

COMPLEX COPING AND COMPLEX CARING:

THE EXPERIENCES OF FAMILIES AND HEALTHCARE PROFESSIONALS SUPPORTING PEOPLE WITH DISORDERS OF CONSCIOUSNESS.

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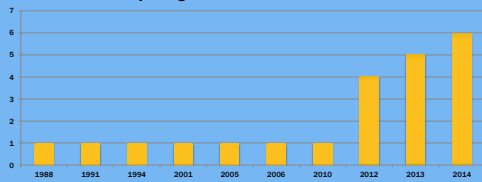


THE BIG 4 QUESTIONS IN 40 MINUTES

- What is known about families psychological experiences in DoC?
- What is it like to have a close relationship with someone with a DoC?
- What do Healthcare professionals think and feel about their work with families of people with DoC?
- Can an intervention with healthcare professionals boost their knowledge and sense of confidence at better supporting families of people with DoC they work with?

UNTIL RECENTLY LITTLE HAS BEEN STUDIED ABOUT DOC FAMILIES

Number of articles published on families of people with a prolonged disorder of consciousness



Soeterik, S.M, Connolly, S., Playford, D., Dupont, S. & Riazi, A. In preparation. The psychological impact of prolonged disorders of consciousness on families: A systematic review of quantitative studies.

WHAT DOES A DISORDER OF CONSCIOUSNESS IN THE FAMILY MEAN?

- 1. Loss and grief
- 2. Wellbeing changes
- 3. Burden
- 4. Coping
- Time alone does not improve things
- Gender has little difference
- Some will manage alone, others will need professional help



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AREN'T THEY JUST "NORMAL"?

- Encourage clinicians to respect the variety of ways families may cope with the injury
- See these as normal responses to an abnormal and deeply distressing situation



Kitzinger C, Ritzinger J. (2014). Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising. *Clinical Rehabilitation*, 28, 29 (7), 627-632.

AREN'T THEY JUST "NORMAL"?

- "...personal and family problems – not because of flaws in the psyches ... but because of situations beyond their control or outside the constraints that block the coping and grieving response"



Pauline Boss (1999)

Ambiguous Loss:
"A goodbye without leaving"

WHAT IS IT LIKE TO HAVE A CLOSE RELATIONSHIP WITH SOMEONE WITH A DOC?

- **Aim:** explore the experience of women who have a close relationship with a person with a disorder of consciousness.
- 9 semi structured interviews with female primary caregivers
- Analysed using Interpretative Phenomenological Analysis (IPA)
- 4 key findings



Seetick, S.M., Connolly, S., & Riess, A. In preparation. The experiences of females supporting family members with a disorder of consciousness: An interpretative phenomenological analysis.

FINDINGS

Super-ordinate themes	Sub-themes
LOSS WITHOUT A NAME "who I know is gone but there's still a body there"	Not a death and worse than a death Constant threats of loss
RELATIONSHIP WITHOUT A TITLE "what's my relationship with him?"	Not being known Unreciprocated one-sided relationship Transformed relationship not easily understood
SYMBIOTIC RELATING "We've never been assessed"	Advocacy Abandonment Fighting with professionals
FROZEN FUTURES "This is how she is"	Coping with an uncertain prognosis

LOSS WITHOUT A NAME:

"WHO I KNOW IS GONE BUT THERE'S STILL A BODY THERE"

- "...**you either get up or you die**. Simple. There's nothing in between, well ...I didn't know there was **anything in between**..."
Anna
- "he went on the [the date of the accident], that, that's you know, **the person I see I don't feel is him**. I don't really see much of [my partner] in him really"
Kate

RELATIONSHIP WITHOUT A TITLE: "WHAT'S MY RELATIONSHIP WITH HIM?"

- I'm quite worried **about society** in a sense, its like, you know, am I, **am I single? Do I still have a partner**, yes I have a partner, but he's, I haven't spoken to in 9 months, **that whole where do you fit?**
Rebecca
- "Well, he can **no longer a be a proper husband** to me. He can't, **he can't return the feelings**. Um but I'll always, always love him, um but that sort of husband/wife relationship, doesn't really exist anymore. It's **evolved into something different** really. Um but that in itself takes time to adjust yourself to. So again, I just try to not sort of think too hard about it".
Jessica

SYMBIOTIC RELATING: "WE'VE NEVER BEEN ASSESSED"

- "You know, and **we never had the rehab** because he wasn't well enough. As I say I'm really cross about that, yeah **I feel really cheated**..." Anna
- "And **we've had period of stability** but then we just got another infection which is kind of **thrown it all out again**"
Jessica
- "because he can't speak and say the things, so that you're having to **advocate on his behalf**. And it's partially, **you know his medical history so well now**" Samantha

FROZEN FUTURES: "THIS IS HOW SHE IS"

- "I try to not look too far into **the future**, because **it's overwhelming**". Jessica
- "mmm....its just the **permanence** of it all I think, if he'd died, that would be it - it would be over, but we haven't got that, we've got this for 5 years? 10 years? 15 years? 20 Years? **We don't know**. We don't know if we'll ever get any more, ...we just don't know, ...and **that's the worst thing of all**" Anna
- I'm reading **bits that he would've have enjoyed** and what he would be interested in, not necessarily, what I would be interested in, but that **I found myself really enjoying them** which is interesting" Jessica

What families describe	Post modern grief/loss theory
Coping with someone they love who is there but – not there	Ambiguous Loss (Boss, 1999)
A loss that is not validated, recognised or acknowledged by others –as there is no death	Disenfranchised Grief (Doka, 1989)
Everything is different and they are moving between loss and having to keep on keeping on	The Dual Process Model (Stroebe & Schut, 1999)
Finding a new way of remaining bonded	Continuing Bonds Theory (Klass, Silverman & Nickman, 1996)
Trying to make sense of what has happened and what this means	Meaning-Making in Bereavement (Neimeyer, 2006)



EXPERIENCES OF HEALTH CARE PROFESSIONALS SUPPORTING PEOPLE WITH PDOC



- Mixed Method: basic demographic and burnout questionnaire
- 3 focus groups (n=21) MDT healthcare professionals employed at a national specialist referral service for patients with PDOC.
- Participants had to be able to converse in English satisfactorily to participate in talking based focus group and read and write to complete the questionnaire.

Soeterik, S.M., Connolly, S., Playford, D., Dupont, S., & Rizzi, A. In preparation. The experiences of healthcare professionals working with people with disorders of consciousness...

SUPPORTING FAMILIES

Activity	Percentage of participants
Things to support families within last week	95%
Things done were within their professional role	68%
Received specific training to support families	27%
Interaction was upsetting to the healthcare professional	18%
Pre-planned contact with families over past week	53%
Ad hoc contact with families over past week	89%
Contact focused on emotional support to family	68%
Contact focused on educational support to family	58%
Contact focused on managing concerns raised by family	58%

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FINDINGS IMBALANCE...



- (1) use of clinical time spent with the patient versus their wider networks
- (2) managing families hope versus their grief
- (3) managing the professionals own self care versus care for the family in distress
- (4) knowing what is contracted versus the sense of what is right or required
- (5) coping with the loss of the old person in the presence of the new person

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USE OF CLINICAL TIME: AD HOC COMMUNICATION IMPACTS ON PATIENTS

- *"Yeah, like you could have another patient timetabled, but a family member will catch you, talk to you for 20 minutes ... they're eating into another patient's therapy time... And it's really difficult to try to get out of conversations, even when you say you have another patient and you've got to move on, they just ... I think it's quite difficult because families can only catch you at certain times, once they catch you, they kind of don't want to let go of you. See, that does affect other patients."*

Soeterik, S.M., Connolly, S., Playford, D., Dupont, S., & Rizzi, A. In preparation. The experiences of healthcare professionals working with people with disorders of consciousness.

MANAGING FAMILIES HOPE VERSUS THEIR GRIEF

- *"Sometimes when you come away and reflect on how a conversation went you wish I was a bit more, I wish I had couched it, rationalized about it, wish I had... or the other way where you reflect you did that too much and you were too kind of blunt, or too kind of, you know what I mean, its such a fine, fine, delicate balance between being realistic and giving people accurate information, not colluding with them, not you know... but doing it in a supportive way but allowing them to retain a measure of hope because that is so important to them going forward, its such a fine line to tread, we haven't had that kind of specialist training"*

MANAGING THE PROFESSIONALS OWN SELF CARE VERSUS CARE FOR THE FAMILY IN DISTRESS

- "... there's the idea of losing your loved one and yet not losing them... And that's really ... that's ... I don't know, it must be so so hard, and then, yeah, it is quite big, life and death questions you're faced with."
- *"That's one of the hardest parts, like this was what they were like before. You kind of end up just dissociating a little bit, don't you, to make it easier to work with, but I do find that really sad, for me its to see the photos up around the bed."*

Soeterik, S.M., Connolly, S., Playford, D., Dupont, S., & Razi, A. In preparation. The experiences of healthcare professionals working with people with disorders of consciousness.

PEOPLE CARING FOR PEOPLE...



- Highly skilled in own role
- No direct training on families in professional training
- Understandings of loss/ grief/adjustment outdated
- Expectations about what = success
- Many HCP task focused roles - Family distress doesn't lend itself to being "fixed"
- Feel working with families is part of their clinical role
- But that systemic work with families more challenging than direct clinical role
- Burnout

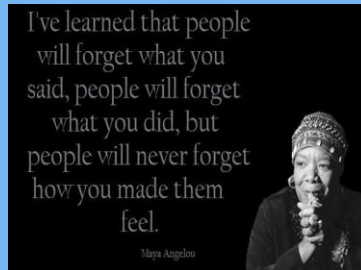
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PSYCHO-EDUCATIONAL TRAINING SESSION

- Single session training session
- (n = 56) multi disciplinary healthcare professionals who work with people with disorders of consciousness
- Pre and post self rated measures of confidence and knowledge on how to best support families when distressed
- Standardised measures of attitude to collaboration with families (Family and Staff Relationship Attitude Tool) and general self efficacy (New general Self Efficacy Scale)
- Lecture style psycho-educational training session (60 minutes)
- Loss and grief models, family experiences, staff experiences, techniques and aims of contact



Soeterik, S.M., Connolly, S. & Razi, A. In preparation. The effectiveness of psycho-educational training education to healthcare professionals supporting people with a disorder of consciousness.



"WHAT SHOULD I SAY WHEN"....

RESULTS

- Overall participants rated a they gained more knowledge of psychological models and that framework helped participants feel more confident in responding to families in distress.
- 80% thought they had a degree of awareness about families needs before the training session but 90% felt they had gained new knowledge by attending
- 57% identified a greater degree of confidence at supporting a distressed family member in an ad hoc setting
- 43% more confident in a scheduled session with a family



CLINICAL IMPLICATIONS

- Training/induction on post modern loss models and systemic working for supporting families
- Psychological support to demonstrate a sensitivity to this unique complex loss, a validation of their loss, a framework for naming the loss, provision of education about the condition and ways to enhance coping with a chronic situation seem useful starting points
- Combine training with a supervision and reflective practice group to enable healthcare professionals to have key learning opportunities through their practice
- Support for healthcare professionals themselves to manage the challenging nature of this work and what it means to work with disorders of consciousness to them

CLINICAL IMPLICATIONS

- Increase thinking about the family system rather than just focus on the identified patient
- Recognition of families and validation of their relationship with with the injured person
- Consider how we meet the information and support needs of families – are MDT meetings the best approach?

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