BEYOND MULTI-MORBIDITY: PATIENT PERSPECTIVES ON THE IMPACT OF ILLNESS (WORKING PAPER SERIES)



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CONTEXT

Studies on patient complexity have tended to focus on multimorbidity, with less attention, in general, to the dynamic interplay between health and social circumstances. In a previous study, the research team identified two themes that appeared to alter the care experiences of patients: Illness trajectory—the onset of illness (gradual or sudden) and life circumstances- or context of the patient-- social, financial, practical, and other non-bio-medical circumstances.

OBJECTIVES

This study aims to identify the impacts of illness among patients in the two illness trajectories (gradual/ongoing illness and sudden onset), and determine aspects of patients' life circumstances that characterize the illness experience within and across these trajectories.

METHODS

The research team conducted a directed content analysis of a sub-set (N=14) of in-depth interviews acquired from an initial data set (N=116). To explore the relationship between illness trajectory and life impacts, the Principal Investigator (KK) selected transcripts purposively, to explore impacts related to the two trajectory themes (sudden illness and ongoing illness) across a range of participant ages (young, mid-life and older adults). Following selection of the sample, research assistants (DM, JH) each independently conducted open coding of 1 transcript, identifying major themes. The research team met to consolidate the major themes into a list of 5 broad codes through consensus. These broad codes were then applied to the analysis of the remaining transcripts. The final codebook was then applied to the entire set of coded data, by re-organizing codes/coded excerpts under the updated schema. DM conducted an in-depth analysis, primarily aimed at identifying and articulating patterns within, and relationships between, the health trajectory and life circumstances.

FINDINGS

Regardless of a patient's illness trajectory factors such as the availability and quality of social supports and income security played keys roles in shaping the illness experience. Patients in the *Sudden Illness* trajectory described impacts specific to the *recent transition* from healthy to ill, such as the psychological and social adjustments involved in facing long-term disabilities for the first time, and the effects on family. Patients within this group varied in their expectations for recovery, parental obligations, and differences in perspective/disposition.

Patients in the *Ongoing Illness* trajectory described how life impacts had played out, or been experienced over time, and contributed to their current circumstances, even before recent crises. So even though they had been ill for some time, each fluctuation or set-back layered onto pre-existing issues, adding further complexity. Patients within this group varied based on the nature of their chronic conditions (e.g., ongoing/fluctuating conditions), the type and extent of previous impacts (previous level of disability) and significance of a particular health crisis, relative to a patient's prior state and adaptations.

CONCLUSIONS

The variations that make patients complex create opportunities to improve their care. The challenge, then, for health providers, policy-makers and researchers, is incorporating these considerations into the dynamic world of healthcare, where providers are faced with the (often urgent) needs of individuals they come into contact with. How can these points of contact be turned into opportunities to address social complexity and thereby influence future trajectories for the better?