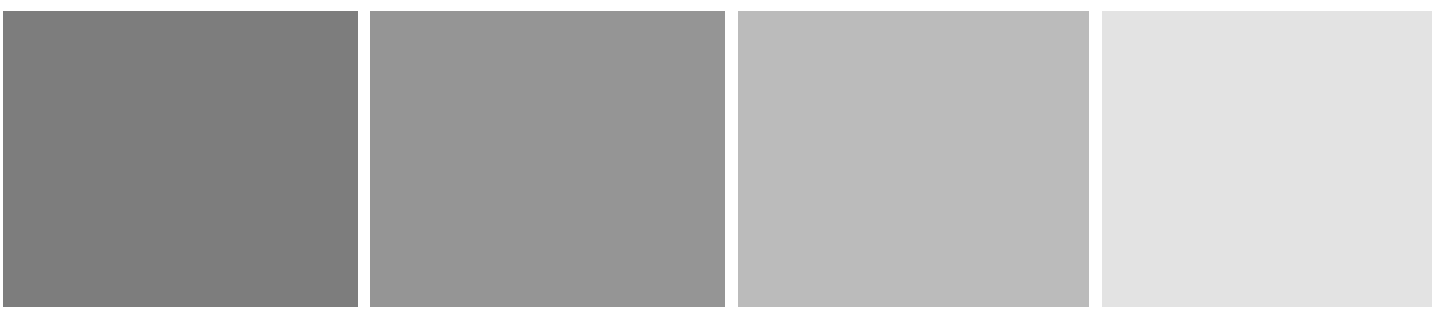
ESSENTIALS OF NURSING CHILDREN AND YOUNG PEOPLE

2ND EDITION

ESSENTIALS OF NURSING CHILDREN AND YOUNG PEOPLE



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DEDICATION

Jayne: In memory of David J. Thomas, an inspirational children's nurse whose impact on the care of children with cancer/palliative care needs and their families will never be forgotten.

Orla: To Alex and Sharon, thank you for all that you do. I am ever grateful for the care and love you show for children with complex needs.

Zoë: For the previous and current undergraduate children's nursing students at UWE Bristol – you are my inspiration.

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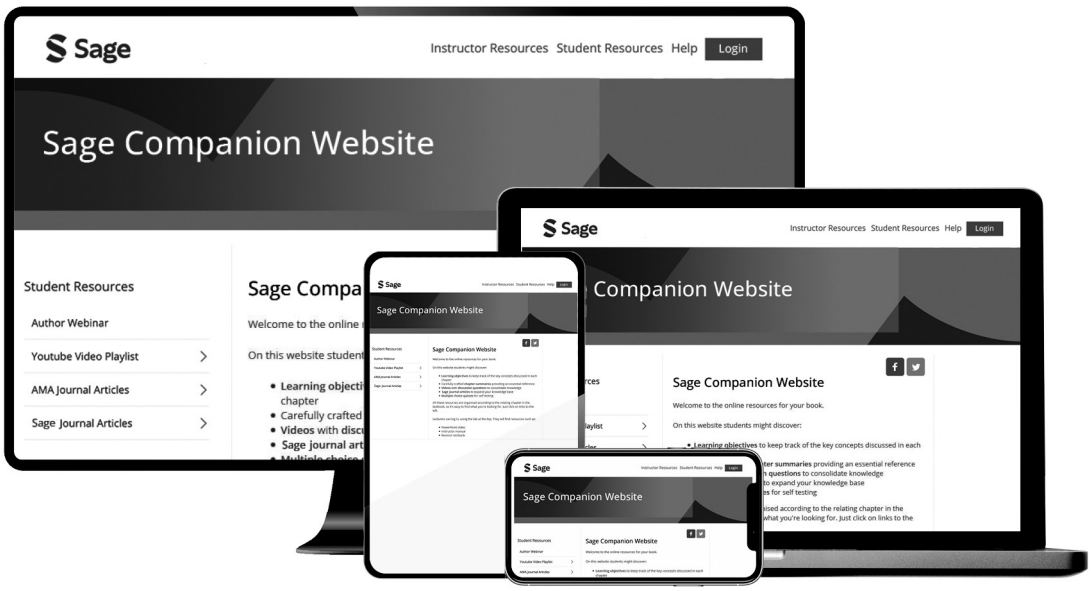

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FOREWORD

BERNIE CARTER

THE MORE PLACES YOU'LL GO

This second edition of *Essentials of Nursing Children and Young People* provides the building blocks for a lifetime of learning about nursing children, young people and their families. Education is often talked of as a gift that provides the platform for growth, transformation, enabling the person to achieve and to be an asset to their community and then to share their knowledge with others. Those learning about the essentials of how to nurse children, young people and their families are at the start of an exciting, challenging and ultimately highly rewarding journey that will support them to become the future expert practitioners, innovators, managers, leaders, educators, researchers and policy-makers within their field.

As someone nearer the end of a lifetime involved with nursing children and young people, I am still learning and critically reflecting on what I know and what I still need to better understand. The never-ending nature of education and learning could seem daunting, but it is both crucial for the children and young people who are the focus of our professional attention, and it is also an adventure in curiosity that can lead to improvements in care, innovation and the ways we can provide skilled compassionate care.

Nursing children and young people requires nurses to have an extensive knowledge base and skill set that allows them to engage with and care for children and young people in an increasingly unpredictable world. Nurses who work with children and young people practise in a wide variety of settings, ranging from the very highly technological tertiary settings such as critical care through to primary care settings and the home. Each setting and every individual engagement with a child or young person and their family requires us to draw on the skills and knowledge we gained from education and learning to meet their particular and unique needs.

Nurses work in a world that does not stay still so the skills and knowledge we learn on our journey to become a registered nurse who is qualified to care for children and young people are essential elements to be drawn on as well as questioned and challenged. The education of nurses who care for children, young people and their families increasingly accommodates and responds to changes in the epidemiology of childhood illness and the increasing complexity of need, as well as changes in demographics. What we know now will not be sufficient to meet future needs; hence, the need for us to continue to read, learn, question our assumptions, and add to the evidence base for our practice.

Educators have a major part to play in creating the leaders, managers and innovators of the future; they light the flame, inspire and nurture. Nursing children and young people requires nurses to think boldly and think how they can inspire change and make changes that will improve care. We need to have our eyes on the horizon. Leadership, mentorship and being a change agent is not something that

should be left to the more or most experienced people. Nurses who care for children and young people need to be encouraged, and encourage others, to share ideas and to propose, implement, manage and sustain change. Leadership is not a role, it is a way of thinking, being and acting in partnership with colleagues, children, young people, and families and other stakeholders. Leadership is about being adaptable and flexible in your thinking, inspiring others to ensure best practice. We should all aspire to be leaders, even if only in a small way.

Nurses who care for children and young people often say or are taught that they are the child's advocate. This is true, but too often this is a narrow view of advocacy where we speak up for one child or one situation; this is important as it can make a real change for the child or young person or that situation. However, true child-centred advocacy comes when we become more politically aware and active around the challenges that children and young people face. Child poverty and health inequalities exert malign effects on children's health and wellbeing and even in wealthy countries with good health systems progress against poverty and its impacts on children is precarious. Children and young people live with these impacts and nurses see these impacts every day in their practice. Asthma is one example where our knowledge, skills and experience need to reach out beyond delivering the best possible care to encompass political activism in demanding that the causes of asthma such as air pollution should be addressed. Nursing children and young people activism needs to be based on social justice and we need to be engaged.

Activism is also vital to protect the pre-registration education of children and young people's nurses. Looking back over the history of children's nursing education, it has been threatened with marginalisation and there is almost always an underlying rumbling threat to withdraw pre-registration child nurse training. For those who want to protect pre-registration training, activism is one of the ways in which we can fight future threats.

I come back to the point made at the start: education is a gift we should treasure and should never take for granted. The better educated we are as nurses, the better we can serve the children and young people we care for and the better we can shape the future of children and young people's nursing.

I'll leave you with words from Dr Seuss which perhaps sum things up more aptly than even the best-written textbook or academic paper:

> The more that you read,
> the more things you will know.
> The more that you learn,
> the more places you'll go.

Professor Bernie Carter
Professor of Children's Nursing, Faculty of Health, Social Care and Medicine
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VOICES

We would like to give special thanks to all the families who contributed their voices to this book, the book is richer for your contributions. We would also like to thank the students and nurses who also contributed their voices. All voices have been anonymised to protect privacy unless otherwise requested.

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INTRODUCTION

JAYNE PRICE, ORLA McALINDEN AND ZOË VEAL

This book has been written for nurses everywhere who look after children and young people with a healthcare need.

Whilst the book is primarily aimed at children's nursing students in years 2 and 3 of their degree programme, it also presents a solid foundation of relevant material for any nurse and in particular those registered nurses (RNs) who may be working in a children's area which is not familiar to them. It should serve as an excellent source of reference material throughout your degree and beyond.

This book was developed by a dedicated team of lecturers, practitioners, students and, of course, by children and their families/carers to support your study, practice and future continuing lifelong learning. All contributors have been keen to be involved because they know how important good nursing care is and are aware of the challenges you will face in providing quality care. Everyone involved in this book is passionate about providing you with the knowledge, skills and confidence to be the type of children's nurse who inspires and provides best evidence-based care to children and their families. In addition, we aim to enable you to create an environment for practice that prevents the negative situations you may see in the media from time to time.

The care of the child is first and foremost in all considerations; you will notice that the design and content of the book promote listening to what children tell us as well as signposting further information for you to read widely and deeply around topics. We recognise that no one text or resource can meet all your learning needs and for that reason this textbook uses a variety of features to lead you towards other evidence and learning opportunities, not least of which is respecting the needs, views and wishes of children, young people and their families at all times.

Eight key themes underpin the entire text:

1. Child- and family-centred care
2. Critical thinking and depth of theoretical thinking
3. Integration of acute and community care
4. Interprofessional working and collaboration
5. Evidence-based nursing
6. Preparation for practice placements
7. Health promotion
8. Safeguarding

These themes have been selected in consultation with a large number of course leaders in children's nursing degree programmes, and represent what they feel are essential areas of focus to be a successful children's nursing student. Keep these in mind and reflect on how you might develop your skills in these areas as you read through the text, and throughout your degree programme and practice placements.

Becoming a competent children's nurse is a long journey, and as students you are at the start. The contributors are all companions, and are at different stages of that journey. Their insight, experience and skills are freely shared with you to make you the best you can be as a children's nurse. The voices of children, young people and their families will serve as a reminder to keep them always at the heart of decisions and interventions. To care for children and young people is both a privilege and a big responsibility which will require you to be honest, transparent, inclusive and willing to be open to challenge and change. Advocacy and accountability are needed alongside excellent interpersonal and clinical skills.

A note on terminology: throughout the text we have usually referred to 'children' in place of the longer 'children and young people', and, in some cases, infants too. This is for the reason of brevity and to prevent repetition; however, in most cases (unless specified), the shorter term should be understood to refer to both children *and* young people. In the same way, the term 'family' should be understood to refer to family and/or carers.

We hope that this book will give you a great start in the practice of children's nursing. We wish you much joy and success in this wonderful field of nursing.

Professor Jayne Price
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PART 1 PRINCIPLES OF NURSING CHILDREN AND YOUNG PEOPLE

INVOLVING CHILDREN, YOUNG PEOPLE AND FAMILIES IN CARE

1

NICOLA MITCHELL, JOANNA SMITH AND JACKIE VASEY

THIS CHAPTER COVERS

- Social and political contexts underpinning the nursing care of children, young people, and families
- Involving children and young people, and families in care
- Family-centred care
- Child-centred care
- Key skills required when involving children, young people, and families in care

> **"Historically, involving children and young people, as appropriate, and parents in care has not been embedded into everyday practice. In the 1990s parental participation in care was described as 'one of paediatric nursing's most amorphous and ill described concepts."**
>
> **Darbyshire, 1993, p.1672.**

INTRODUCTION

Evidence suggests that involving children, young people and parents in care improves satisfaction with care and may have a positive impact on health outcomes for children and young people (Shields et al., 2012; Arabiat et al., 2018). Historically, involving children and young people, as appropriate, and parents in care has not been embedded into everyday practice. In the 1990s parental participation in care was described as 'one of paediatric nursing's most amorphous and ill described concepts' (Darbyshire, 1993, p.1672). A key role of the children's nurse includes supporting children, young people, and their families to be involved in care and care decisions; yet long-standing challenges to the implementation of family-centred care persist (Coyne, 2015; Arabiat et al., 2018; Kokorelias et al. 2019), which have been confounded by the COVID pandemic (Al-Motlaq et al., 2021; Goga et al., 2021).

While involving the whole family in the child's care is widely advocated, children have not always been encouraged to contribute to decisions about their care (Royal College of Paediatrics and Child Health (RCPCH), 2011). Children's nurses are in an ideal position to advocate on behalf of the child and enable children's views to be heard. While children's nurses will be familiar with the concept of family-centred care, a move towards a child-centred model of care could support children's nurses to foster a collaborative approach to working with children and young people. This chapter will explore both family-centred and child-centred care, and help you develop a critical approach when considering how to involve children, young people and families effectively in care.

ACTIVITY 1.1: CRITICAL THINKING

Research exploring parent–professional interactions found that the way information is communicated is not always conducive to involving families in care and care decisions (Smith, Cheater et al., 2015), highlighted in the followed extracts:

> I needed to know what was happening so I could let family know back at home. I was just having to guess because nobody told me anything. (*Admission 7, dad*)
> There is so much conflicting information really. They [doctors and nurses] do not seem to take on board what you are saying, that is my feeling. No, they really have their own agenda and that is what we are on now – their agenda. (*Admission 2, mum*, Smith, Cheater et al., 2015, p.1308)

- How can nurses ensure parents are fully informed about all aspects of their child's condition and care?
- What can nurses do to involve parents in care and care decisions?

Involvement in care and care decisions enables parents, children, and young people to contribute to choosing care interventions that meet their needs, and empowers them to contribute to the child's care (Shields et al., 2012). While both parents and health professionals expect to work in partnership, they often have different expectations and priorities, with parents often perceiving their contribution is not prioritised (Smith and Kendal, 2018). Furthermore, parents perceive their knowledge, experience, and expertise relating to their child is not always valued (Smith et al., 2015). Similarly, children and young people want to be part of decisions about them (Garnett et al., 2016). Giving children a voice enables them to develop a sense of self and improves their confidence and communication skills. In contrast, lack of involvement can lead to children and young people being fearful and anxious, and unprepared for procedures, and reduces their self-esteem (Coyne and Cowley, 2007).

SOCIAL AND POLITICAL CONTEXTS UNDERPINNING THE NURSING CARE OF CHILDREN, YOUNG PEOPLE AND FAMILIES

Understanding the historical and political contexts that influence children's nursing, and service and care delivery will help you to contextualise the changing role of the children's nurse in optimising the health and wellbeing of children. Care delivery is influenced by a range of factors, including: societal norms and values; national and international health policy and the allocation of health resources; changing disease profiles; technological advancements; and the impact of lifestyle choices on health. Children's health and wellbeing are often viewed as an important marker of a nation's wellbeing and prospects. Proportionally, children are high users of health services, yet the development of health services for children has historically been inconsistent.

One of the first hospitals specifically for children opened in Paris in 1802, with London's Great Ormond Street Hospital opening in the 1850s. Prior to this, children were often cared for alongside adults. Care specifically aimed at children began with dispensaries offering advice to mothers from poor backgrounds, who could not pay for medical care, and provided medicines for children, based on the belief that treatments for children would be best achieved by mothers caring for ill children at home. Despite promising developments during the early and mid-20th century, many children were admitted to hospital for extensive periods of time, often to recuperate from infectious diseases or minor surgery. Many wards nursed both adult patients and children, with restricted visiting for parents, and few nurses were trained in the specific needs of children.

Greater understanding about the impact of separating children from their families and reduced in-patient and institutional care influenced the approach to caring for children. The seminal work of Bowlby (1953) and Robertson (1958), a psychiatrist and psychoanalyst respectively, highlighted the emotional trauma of children when separated from their mothers. Although Bowlby's and Robertson's classical theories on young children's responses when separated from their mother have been criticised, they were a catalyst for change (Alsop-Shields and Mohay, 2001). The plight of children in hospital was highlighted in *The Welfare of Children in Hospital* report (Ministry of Health, 1959), commonly known as the 'Platt Report', which was heralded as one of the most influential documents of its time. Key messages included staff caring for children should understand child development, recognise the family's role when a child is in hospital and provide unrestricted visiting for parents (Smith and Long, 2002). Increased parental presence in hospital contributed to the impetus for parents to become more involved in their child's care.

In recent times, ensuring children and families can be together during hospital admissions has been threatened by the safety measures required during the COVID-19 pandemic. Guidance for visiting inpatient settings set by NHS England (2020) recognises parents as essential visitors, but healthcare organisations had greater discretion in how they implemented visiting polices. During the pandemic the many Trusts, including specialist children's hospitals, limited visiting to one parent. These measures focus on safety of COVID-19 transmission, but do not take account of the benefits of parental presence for both child and parent (Goga et al., 2021). Every attempt should be made to keep children, particularly neonates, and their families together (Tscherning et al., 2020; Goga et al., 2021).

Children with life-limiting conditions and complex health needs are now surviving into adulthood. The profile of childhood diseases, particularly in developed countries, significantly changed during the latter part of the 20th century, with a decline in the incidence and outcome of previously fatal communicable infectious diseases and an increase in long-term conditions. The management of children with long-term conditions, complex needs and those dependent on advanced technologies primarily takes place in the home environment, with the responsibility for monitoring symptoms and responding to changes in the child's condition becoming primarily the role of parents (Wang and Barnard,

2004). Consequently, the role of the nurse shifts from care provider to one of educator, supporter and advocate. Case study 1.1 outlines Amy's experience as a health visitor of supporting a family at home to care for their baby, Aisha, who had a life-limiting condition.

CASE STUDY 1.1: AISHA

While on the postnatal ward, establishing Aisha's feeding was challenging, causing her parents anxiety about taking Aisha home as they perceived there would be lack of support to ensure her nutritional needs would be met. In my role as health visitor, I ensured all members of the multidisciplinary team (hospital, community and hospice) along with Aisha's parents were aware of Aisha's needs, and established a plan of care and schedule of visits; a priority was for Aisha to spend as little time as possible in hospital and the number of home visits not to be intrusive.

As Aisha's parents became more confident in caring for her and learned her behavioural cues they were able to share this knowledge with nursing and medical staff and provided supportive care, with Aisha at the centre of all decisions. Health professionals were able to work collaboratively and in partnership with Aisha's parents; they did not initially want to carry out invasive procedures such as passing a nasogastric tube, which was respected. There was a gradual transition from professionals making most decisions about Aisha's care to transferring almost all care to parents as their skills and confidence grew. Right to the end of Aisha's life her parents were fully involved in all discussions and decisions about her care, with consideration to her siblings' needs throughout.

Aisha died at 4 months of age. At bereavement visits provided following Aisha's death her mother spoke with pride about Aisha's life and her amazement at the care that had been wrapped around her; her worries of being forgotten after leaving hospital were unfounded.

- What contributed to the success of the team in involving Aisha's parents in her care?
- Reflect on any similar experiences you have – what were the challenges and facilitators to involving the family in care?

INVOLVING CHILDREN AND YOUNG PEOPLE IN CARE AND CARE DECISIONS

The social constructs of childhood influence how children are viewed and beliefs about the abilities of children to participate in care decisions. Traditionally, society has been divided into two broad groups, namely childhood and adulthood, with the passage into adulthood synonymous with rights, privileges and obligations (Franklin, 1995). The concept of 'agency' is particularly relevant to the children's nurse and can be thought of in terms of the child's ability to reflect and act on information and an understanding that any decisions made have consequences (Mayall, 2002). The concept of child agency is complicated because children are often perceived as lacking adult reasoning and the cognitive capacity to participate in complex decisions.

The philosophical perspectives of paternalism, interventionalism and libertarianism can offer explanations about how individuals view the child's ability to participate in decisions and the rights bestowed on them (Franklin, 1995). Paternalists make choices on behalf of the child because they perceive that children are vulnerable and not capable of making autonomous rational decisions.

Interventionists assume it is the responsibility of the decision-maker to act in a child's best interests and while like paternalism, the power balance has shifted to the health professional. Evidence suggests that children want to be heard but view health professionals as interventionists who do not support their involvement in care decisions (O'Quigley, 2000).

Unlike paternalists, libertarians advocate that children can make informed choices and through experience would learn to contribute to decision-making processes (Franklin, 1995). Intuitively, a libertarian approach for a young child, who is unlikely to have the cognitive capacity to make complex healthcare decisions, seems inappropriate. However, young children can be involved in some choices about their care, which may depend on the relative importance of the decision. A more pragmatic approach to involving children and young people in care decisions is to be mindful of the differences in the way children think and process information. Children and young people should be supported to make decisions as appropriate and their participation in care valued, whilst recognising that the level of agency will evolve as the child matures (Mayall, 2002). Ravi Mistry, the Youth Advisory Panel Member at the Royal College of Paediatrics and Child Health (RCPCH), who actively promotes the inclusion of young people in healthcare, stated:

> Participation encourages integration and inclusion, lets youth feel valued and leads to progress. It is a right and should not be tokenistic, where services merely ask youth for their views just so they fit in with a trend. I would urge all to include the views of children and young people wherever possible, the benefits are clear. (Ravi Mistry, Youth Advisory Panel Member, RCPCH, 2011, p.3)

NICE (2021) guidance on babies, children and young people's experience of healthcare advocates that all who wish to be, are involved in decisions about their care. Children enjoy being involved in care decisions (Garnett et al., 2016), and it improves the relationship between children and health professionals because issues important to children are more likely to be addressed (RCPCH, 2011). Children and young people should be provided with age and developmentally appropriate information to help them be involved in decisions about them (NICE, 2021). Involvement in decisions is particularly important in the context of childhood long-term conditions, where the young person will be preparing to make the transition to adult services. Case study 1.2 highlights how Sarah perceived her son was involved in care on a Teenage Cancer Unit.

SEE ALSO CHAPTERS 8 AND 12

CASE STUDY 1.2: ALEX

We were asked at the time of Alex's diagnosis, 'What do you want to tell Alex?' Al was 14-and-a-half years old, sensible, able to verbalise emotions and debate the rationale for decisions made. So we took the view he should be included in everything – nothing to be hidden from him. We did not want to have discussions in secret or whisper behind closed doors. Al could consent to everything himself, although we were all involved in the discussions about whether he would go on a drug trial treatment protocol or offered alternative options, and what the pros and cons for all care and treatments were so he (and we) could make informed decisions. Al was the one who knew how he was feeling and Al was the one to live with the consequences of decisions made so it seemed right he should be involved.

- How can nurses communicate effectively with children, young people and their families when breaking bad news or negotiating care?

SEE ALSO CHAPTER 2

A shift from a paternalistic model of involving children and young people in care was reflected in the 1989 United Nations Convention on the Rights of the Child. Articles 12 and 13 are particularly relevant to children's nurses as they focus on children's right to participation, right to articulate an opinion and right to freedom of expression. For example, Article 12 states that 'the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child: the views of the child being given due weight in accordance with age and maturity of the child' (United Nations, 1989). Children's nurses are often faced with a range of dilemmas in relation to involving children and young people in care. This may occur when the adults involved have differing opinions to children and young people about their care.

SAFEGUARDING STOP POINT

SEE ALSO CHAPTER 34

The views of children or young people with a learning disability have not always been actively sought or valued (Council for Disabled Children, 2018). Yet these children are particularly vulnerable members of society.

FAMILY INVOLVEMENT IN CARE

Evidence suggests that parents want and expect to be involved in their child's care, share care decisions and work in collaboration with health professions but want choices about their level of involvement (Power and Franck, 2008; Smith et al., 2015). Parents who manage their child's care at home perceive that their expertise is not valued when their child is admitted to hospital (Smith et al., 2015). Involving parents in care can reduce their anxiety and feelings of helplessness when their child is acutely ill (Twycross and Stinson, 2014), and is essential when the child has a long-term condition and parents have responsibility for delivering treatments and care at home (Smith et al., 2015). Parental involvement in care is particularly salient for the pre-verbal child and children who have difficulties with communicating where parents' unique understanding of their child must be incorporated into care.

SEE ALSO CHAPTER 2

WHAT'S THE EVIDENCE?

Research continues to identify that involving parents in their child's care is challenging, as highlighted in the evidence presented in Table 1.1; you may wish to discuss with peers and practice supervisors the reasons why implementing research about involving families in care in practice is challenging.

Table 1.1 Findings from studies about involving parents in their child's care

Author	Study aim	Key findings
Arabiat et al. (2018) Australia	Cross-sectional survey to understanding of how parents experience family-centred care	• Parents defined family-centred care as the family being included in the child's care, and health professionals supporting the whole family. • Although 85% of parents reported positive experiences of family-centred care, some parents did not perceive their contribution to care was valued or important.

Author	Study aim	Key findings
Smith and Kendal (2018), England	Qualitative study exploring parent and healthcare professionals' views of collaboration in care in the management of childhood long-term conditions	• Although parents and professionals agree that collaboration is needed, parents perceived their needs are often unmet. • Health professionals' expectations are influenced by their knowledge, experience, and relative objectivity. • Relationship-building and good communication are central components of collaboration.
Coyne (2015), Ireland	Qualitative study exploring children, their parents and health professionals' perspectives and expectations of family-centred care	• Family-centred care reduces children's distress when in hospital and improve the quality of care. • Nurses perceived that family-centred care was central to care delivery but the roles and boundaries between parent and nurse were unclear. • Family-centred care operated in the context of minimal collaboration or negotiation with parents.
Coyne et al. (2013), Ireland	Survey of nurses' perceptions and practices of family-centred care	• Family-centred care was central to valuing family individuality. • Family is a resource in providing information about the unique needs of the child. • Although nurses supported the philosophy of family-centred care they struggled to apply the principles to practice.
Macdonald et al. (2012), Canada	Observational study that explored the family's experience of family-centred care	• Embedding family-centred care into practice is challenging; differences exist in the way family-centred care operated between families and professionals. • Care practices should not solely rely on better information exchange but require health professionals to consider reducing the barriers to involving the family in care.
Sousa et al. (2013), Portugal	Survey of parents' perspectives about being involved in their child's care	• Gaining information about their child's condition was an overwhelming priority for parents. • Parents wanted to participate in their child's care but did not want to disrupt nursing routines. • Being present during their child's hospital stay was thought to be essential to their child's safety and wellbeing.
Uhl et al. (2013), USA	Mixed methods study exploring parents' experiences of family-centred care following their child's admission to hospital	• A child's admission to hospital is a stressful event, associated with uncertainty, fear and lack of control in relation to meeting their child's needs; involving parents in care can ameliorate their emotions, anxiety and stress • Characteristics valued by parents in health professionals included treating them with dignity, being courteous and actively listening to their concerns. • Information sharing was identified as central to involving parents in care.

Despite the development of a range of models and frameworks that aim to foster the family's involvement in care over the past two decades, concepts such as 'parental participation', 'partnership with parents' and 'family-centred care' remain poorly defined and are often used interchangeably (Hutchfield, 1999; Franck and Callery, 2004; Coyne et al., 2013; Smith, Swallow et al., 2015). Lack of clarity and understanding of terminology have contributed to poor implementation of these concepts

into practice; how nurses develop effective partnerships with the child and their family. Establishing the level of involvement in care and decisions about care that children, young people and parents are willing and/or able to undertake is fundamental to working in partnership with the family. At times parents may have minimal involvement in their child's care – for example, on first contact with services or during emergency care, while at the opposite end of the spectrum parents may lead care – for example, in the context of childhood long-term conditions (Smith et al., 2010). However, being valued, experiencing effective information exchange and, if desired, being supported to undertake usual childcare activities, should be the minimal involvement parents can expect (Hutchfield, 1999). Individual family needs and preferences are unique and may change over time, reflecting changing levels of involvement in care. Table 1.2 highlights the relationship between the terminology associated with involving parents in care and levels of involvement.

Table 1.2 Levels of parental involvement in care

Hierarchy of care (Hutchfield, 1999)	Level of involvement (Smith et al., 2010)
Family-centred care • Parents lead care and are fully involved in all decision-making as equal partners. • Parents are expert and knowledgeable in all aspects of care for their child, which is respected. • The nurse's role is one of consultant and counsellor. • The child and other family members are involved in care.	**Parent, and child as appropriate, lead care** Family leads care with support from health professionals.
Partnership with parents • Parents have equal status as caregivers, are knowledgeable and have skills required to deliver care. • Parents are empowered to give care; parents and nurses negotiate roles parents undertake. • Parents are primary, but not total, caregivers. • Nurses support, advise and facilitate parents to care for their child.	**Parents and nurses work in partnership** Parents and nurses have equal status for care and in decisions about care delivery.
Parental participation • Parents participate in usual childcare and through negotiation undertake some aspects of nursing care. • Nurses remain responsible for ensuring all care is given, and often act as gatekeepers for the care parents undertake. • Nurses act as primary caregivers, but support and teach parents how to provide care as appropriate.	**Involvement of parents in care** The nurse involves parents in care but retains responsibility for care and leads care delivery.
Parental involvement • Nurses respect parents as a constant in the child's life and their unique knowledge of their child. • Nurses provide care and support parents to undertake usual childcare and emotional support to their child. • Nurses ensure parents have appropriate information and are advocates for the child and family.	**No/minimal involvement of parents in care** The nurse leads and delivers care.

Partnership in care

You may be familiar with the 'partnership in care model of paediatric nursing', widely adopted within the UK, as the underpinning philosophy for the care of children (Casey, 1995). Central to the model was the interconnected relationship between the four dimensions associated with nursing: person (or in this case child and family), health, environment, and nursing. The model emphasised that care is best undertaken by the family with support from skilled health professionals by empowering parents,

and children and young people as appropriate, to contribute to care (Casey, 1995). However, there were concerns that a shift from parent involvement to one of partnership occurred in the absence of the essential component of negotiation, and that parents may not have been empowered to become responsible for delivering treatments and care, but expected to undertake new roles delegated to them by the nurse (Coyne, 1996).

Parent participation in care has been widely researched in hospital settings with key findings suggesting: a coercive system of involving parents exists that hinders the development of effective parent–professional partnerships (Corlett and Twycross, 2006); parents being disempowered with care delegated to them by health professionals, resulting in anxiety when undertaking complex care tasks (Coyne and Cowley, 2007); and different perspectives about what constitutes collaboration and participation between parents and health professionals (Power and Franck, 2008). For participation to be meaningful, health professionals need to understand parents' perspectives (Power and Franck, 2008), which can be challenging because healthcare is increasingly varied with patients' expectations, experiences, knowledge of health and health-related issues, and the degree they wish to participate in care, being highly diverse. Although partnership in care has been positioned as a philosophy underpinning the care of children and young people (Casey, 1995), there is increasing consensus that partnership in care is a central component of family-centred care (Shields et al., 2012; Smith, Swallow et al., 2015).

Family-centred care

The Institute for Patient- and Family-Centered Care (2017, p.2) defines family-centred care as 'an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families'. Family-centred care both guides care based on recognising the importance of the family in optimising the child's health and wellbeing and is a philosophy that shapes policy and health services (Shields et al., 2012). The eight core elements central to family-centred care developed by the American Association for the Care of Children's Health (Harrison, 2010, p.336) are:

SEE ALSO CHAPTER 6

1. Recognition that the family is the constant in a child's life is incorporated into child health policy.
2. Facilitating family/professional collaboration at all levels of hospital, home, and community care.
3. Exchanging complete and unbiased information between families and professionals.
4. Honouring cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
5. Recognising and respecting different ways of coping and providing developmental, educational, emotional, environmental, and financial supports to meet diverse needs.
6. Encouraging and facilitating family-to-family support and networking.
7. Ensuring that hospital, home, and community service and support systems for children needing specialised health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
8. Recognising families have strengths, concerns, emotions, and aspirations beyond their need for specialised health and developmental services and support.

Embracing family-centred care requires that nurses caring for children view the family as an integral part of the child's life (Smith et al., 2010), which is reflected in the way care is organised, planned, delivered, and evaluated around the whole family (Shields et al., 2012; Coyne et al., 2013). While many children's nurses endorse family-centred care and are passionate about involving families in care, evidence suggests that family-centred care is not consistently and effectively embedded into practice (Shields et al., 2012; Coyne et al., 2013). Furthermore, there is a lack of robust evidence to

support the impact of family-centred care on the health of children and the impact on the child and family experiences (Shields et al., 2012). Consequently, family-centred care has been criticised for being espoused rather than embedded into care delivery (Coyne et al., 2013). Lack of understanding of how to implement and embed family-centred care into practice hinders parental involvement in care. Nurses need to adopt the principles of empowerment, negotiation, and participation, to actively involve parents in their child's care (Smith et al., 2010).

Activity 1.2 helps you to consider ways to work in partnership with children, young people, and families.

ACTIVITY 1.2: CRITICAL THINKING

- What is meant by the term 'family'?
- What is patient- and family-centred healthcare?
- What is family nursing and how does this differ from family-centred care?
- How does family-centred care relate to nursing and nursing practice?

Think about the questions above and discuss with peers.

KEY SKILLS REQUIRED WHEN INVOLVING CHILDREN, YOUNG PEOPLE AND FAMILIES IN CARE AND CARE DECISIONS

Valuing children's, young people's and parents' contribution is central to their involvement in care decisions. The relationship between the family and health professional must be based on developing mutual trust and respecting each other's skills, experiences, and perspectives. Facilitating partnership working requires nurses to move away from a paternalistic approach and work to actively reduce the power imbalance between them and parents. Involving parents as partners in care requires health professionals to recognise and embrace parents' unique knowledge of their child and incorporate that knowledge into clinical decisions (Smith, Cheater et al., 2015). The principles of involving children, young people and families in care and care decisions include:

- Developing a trusting relationship with the child and family by getting to know the family, and valuing their knowledge and experiences.
- Respecting and being sensitive to the individual family context.
- Focusing on problem-based communications by listening and responding to the child and family's concerns and drawing on their expertise.
- Providing regular opportunities for a mutual exchange of information that is meaningful and delivered in a way that meets the child and family's needs.
- Facilitating children and parents to be involved in the child's care; clarifying and negotiating roles to reach a mutual agreement about care responsibilities.
- Including children and parents as members of the interdisciplinary care team and valuing their contribution.
- Collaborating and sharing decisions about care; maintaining contact and offering ongoing support (Smith, Cheater et al., 2015; Smith, Swallow et al., 2015).

Effective communication with children and families enables them to make informed choices about their involvement in care and the delivery of treatments (Smith et al., 2010).

SEE ALSO CHAPTER 2

CHILD-CENTRED CARE

Children's nurses must advocate for children and young people and ensure they have opportunity to participate in care, and that they and their families are central to care decisions. Child-centred care is an approach to care that places the child and their interests at the heart of healthcare practice and reflects the rights of children to participate in care and care decisions (Carter et al., 2014). The concept of child-centred care has been gaining international momentum because of widespread acknowledgement that children should be included and participate in decisions about them (Ford, Campbell et al., 2018). Child-centred care is not mutually exclusive with family-centred care but can be thought of as being complementary to family-centred care (Carter et al., 2014). Both models recognise the social and cultural contexts that shape children's lives and influence their health and wellbeing. However, child-centred care differs from family-centred care in that there is greater emphasis on the concerns of the child and young person, which may not be the same as those of their parents or health professionals (Soderback et al., 2011) and acknowledges children as having agency (Carter et al., 2014), as previously outlined. Family-centred care is typically framed around collaboration between parent/s and health professionals, with the child or young person often the passive partner even when they have capability to make decisions (Ford, Campbell et al., 2018). In contrast, in child-centred care the child's concerns and needs are the primary focus of care.

The core principles of family-centred care, previously outlined, such as complete and unbiased information sharing, valuing the family as constant, facilitating parent–professional collaboration, and empowering the family to be partners in care, and respecting the cultural diversity of families (Smith, Swallow et al., 2015) are equally important when adopting a child-centred philosophy of care. However, the values underpinning child-centred care include:

- Placing children's needs and their best interests at the centre of all care decisions.
- Recognising children and young people as individuals, albeit part of a wider family.
- Listening to and supporting children, irrespective of age and ability to express their views.
- Recognising that children's views are not always the same as those of their parents/carers.
- Understanding children and young people's perspectives of health and illness.
- Positioning the child or young person as the central member of the family–health professional partnership.
- Supporting and providing opportunities and space to enable children and young people to be active participants in their care and involving them in decision-making processes.
- Respecting children and young people's privacy and dignity.

(Soderback et al., 2011; Carter et al., 2014)

Children and young people need support to develop the confidence and communications skills to participate in decisions about their health in consultation with health professionals. Interventions to promote participation in consultations and support young people to develop communication skills when interacting with health professionals are emerging with positive outcomes (Milnes et al., 2014). The extent to which children can be fully involved in care depends on their age and developmental stage. Young children have the capacity to make complex decisions about the management of their condition, but many children want to share decisions with parents (Garnett et al., 2016). Although children want to be involved in decisions that impact on them, a UK national survey of almost 19,000

children's experiences of being in hospital identified that 43% of 12-year-olds felt they were not fully involved in decisions about their care (Care Quality Commission, 2015). Involving children and young people to participate in care and care decisions requires health professionals to hear, value and appreciate their views, which can be achieved by:

- Providing age-appropriate information for the child to express their views.
- Allowing children to tell the 'whole story' without interrupting.
- Remaining open-minded and non-judgemental.
- Viewing children's abilities and competencies as being different rather than of less importance to those of adults.
- Being alert to signs of distress in the child.
- Being aware of the impact of developmental and cultural factors, and that some children will not want to be involved in care and care decisions.
- Assuring or clearly identifying limits of confidentiality.

(O'Quigley, 2000)

Below, Georgia, a 3rd-year student nurse at the time of writing, shares her experience of implementing child-centred care for a young person.

CASE STUDY 1.3: GEORGIA

Throughout my child nursing degree, I gained theoretical learning around a range of aspects of nursing practice, including mental health and psychology when caring for children and young people. While working in practice, I was able to implement my knowledge and understanding of the recognition, management, and treatment of children with mental health illness. During my second year I undertook a placement within the Children and Adolescent Mental Health Service (CAMHS), where support and care is provided to children, young people with their mental health illness and their families. While working within the CAMHS service I learned the importance of understanding the child as a whole and not focusing just on their mental health illness. In one episode of care, I accompanied a consultant psychiatrist who was reviewing a young person with a history of self-harm and suicidal ideations and struggled to communicate their feelings and emotions, finding it difficult to open to health professionals. Whilst talking to the young person, I was able to introduce normal conversation that did not focus solely on their mood that day or their mental health, but a chance to talk about day-to-day things and find out more about them as a person. Building this relationship enabled the young person to become comfortable to share some of their experiences of living with their mental health and its impact on their daily life. During this experience, I learned the importance of gaining insight about the person as an individual, as well as understanding the impact of their mental health illness. It is essential when caring for children and young people to help them to manage their emotions, thoughts and feelings and provide tools that work for the individual, and tailored coping strategies.

- Georgia outlines useful strategies to develop therapeutic relationships with young people. Consider how you may do this with children of other age groups, for example preschool children or early adolescence.

FUTURE DIRECTIONS

While family-centred care has evolved and developed over time, implementation remains problematic (Shields, 2015; Kokorelias et al., 2019), which has been attributed to unclear roles and boundaries between parents and health professionals, entrenched professional practices and attitudes towards working with families, and lack of organisational or managerial guidelines aimed at supporting the implementation of patient-centred care (Smith, Swallow et al., 2015). In addition, although there is an extensive amount of literature, and research on family-centred care, evidence in relation to health outcomes for the child and family is limited (Shields, 2015). Research has primarily focused on observations of parent–nurse interactions, perspective of parents or family caregivers, and perspective of health professionals, and primarily in hospital settings (Harrison, 2010). While family-centred care is multifaceted and the complexity of attributing improved health outcomes specifically to family-centred care makes undertaking intervention studies challenging, additional research is needed to explore the outcomes for families, children and healthcare professionals, across care contexts, of family-centred care.

Child-centred care is a relatively new concept, and therefore children's nurses and child-focused researchers could work together to ensure child-centred care has a sound and robust evidence base and does not succumb to the criticisms of family-centred care. Current research is focusing on defining child-centred care and identifying its conceptual boundaries (Ford, Campbell et al., 2018), and researchers are already developing measures of child-centred care such as a self-reported psychosocial, physical, and emotional needs questionnaire for children in hospital (Foster et al., 2019).

Globally, healthcare delivery is shifting from treating acute illness to supporting people who manage with long-term conditions, necessitating health professionals to move from a position of care prescriber to one of collaborator, working in partnership with individuals and their families. Shared decision-making has gained prominence in clinical practice and is based on the premise that the patient has unique experiences and insights, while health professionals have experiences and knowledge of care in similar situations, with the aim that treatment and care decisions are mutually agreed (Entwistle, 2009). Empowering patients to self-manage their care has the potential to improve health outcomes; patients are more likely to respond and act on illness symptoms, use medicines and treatments more effectively, have greater understanding of the implications of professional advice and are better able to cope with their condition (Coulter et al., 2008). Shared decision-making has relevance for individuals with long-term conditions because the day-to-day care and management of their condition becomes primarily their responsibility and/or their families' responsibility.

CHAPTER SUMMARY

- Involving and supporting children and young people, as appropriate, and their families in care and care decisions should be embedded within children's nursing
- The models and frameworks to support children's nurses to work effectively with children, young people and families appear difficult to embed into everyday practice
- However, the underpinning principles of involvement are essential to effective care delivery and include: valuing parents' expertise and knowledge about their child; forming effective partnerships with the child and family; facilitating the child and family to participate in care delivery
- Successful involvement as highlighted in this chapter can be achieved through the process of negotiation, empowerment, and shared goal-setting, and ensuring effective information provision to enable the child and family to collaborate in care decisions

BUILD YOUR BIBLIOGRAPHY

Books

FURTHER READING

- Carter, B., Bray, L., Dickinson, A., Edwards, M. and Ford, K. (2014) *Child Centred Nursing: Promoting Critical Thinking*. London: Sage.

  Provides varied and contemporary perspectives on involving children and young people in their care.
- Smith, L. and Coleman, V. (eds) (2010) *Child and Family-Centred Healthcare: Concept, Theory and Practice*. 2nd ed. Basingstoke: Palgrave Macmillan.

  This book provides a useful introduction to the concept of child and family-centred care from a range of perspectives against the backdrop of child healthcare in the UK.

Journal articles

FURTHER READING: ONLINE JOURNAL ARTICLES

These articles will help you to explore some key concepts of child and family involvement in care and decision-making.

- Arabiat, D., Whitehead, L., Foster, M., Shields, L. and Harris, L. (2018) 'Parents' experiences of Family Centred Care practices'. *Journal of Pediatric Nursing*, 42: 39–44.
- Coyne, I. (2015) 'Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles'. *Health Expectations*, 18 (5): 796–808.
- Ford, K., Dickinson, A., Water, T., Campbell, S., Bray, L., and Carter, B. (2018) 'Child centred care: challenging assumptions and repositioning children and young people'. *Journal of Pediatric Nursing*, 43, e39–e43.

Weblinks

FURTHER READING: WEBLINKS

- www.nice.org.uk/guidance/ng204 NICE guideline making recommendations on providing a good patient experience for babies, children, and young people.
- www.ipfcc.org – Institute for Patient- and Family-Centered Care Website designed for health professionals, children, and families as a resource to highlight the importance of child and family participation in healthcare decisions and delivery. The Institute for Patient- and Family-Centered Care (IPFCC) is an American-based non-profit organisation founded in 1992 and aims to enhance understanding and practice of patient- and family-centred care. IPFCC serves as a central resource for policy-makers and patient and family leaders.
- https://incfcc.weebly.com/ – website detailing the work of The International Network for Child and Family Centred Care (INCFCC). The International Network for Child and Family Centred Care is a collaboration of experts from around the world who work together in research, practice development and education on the topic of child- and family-centred care.

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