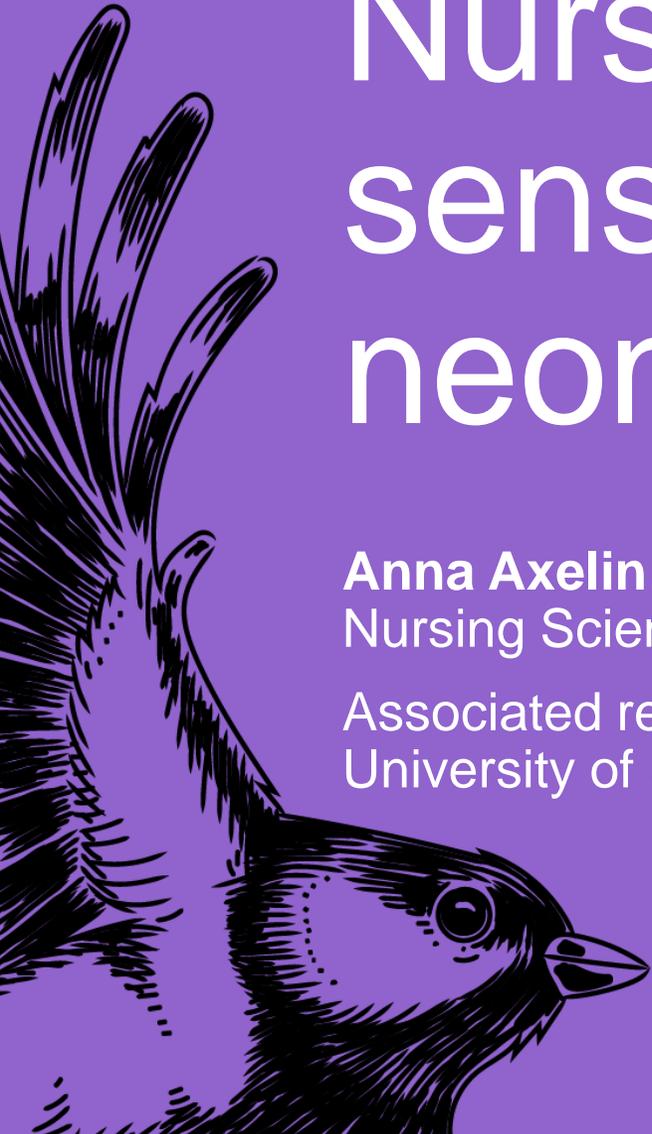


Nursing and parenting sensitive outcomes in neonatal care

Anna Axelin, RN, PhD, Associate Professor, Department of Nursing Science, Finland

Associated researcher, International Maternal and Child Health, University of Uppsala, Sweden



**TURUN
YLIOPISTO**
UNIVERSITY
OF TURKU

Definitions

- Outcome research
 - Investigates the outcomes of care
 - Relates these outcomes to attributes of care delivery
 - Quantitative by nature
 - Data obtained from pre-existent sources e.g. registries, administrative databases
- Nursing/parenting sensitive outcome
 - Outcome influenced by nursing/parenting care, decisions, actions, or attributes
 - May not be caused by nursing/parenting, associate with them
- Outcomes should be determined based on what **parents** expect and want

Reflections for this lecture

- All outcomes (**medical, nursing and parenting**) are a result of collaboration between staff and families
- Who has the main competencies, responsibility and **power** to influence on a certain outcome?
- Which ones are important to follow?
 - **Those which predict**
 - Parent well-being
 - Infant development
 - Healthcare costs
 - Staff satisfaction, burnout
- Who should evaluate which outcome and when?



Donabedian's framework of quality

(Donabedian 1988, McDonald KM et al. 2007)

- Structure (context of care) – unit architecture, equipment of care, staff education/skills, staff resources
 - Processes (actions) – degree of patient participation, patient-practitioner interaction, actions taken by patients & their families
 - Outcomes (effects of care) – satisfaction with care, health and well-being – the most important indicator of quality
- When possible, outcomes should be clearly linked with the processes and structures



Nursing sensitive outcomes

- What are the core outcome of neonatal nursing?
- My suggestions for you to consider:
 - 1) Structure of care - Nursing resources (knowledge, skills, patient/nurse ratio), architecture (single family rooms/open bay), organization of care (maternity/neonatal care, couplet care)
 - Preferably variables that are available in administrative databases
 - 2) Process of care - Family centred care
 - 3) Outcomes of care - Parents well-being: anxiety, stress and depressive symptoms

2) FCC measures

- process

Symptoms of depression in parents after discharge from NICU associated with family-centred care

Anna Axelin^{1,2} | Nancy Feeley^{3,4} | Marsha Cambell-Yeo⁵ | Bente Silnes Tandberg⁶ | Tomasz Szczapa⁷ | Joke Wielenga⁸ | Janne Weis⁹ | Anita Pavicic Bosnjak^{10,11} | Raket B. Jonsdottir¹² | Kendall George¹³ | Ylva T. Blomqvist^{14,15} | Kajsa Bohlin^{16,17} | Liisa Lehtonen^{18,19} | Separation, Closeness Experiences in Neonatal Environment (SCENE) research group

TABLE 3 The means and standard deviations for each DigiFCC-P item and total scores for the mothers and fathers

	Mother (n=564)		Father (n=404)	
	M	SD	M	SD
1. To what extent did the staff listen to you today?	6.18	1.24	6.21	1.26
2. To what extent did you participate in your baby's care today?	5.81	1.63	5.46	1.77
3. To what extent did the guidance provided by the staff meet your needs today?	6.02	1.37	6.22	1.20
4. To what extent was your opinion considered in decisions made about your baby today?	5.53	1.74	5.55	1.81
5. To what extent did you trust the staff in the care of your baby today?	6.28	1.18	6.27	1.19
6. To what extent did the staff trust you in the care of your baby today?	6.30	1.26	6.33	1.15
7. To what extent did you participate in discussions during the doctor's round/visit?	4.63	2.35	4.74	2.30
8. To what extent did the information provided by the staff meet your needs today?	6.09	1.30	6.10	1.31
9. To what extent did the staff offer you emotional support today?	5.28	1.87	5.31	1.83
Total	5.92	0.77	5.84	0.83

Note: M and SD indicate mean and standard deviation respectively.

TABLE 4 The means and standard deviations for each FCCQ subscale and total scores for the mothers and the fathers at discharge.

	Mother (N = 553)		Father (N = 354)	
	M	SD	M	SD
Respect Subscale Total	3.47	0.47	3.44	0.51
Collaboration Subscale Total	3.41	0.43	3.35	0.44
Support Subscale Total	3.19	0.55	3.12	0.58
FCC Measure Total	3.37	0.38	3.32	0.40

Note: M and SD indicate mean and standard deviation respectively.

- Short measures - 9 and 20 questions
- Both tools correlated with parental depression (outcome)
- Evaluation during hospitalization or at discharge by parents
- Risk for ceiling effect

3) Parental well-being - outcomes

Edinburgh Postnatal Depression Scale¹ (EPDS)

Name: _____ Address: _____

Your Date of Birth: _____

Baby's Date of Birth: _____ Phone: _____

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt **IN THE PAST 7 DAYS**, not just how you feel today.

Here is an example, already completed.

I have felt happy:

- Yes, all the time
 Yes, most of the time This would mean: 'I have felt happy most of the time' during the past week.
 No, not very often Please complete the other questions in the same way.
 No, not at all

In the past 7 days:

- | | |
|---|--|
| <p>1. I have been able to laugh and see the funny side of things</p> <ul style="list-style-type: none"> <input type="checkbox"/> As much as I always could <input type="checkbox"/> Not quite so much now <input type="checkbox"/> Definitely not so much now <input type="checkbox"/> Not at all | <p>*6. Things have been getting on top of me</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, most of the time I haven't been able to cope at all <input type="checkbox"/> Yes, sometimes I haven't been coping as well as usual <input type="checkbox"/> No, most of the time I have coped quite well <input type="checkbox"/> No, I have been coping as well as ever |
| <p>2. I have looked forward with enjoyment to things</p> <ul style="list-style-type: none"> <input type="checkbox"/> As much as I ever did <input type="checkbox"/> Rather less than I used to <input type="checkbox"/> Definitely less than I used to <input type="checkbox"/> Hardly at all | <p>*7. I have been so unhappy that I have had difficulty sleeping</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, most of the time <input type="checkbox"/> Yes, sometimes <input type="checkbox"/> Not very often <input type="checkbox"/> No, not at all |
| <p>*3. I have blamed myself unnecessarily when things went wrong</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, most of the time <input type="checkbox"/> Yes, some of the time <input type="checkbox"/> Not very often <input type="checkbox"/> No, never | <p>*8. I have felt sad or miserable</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, most of the time <input type="checkbox"/> Yes, quite often <input type="checkbox"/> Not very often <input type="checkbox"/> No, not at all |
| <p>4. I have been anxious or worried for no good reason</p> <ul style="list-style-type: none"> <input type="checkbox"/> No, not at all <input type="checkbox"/> Hardly ever <input type="checkbox"/> Yes, sometimes <input type="checkbox"/> Yes, very often | <p>*9. I have been so unhappy that I have been crying</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, most of the time <input type="checkbox"/> Yes, quite often <input type="checkbox"/> Only occasionally <input type="checkbox"/> No, never |
| <p>*5. I have felt scared or panicky for no very good reason</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, quite a lot <input type="checkbox"/> Yes, sometimes <input type="checkbox"/> No, not much <input type="checkbox"/> No, not at all | <p>*10. The thought of harming myself has occurred to me</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes, quite often <input type="checkbox"/> Sometimes <input type="checkbox"/> Hardly ever <input type="checkbox"/> Never |

Administered/Reviewed by _____ Date _____

¹Source: Cox JL, Holden JM, and Sagovsky R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry* 150:782-796.

²Source: K. L. Wisner, B. L. Parry, C. M. Plontek, Postpartum Depression *N Engl J Med* vol. 347, No. 3, July 18, 2002, 194-199

Users may reproduce the scale without further permission providing they respect copyright by quoting the names of the authors, the title and the source of the paper in all reproduced copies.

	Mothers		Fathers		p-value
	Mean	SD	Mean	SD	
Sights and sounds	1.86	0.79	1.74	0.77	0.352
Looks and behave	1.57	1.02	1.65	0.90	0.508
Parental role	3.29	1.22	2.84	1.24	0.095
Total score	2.09	0.90	1.99	0.80	0.555

NICU stress & anxiety

- PSS-NICU (Miles et al. 1993)
- Spielberger State-Trait Anxiety Inventory (STAI) - 20 items, rated 1–4 with a total score ranging from 20 to 80. Captures subjective anxiety with respect to one's present situation. **A score of 41 or greater indicates clinically significant anxiety.**

- Parental well-being has been measured years after the infant discharge
- Choose the right tool for each measurement point
- Diagnostic qualities: access to care must be secured if needed

Parenting sensitive outcomes

- What are the core outcome of parenting in NICU?
- My suggestions for you to consider:
 - 1) Structure of care - Social support
 - 2) Process of care - Participation in care (decision-making, presence, skin-to-skin care)
 - 3) Outcomes of care - Readiness for discharge (or breastfeeding)

1) Social support – structure

- Duke-UNC Functional Social Support Questionnaire (FSS) (Broadhead et al. 1988)
- Includes 14 items describing different types of support (e.g. visits with friends and relatives, help around the house, help with money, people who care what happens to me)
- Tool has explained 21%-26% of the variance in depression, anxiety and post-traumatic stress symptoms at 3-months after discharge (**outcomes**) (Haeusslein et al. 2021)

Duke-UNC Functional Social Support Questionnaire

HERE IS A LIST OF SOME THINGS THAT OTHER PEOPLE DO FOR US OR GIVE US THAT MAY BE HELPFUL OR SUPPORTIVE. PLEASE READ EACH STATEMENT CAREFULLY AND PLACE A CHECK (✓) IN THE BLANK THAT IS CLOSEST TO YOUR SITUATION.

HERE IS AN EXAMPLE:	As much as	Much less
I get . . .	I would like	than I
enough vacation time	_____ ✓ _____	would like

If you put a check where we have, it means that you get almost as much vacation time as you would like, but not quite as much as you would like.

ANSWER EACH ITEM AS BEST YOU CAN. THERE ARE NO RIGHT OR WRONG ANSWERS.

I get . . .	As much as I would like	Much less than I would like
1.* visits with friends and relatives	_____	_____
2.* help around the house	_____	_____
3.* help with money in an emergency	_____	_____
4.* praise for a good job	_____	_____
5. people who care what happens to me	_____	_____
6. love and affection	_____	_____
7.* telephone calls from people I know	_____	_____
8. chances to talk to someone about problems at work or with my housework	_____	_____
9. chances to talk to someone I trust about my personal and family problems	_____	_____

2) Participation in care – process

- CO-PARTNER tool (van Veenendaal al. 2021)
- Measures parent participation and collaboration with 6 domains (31 items): Daily care, Medical care, Acquiring information, Parent advocacy, Time spent with infant, and Closeness and comforting the infant
- Higher scores correlated with less parent depressive symptoms, less impaired parent-infant bonding, higher parent self-efficacy, and higher parent satisfaction (**outcomes**)
- Parents in a family integrated care model had higher scores than in standard care (**link to nursing process**)

Table 1. CO-PARTNER tool.

Activity	Response
Domain 1. Daily Care	
1. Bath my child/clean my child with a washcloth.	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable
2. Change my child's diaper.	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable
3. Feed my child (breast or bottle).	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable
4. Change my child's clothing.	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable
5. Get my child out of the incubator/cradle.	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable
6. Give my child medication.	<input type="radio"/> The nurse does this <input type="radio"/> I do this together with the nurse <input type="radio"/> I do this independently (without the help of the nurse) <input type="radio"/> This is not applicable

3) Readiness for discharge – outcome

- Measures 4 domains of discharge readiness: **Personal status** (how the patient feels on the day of discharge); **Knowledge** (the patients knowledge about care after discharge); **Perceived Coping Ability** (how the patient will be able to cope at home); **Expected Support** (how much help the patient will have if/when needed at home).
- Administered on the day of discharge
- Patient self-report tool and nurse assessment tool

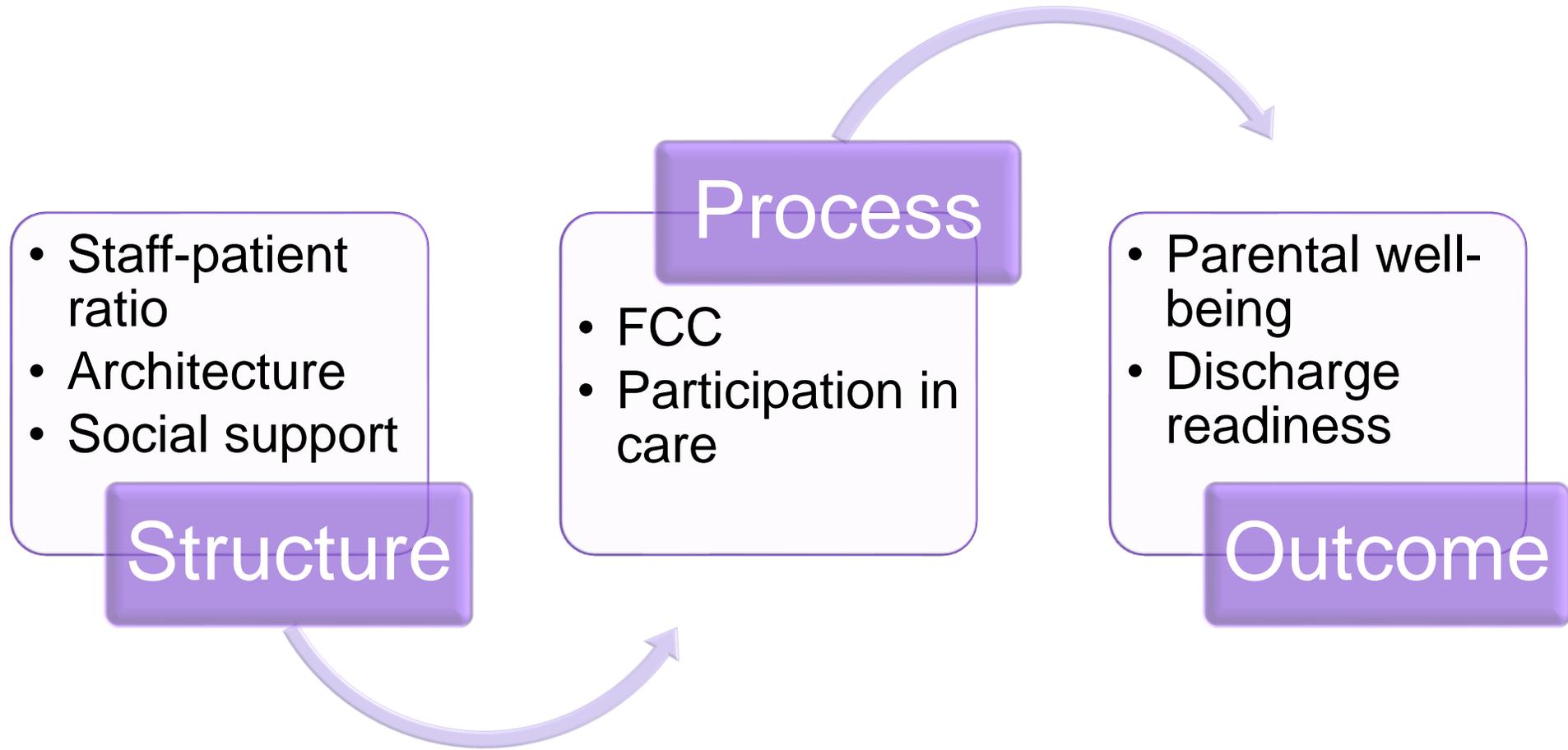
READINESS FOR HOSPITAL DISCHARGE SCALE -- PARENT -- SHORT FORM ©

Please check or circle your answer. Most of the responses are on a 10-point scale from 0 to 10. The words below the number indicate what the 0 or the 10 means. Pick the number between 0 and 10 that best describes how you feel. For example, circling number 7 means you feel more like the description of number 10 than number 0 but not completely.

1a. How would you describe <u>your</u> strength today?	0 1 2 3 4 5 6 7 8 9 10 Weak Strong
1b. How would you describe <u>your child's</u> strength today?	0 1 2 3 4 5 6 7 8 9 10 Weak Strong
2. How much do you know about problems to watch for after you go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
3. How much do you know about what your child is allowed and not allowed to do after you go home?	0 1 2 3 4 5 6 7 8 9 10 Know nothing at all Know all
4. How well will you be able to handle the demands of life at home?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely well
5. How well will you be able to perform your child's medical treatments (for example, caring for a wound, breathing treatments, using equipment, or giving medications in the correct amounts and at the correct times) at home?	0 1 2 3 4 5 6 7 8 9 10 Not at all Extremely well
6. How much help will you have, if needed, with <u>your child's personal care</u> after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal
7. How much help will <u>you</u> have, if needed, with household activities (for example, cooking, cleaning, shopping, babysitting) after you go home?	0 1 2 3 4 5 6 7 8 9 10 None A great deal

© Dr. Marianne Weiss, DNSc,RN
marianne.Weiss@marquette.edu

Who has the major influence on what?



Power balance between staff & parents

Family Centered Care = Partnership

- **Mutuality & shared goals** (infant well-being & optimal health)
 - **Shared responsibility** - information, decision-making and caretaking
 - **Negotiation** - defines roles and responsibilities, parents choose their level of involvement
 - **Parent autonomy and control** - parents will evolve experts in infant's care
 - **Support of family** - emotional support, parents advocate for the infant best

Conclusions

- Important to understand how structural, process and care outcome variables link to each other
 - Which ones to measure?
 - Those which are linked to and measure infant development?
- What are the important variables from family perspective?
- Choose measures that are valid, reliable, sensitive and feasible
- Your thoughts?



Photo Credit:
Turku University Hospital



**UNIVERSITY
OF TURKU**

Thank you!

anna.axelin@utu.fi