Ambiguous Loss and Value Co-Destruction in Fragmented Service Systems

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Purpose: In response to increased calls for research on family/carer roles, experiences, emotions and contributions in family systems (Cox and Paley 2013, Danaher and Gallan, 2016; Sharma and Conduit, 2016), this study explores the nature of ambiguous loss (Boss, 1999, 2016) experienced in families with Autism Spectrum Disorder (ASD) and Down syndrome. Ambiguous loss is defined as a situation of unclear loss that remains unverified and thus without resolution, where the outcome is unpredictable, and where the stressors are unclear or ambiguous (Boss, 1999; 2007). Extending beyond the carer-child dyad, we investigate parents' experiences of how ambiguous loss and service system fragmentation in these contexts affects not just individual members, but both value co-creation in and the self-adaptability of family and service systems.

Study design/methodology/approach: Adopting a participatory action research (PAR) approach, our qualitative study of 12 participants from families with ASD and Down Syndrome revealed several key themes which illuminate the nature of ambiguous loss and fragmentation in service systems.

Findings: Specifically, we identity *context ambiguity* related to the condition, *identity ambiguity* linked to shifting roles in and beyond the family and *temporal ambiguity* and its relationship to future expectations of formal healthcare providers. We find that ambiguous loss is acutely experienced where the boundaries between the family and service systems are blurred or fragmented. This leads to ongoing value co-destruction in service systems.

Originality/value: While service scholars have focussed on the optimal function of service systems and how value is co-created, we expose the fragmentation in both formal and informal healthcare systems. We also discuss the implications of service system fragmentation on value co-creation between multiple actors in service systems. In terms of managerial implications, we call for failures in service systems, in particular in the contexts of health and social care, to be addressed in order to appropriately support families who require these services most acutely.