

PATIENT AND FAMILY PERSPECTIVES IN RESILIENT HEALTHCARE STUDIES: WHEN, WHERE AND HOW TO INTEGRATE THEM?

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Abstract

Whilst interest in resilient healthcare (RHC) research has increased over the past five years, our understanding of the role of patients, families and carers in supporting system resilience remains limited (Berg et al, 2018; Laugaland & Aase, 2015). The extant empirical evidence for RHC has almost exclusively been undertaken from the perspective of staff. However, evidence is emerging suggesting that patients, families and carers impact on variability and outcomes within complex health systems, and as such could be regarded as co-creators of resilience (Schubert et al, 2015; O'Hara et al, 2018). Within health services research and improvement, engagement of patients and the public is widespread, with an ever building evidence base examining how, and in what ways such engagement should be done (Kirwan et al, 2017). Thus, as it grows as a discipline, there is no doubt that this 'moral' argument for the involvement of patients and families in RHC research will increase. However, in this paper we argue that whilst involving patients and families in RHC research is clearly a moral imperative, it is also – and perhaps more importantly – driven by the logic of doing so. We will discuss six case studies of RHC research both with, and without, the integration and modeling of patient, family or carer perspectives. The aim is to demonstrate how without these perspectives, our understanding of work-as-done is limited, and may not account for variability introduced by these key actors within the system, that both supports, and compromises, the resilience of that system. We argue that without exploring and modeling this important source of variability, we risk misunderstanding the resilience of our healthcare systems. Finally, drawing on the case study examples, we present a planning support tool for the involvement of patient and family perspectives in RHC studies, which will provide practical guidance about when, and how, to examine and model this unique perspective.

Keywords: Patient engagement; resilient healthcare; system modelling.

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