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Implementing & evaluating models of family centred care for children with long term conditions - where next?

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Professor Imelda Coyne, Trinity College Dublin
Background

- Effective collaboration between nurses & families is fundamental to care delivery.
- Family-centred care model is widely espoused as an effective framework.
- Evidence suggests many parents perceive that:
  - They are not supported in their role as manager for their child’s condition.
  - Their expertise & contribution to care are not valued.
Rationale & aim

Usefulness of family-centred care model & how implemented & evaluated in practice requires further scrutiny.

Implementation

Evaluation

Complementary critical evaluations of family-centred care research, in the context of childhood long-term conditions, will be presented.
Embedding family-centred care into practice

- Family is a constant in child’s life
- Parent-professional collaboration facilitated
- Ethnic, cultural, socio-economic & diversity of families respected
- Family strengths & individuality respected
- Complete & unbiased information sharing
- Family-to-family support & networking encouraged & facilitated
- Healthcare practices respond to child & family developmental needs
- Policies & practices provide families with emotional & financial support
- Flexible design of health care services

Based on seminal work of Shelton & colleagues
Theoretical framework

Family-centred care

Value family as constant in the child’s life, with strengths & individuality
Respect individual preferences & values

Accurate & comprehensive information provision
Information sharing facilitates collaboration & partnership working

Patient-professional agree treatments/care plans
Design care in response to family needs
Negotiation of roles / shared responsibility for care

Access to appropriate services
Encourage family-to-family support
Scoping review of instruments measuring collaborative processes

Concept synthesis of family-centred care & partnership-in-care

Focussed on application to childhood long-term conditions
### Methods

<table>
<thead>
<tr>
<th>MEDLINE, CINAHL, PSYCINFO databases searched from 2000 to 2014 to identify instruments that measured family-centred care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scopus, CINAHL, BNI databases searched from 1999-2014 to identify research on implementing family-centred care in practice</td>
</tr>
</tbody>
</table>
INSTRUMENTS THAT MEASURE FAMILY-CENTRED CARE

Other sources (hand search/reference lists/conferences) n = 17

Database Searching n = 1463

Excluded title screen n = 1329

Full text-article assessed for eligibility n = 151

Excluded full article screen n = 99

Studies included in the review n = 52

Shared decision-making (n = 26)

Partnership in care (n = 6)

Family centred-care (n = 16)

Patient-centred health care (n = 4)
**FAMILY-CENTRED CARE**

- **Other sources**
  - n = 3

- **Database searching**
  - n = 376

  - Excluded after title screen
    - n = 324

  - Full text-article assessed for eligibility
    - n = 52

  - Excluded after full article screen
    - n = 32

- **Studies included in the review**
  - n = 20

- **Studies included in the review**
  - Remove duplicates
    - n = 33

**TOTAL INCLUDED STUDIES**

- n = 30

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**PARTNERSHIP in CARE**

- **Database searching**
  - n = 222

  - Excluded after title screen
    - n = 185

  - Full text-article assessed for eligibility
    - n = 37

  - Excluded after full article screen
    - n = 24

- **Studies included in the review**
  - n = 13

**TOTAL INCLUDED STUDIES**

- n = 30
16 studies related to family-centred care

- Processes of Care (MPOC) most used measure; self-report of parents’ perceptions of care

- Measures not specifically developed to evaluate family-centred care in the context of long-term conditions in children
Antecedents & attributes of family-centred care

- 23 studies included relating to embedding family-centred care in practice

- Antecedents: ‘unclear roles & boundaries’ ‘entrenched professional practices & attitudes’ ‘lack guidelines / policies supporting family-centred care’

- Attributes: ‘valuing parents knowledge & experiences’ ‘supporting parents role as care giver’ ‘incorporating parents expertise into care delivery’
# Measures of patient-centred care models

<table>
<thead>
<tr>
<th>Model</th>
<th>Validated Instruments</th>
</tr>
</thead>
</table>
| Shared decision-making (n = 26)       | COMRADE (Edwards et al 2003)  
CONNECT (Haidet et al 2008),  
OPTION (Elwyn et al 2003)  
Control Preference Scale (Degner 1997)  
Decisional Conflict Scale (O’Conner 1995)  
Perceived Involvement of Care Scale (Lemann et al 1995)  
Shared Decision-Making Questionnaire  
Decisional Conflict Scale) (O’Conner 1995) |
| Family centred-care (n = 16)          | Measure of Processes of Care (MPOC -20, MPOC -56 & MPOC-SP)                                                                                           |
| Partnership in care (n = 6) & Patient-centred health care (n = 4) | No validated measures identified                                                                                                                         |
### Framework for involving parents in care of a child with long-term condition

<table>
<thead>
<tr>
<th>Domain</th>
<th>Valuing parents’ knowledge &amp; experiences</th>
<th>Supporting parents in their role as care giver</th>
<th>Incorporating parents’ expertise into clinical &amp; psychosocial care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative processes</td>
<td>Developing effective parent-professional relationships</td>
<td>Negotiating with parents preferred level of support</td>
<td>Ensuring transparency of participatory processes</td>
</tr>
<tr>
<td>Actions</td>
<td>Elicit &amp; respond to parents’ concerns</td>
<td>Mutual information exchange</td>
<td>Involving parents in diagnosis &amp; treatment decisions</td>
</tr>
<tr>
<td></td>
<td>Establishing rapport - develop a trusting relationship through clear communication, learning about family context , active listening &amp; share parents’ experiences</td>
<td>Establish parents’ contribution to child’s clinical care &amp; desired level of involvement</td>
<td>Facilitate parents to express their opinions about care decisions</td>
</tr>
<tr>
<td></td>
<td>Share decisions with parents &amp; other professionals; collaborate when planning care</td>
<td>Share decisions with parents &amp; other professionals; collaborate when planning care</td>
<td>Incorporate parents’ knowledge of child &amp; care experiences in assessment, planning, delivery &amp; evaluation of care</td>
</tr>
</tbody>
</table>

Smith, Swallow & Coyne, 2015
Key messages

- Promoting & facilitating involvement requires nurses to work collaboratively with the family.
- Tools measuring the implementation of & evaluation of family centred-care are limited & need to be informed by evidence & appropriate theories.
- Implementation of family-centred care remains problematic.
Thank you for listening

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References


