CONFEREN CE ABSTRACT

Transitions in care: What can family-members of people who struggle with substance use teach us about care-integration? Findings from the German AnNet Study.

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Introduction: Substance use disorders (SUD) account for high shares of healthcare spending in Germany. Hikes in multi-morbidities and unmet social-needs create complex service-needs and increasingly require transitions between various social and healthcare settings as integral part of support-networks. Under the shift to integrated and patient-centered healthcare, the scientific awareness of the importance of involving family-members (FMs) as participants in addiction-care steadily grew. Whereas studies report family-members’ exposure to higher levels of stress and unpredictability which can lead to decreased well-being, very little attention has been given to how FMs experience participation in addiction-care and care-transitions in the wider context of their own support-needs and care and life-goals.

Methods: Between March 2016 and March 2017 in-depth interviews and focus groups with 81 FMs have been conducted and analyzed in accordance with grounded theory methodology. Because of the exploratory nature of the investigation, only a few preconceived themes were brought to the analysis. An open-ended interview guide was used with questions incorporating the eight dimensions of care as identified by the Picker Commonwealth Program for Patient-Centered Care (e.g., access, coordination, involvement of family members, preparation for discharge, transitions in care etc.) to gain better insight into care-transitions and support-needs from a FM perspective.

Outcomes: Building upon and complementing the existing literature on provider and organization perspectives on integrated-care, which often focus on a specific setting (e.g., primary or specialty care), disease (e.g., legal or illegal drug use), or pathway element (e.g., transition to care), findings add a FM perspective on support-networks and transitions. Crossing care-boundaries within and between health, health-related, and social care services, FM accounts highlight on a systemic and service level how barriers to integration are not only based in different funding mechanisms and organizational capacities, but also in fragmented care systems and ideological differences; and underexplored pathways among addiction services, primary care, and mental health and social services, leading to support overlaps and collaboration gaps. Consequentially, family members are often left to navigate healthcare transitions, locate resources, and manage patient care with limited information and support.
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On the level of FM-professional dyads, privacy laws, over-burdened and under-qualified workforces, and staff attitudes can prevent providers from delivering integrated and person-centered services and determine family participation in treatment and transitions. Application of a relational care perspective showed, how FMs have unique and potentially incongruent goals from those of the client and treatment-specialists. Support for family FMs as well as roles 'assigned' to FMs by the care- system are not always aligned with individual life-situations and therefore require to be balanced against FMs’ needs and goals to avoid alienation from the treatment process, life dissatisfaction and support-burden. Conversely, coordination of patient, professional, and family responsibilities and working with community assets such as self-help groups were described as crucial for managing transitions and addressing support-needs.

Conclusions & Lessons Learned: In addition to professional support, social-services and community resources promote FM empowerment, resilience and transitions and highlight potentials for vertical integration of health, community and social services and the value of social-support as a complement to professional behavioral-health services. Professional perspectives on FMs can be one-sided with an emphasis on FMs care-participant roles whereas professional support for FMs can be limited to illness-specific interventions or focus on a specific setting (e.g., inpatient treatment), or pathway element (e.g., treatment uptake), leaving FMs to manage care transitions with limited information and support.

Limitations: Data obtained from patients, clinicians, and other sources of support-networks would have been useful. Another limitation is the small sample, however, the objective was not to generalize but to apply a qualitative-approach to describe care-integration and transitions from the perspective of FMs.

Future Research: There is a gap in policy and research on the support-needs and roles that family members can play across care-systems and transitions that results in a lack of interventions to assist patients and families in making smooth transitions.

Keywords: care-integration; psychosocial interventions; addiction; co-morbid disorders; participatory research