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

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

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

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)
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

FINDINGS

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Sub-Themes</th>
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<tr>
<td>LOSS WITHOUT A NAME</td>
<td>Not a death and worse than a death</td>
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<td>&quot;who I know is gone but there's still a body there&quot;</td>
<td>Constant threats of loss</td>
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<tr>
<td>RELATIONSHIP WITHOUT A TITLE</td>
<td>Not being known</td>
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<tr>
<td>&quot;what's my relationship with him?&quot;</td>
<td>Unreciprocated one-sided relationship</td>
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<tr>
<td>SYMBIOTIC RELATING</td>
<td>Advocacy</td>
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<td>&quot;We've never been assessed&quot;</td>
<td>Abandonment</td>
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<td>FROZEN FUTURES</td>
<td>Coping with an uncertain prognosis</td>
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<tr>
<td>&quot;This is how she is&quot;</td>
<td>Fighting with professionals</td>
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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 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

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.

SUPPORTING FAMILIES

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage of participants</th>
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<tr>
<td>Things to support families within last week</td>
<td>95%</td>
</tr>
<tr>
<td>Things done were within their professional role</td>
<td>68%</td>
</tr>
<tr>
<td>Interaction was upsetting to the healthcare professional</td>
<td>18%</td>
</tr>
<tr>
<td>Pre-planned contact with families over past week</td>
<td>53%</td>
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<tr>
<td>Ad hoc contact with families over past week</td>
<td>89%</td>
</tr>
<tr>
<td>Contact focused on emotional support to family</td>
<td>68%</td>
</tr>
<tr>
<td>Contact focused on educational support to family</td>
<td>58%</td>
</tr>
<tr>
<td>Contact focused on managing concerns raised by family</td>
<td>58%</td>
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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.”


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 hadn’t 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, it’s... 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.”

"... 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."

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

PSYCHO-EDUCATIONAL TRAINING SESSION

RESULTS

CLINICAL IMPLICATIONS

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

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

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 the injured person
- Consider how we meet the information and support needs of families – are MDT meetings the best approach?

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