

Exploring Family Care Partners' and OTs' Hope When Caring for a Person With Disordered Consciousness Resulting From a Brain Injury

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PURPOSE: The purpose of this study is to describe family care partners' (FCP) and rehabilitation practitioners' (RP) ways of practicing hope in clinical encounters when caring for persons in disordered consciousness (DOC) after severe brain injury. Hope is a practice about creating 'lives worth living in the midst of suffering' that can 'forge new communities of care that span clinical and familial worlds' (Mattingly, 2010).

DESIGN: Qualitative design using narrative interviewing methodology and grounded theory analysis. Cross-disciplinary research team includes family care partners, occupational therapists, speech language pathologists, phenomenologist, and students.

METHOD: Snowball sampling recruited FCPs and RPs. Interviews followed semi-structured interview guides and either occurred in person or using videoconferencing software. FCPs and RPs interviewed participants. Interviews were audio-recorded and transcribed verbatim. Coders reviewed the transcript three or more times prior to manually coding. Coders wrote memos to provide insight on their assumptions and how ideas evolved. At least two members of the team reviewed and independently coded all data. Codes were reviewed with at least three members of the team who interviewed participants to ensure analytic rigor. Codes were collated into categories and themes, then reviewed by the team to ensure each code was reflective of finalized themes; leading to the development of a codebook.

RESULTS: Fourteen FCPs of a loved one in DOC and 21 RPs participated in 1:1 semi-structured interviews. FCPs and RPs describe their interactions with each other as impacting their perceptions of supporting or inhibiting hope. FCPs and RPs shared the ways they practice hope in the midst of the epistemic ambiguity and fluctuating uncertainty of caring for persons in DOC. Both use hope as a strategy to respond to the unique challenges of DOC. Both hope for recovery, yet they don't hope in the same ways. FCPs described their quest for hope in everyday moments such as when their loved one sighs or twitches in a familiar way suggesting that their loved one is "in there." When RPs 'made a big deal of' loved one's behavior, FCPs experienced hopefulness. When FCPs perceived RPs as "just doing their job," or giving them "worst case scenario" explanations, FCPs expressed not receiving hope or even having their hope "crushed." Caring for their loved ones changed FCPs (new roles include everyday caring, advocating, being educated about DOC, interacting with many practitioners and healthcare systems, changing jobs or taking on financial burdens) and hoping is a practice that comes with their transformation. RPs express hope by setting goals and developing treatment plans. RPs use clinical assessments to evaluate patient recovery and prognosis as a way of reducing the inherent ambiguity of DOC including communicating about patient progress to FCPs. RPs use their clinical tools to envision a hopeful future for their patients. When RPs communicate with FCPs, they don't want to "take away hope" by negating caregivers' experiences of their loved one's behavior, but they also don't want to offer "unrealistic hope."

CONCLUSION: FCPs and RPs practice hoping in unique ways based on their experiences and relationships with each other. Hope may be expressed in narrative plots such as "healing as transformative journey" or "healing as a science detective story" (Mattingly, 2010). In these plots, hoping may fulfill different needs.

IMPACT STATEMENT: Understanding hope within the unique life-worlds of family care partners and rehabilitation practitioners is useful for occupational therapists as they support family through their transformational journey to care for persons in DOC.

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