Child and Family-Centred Care: promotion of Person-Centred Care

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Ireland....
Terms....

- Child-centred care
- Nurse-centred care
- Family-centred care
- Patient-centred care
- Person-centred care
Nurse-centred care (the past)
Family-Centred Care (the present)

- Family-centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients (Shields et al, 2012)

Problems with FCC
Summary of Problems with FCC

• Problems with implementation
• No evidence to say that it works
• Professional concept
• Takes away the focus from the child

Summary

**PERSON-CENTRED HEALTH CARE**
- Respect individual preferences & values
- Involve, empower & engage in health decision-making
- Relevant & comprehensive information
- Access appropriate services
- Right to choices

**FAMILY CENTRED-CARE**
- Value family as constant, with strengths & individuality
- Information sharing & collaboration
- Design care in response to family needs
- Encourage family-to-family support
- Respect cultural diversity

**SHARED DECISION-MAKING**
- Inclusion in Information exchange
- Discussions about healthcare options
- Taking part in decisions
- Sharing & agreeing decisions

**PARTNERSHIP IN CARE**
- Negotiation of roles
- Equality in patient-professional relationship
- Reciprocal shared responsibility for care
- Accurate, relevant & comprehensive information provision
- Facilitate decision-making

**Models of patient-professional collaboration**
Confused?
Key concepts

• Rights
• Respect, recognition
• Empowerment
• Choices
• Autonomy
• Partnership
• Information-sharing
• Shared decision-making
• Care, compassion, empathy
Child-Centred Care (now & the future)
Re-framing FCC and CCC

• The approach of family-centred care needs to be redirected towards a child-centred care approach which incorporates the rights of the child to participate in all aspects of health care delivery in conjunction with the need of their family (Söderbäck, Coyne, Harder, 2011)

• The care of children in all areas of child healthcare but specifically in nursing needs to be reframed through a child-centred lens (Coyne, Hallström, Söderbäck, in press)
What is Child-Centred Care?

• It is about considering each child’s preferences, values, family situations, social circumstances; seeing the child as an individual, and working together to develop appropriate solutions.
Theoretical frame

- Respect
- Inclusion
- Child centred care
- Opportunity, space
- Communication
Respecting children’s rights

• “States parties shall assure to the child who is capable of forming his or her own views, the rights to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (UNCRC 1989, Article 12)
Right to full participation

- Children need to be encouraged and enabled to make their view known on issues that affect them and the goals of ‘A World Fit for Children’ will only be accomplished with the full participation of children and young people (UNICEF 2003).
Contribute to decision-making

• The right, the means, the space, the opportunity and, where necessary, the support to freely express their views, to be heard and to contribute to decision making on matters affecting them, their views being given due weight in accordance with their age and maturity. Council of Europe Strategy for the Rights of the Child (2012-2015).
What does this mean?

- Right to be heard
- Right to information
- Right to participation
- Right to be involved in discussions
- Right to participate in decisions
- Right to make decisions
Need to balance protection with participation

- Respect for children as individuals, regardless of their age or capacity.
- Recognition of children’s developing capacity for autonomous agency
- Concern for children’s immediate and longer-term welfare.
Need involvement in communication

• Communication with children about their disease, treatment & care provision is poorly performed in practice (Scott 2003).

• Review of interventions to enhance communication concluded that the evidence was sparse and weak (Ranmal, 2008).
Need involvement in decision-making

- Légaré 2010 reviewed interventions for improving the adoption of SDM by healthcare professionals and concluded that the evidence was sparse and weak.

- Coyne et al (2013) reviewed interventions for promoting participation in shared decision-making for children with cancer and found no studies.
Need child-centred environment

• Children in hospital need to be cared for in an appropriate, safe, child centred environment by competent staff trained in the care of sick children.
Need better educated nurses

• We know that too many staff are still not adequately skilled. Some staff have training only in adult healthcare, whilst others do not have sufficient training in children and young people’s physical and mental health to enable them to undertake their work safely and well.

• Report Of The Children And Young People’s Health Outcomes Forum (2012, p52)
Need holistic care

- Excessive specialization of healthcare can discourage a holistic child- and family- centred approach to health, with adverse consequences for continuity of care.

Need to include children in research

• Research that is scientifically sound and ethically robust, that addresses questions of importance to the health of children and young people, should be seen as essential part of care.

The treatment and all that... you leave to them. You take it for granted they know what they are doing.

Everything else you’re told like, ‘If you don’t do this you will get sicker.’ So you have to do this. I don’t really get to make any decisions.

I usually don’t like making big decisions because I don’t really feel like it’s my place.

No my opinion doesn’t really matter ‘cause I have to go by their saying. I just have to do it. There aren’t decisions.
What is important to children?

- Having time to ask questions & express preferences
- Being heard and knowing if preferences can be facilitated
- Receiving explanations that they can understand
- Knowing what is happening before it happens
- Having guidance and support from parents & nurses on how to be prepare themselves
What you can do to help

• Promote engagement with and respect for children’s views as a core value of the healthcare system.
• Assess child’s understanding and tailor information to child’s needs
• Assess child’s and parents’ preferences for involvement and negotiate care accordingly
• Value child and parents’ knowledge and expertise
• Promote child-friendly environment
Hope you feel like this
You can make a difference

• The person who removes a mountain begins by carrying away small stones.
Tack för att du lyssna
.....frågor är välkomna

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Some references

• Coyne I, Hallström I & Söderbäck M (submitted) Reframing the focus from a family-centred to a child-centred care approach for children in healthcare. Journal of Child Health Care
References