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Review article

Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism

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ABSTRACT

Research on families living with developmental disability generally and autism specifically is dominated by a deficit view that elicits an elaborate representation of problems and risks without the benefit of considering families' potential for adaptation and resilience. A central tenet of developmental psychopathology is that the study of adaptive and maladaptive development is mutually informative. Specifically, one can examine resilience within the context of adversity and the multiple processes and pathways to adaptive and maladaptive developmental outcomes. We believe these concepts can also be extended to the study of families living with developmental disability as they transition through the family lifecycle. This paper provides an overview of the family quality of life (FQOL) construct, including its conceptualization and measurement, and a review of studies on FQOL among families of children with various developmental disabilities. Special attention is given to families of children with autism, as this is a circumstance characterized by unique adversity. We suggest benefits from adopting a developmental psychopathology perspective, and illustrate how relevant concepts can inform our methodologies as we move forward. We will demonstrate how such an integrated, systemic, and temporal approach will help generate more refined questions on FQOL among families caring for a child with developmental disability in order to provide the specific answers needed to directly inform policy and clinical practice.

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1. Introduction

Despite the historical, political and cultural divide between 19th century Russian and 21st century North American societies, Tolstoy's observations on family risk and well-being are surprisingly reminiscent of views espoused by contemporary researchers who study families caring for a child with a developmental disability (DD).[1] This research, however, is dominated by a deficit view, which elicits an elaborate representation of problems and risks without the benefit of considering families' potential for adaptation and resilience.

In this paper, we review the extant literature and attempt a more nuanced view on family functioning (with humble apologies to Tolstoy) by adopting a developmental psychopathology perspective on family quality of life (FQOL) as it relates to those caring for a child with DD. We take a family systems perspective which views individuals as interconnected parts of a system that cannot be understood in isolation from one another, but as embedded within their family. We incorporate developmental notions of risk, resilience, equifinality, and multifinality to better understand stability and change throughout the family life cycle. We present a synthesis of previous FQOL conceptualizations, measurement approaches, and findings, as well as identify existing gaps in the literature and methodological limitations. We conclude with suggestions on directions for future research, particularly with regard to autism,[2] and encourage researchers to contextualize families' quality of life within family systems and developmental psychopathology frameworks. We suspect that this perspective on FQOL will enrich our understanding of FQOL, as well as propel advances in methodology that may capture the full range of possible adaptive and maladaptive family outcomes.

Studies were identified by conducting a search for the terms "family quality of life" and "disability", "family quality of life" and "autism", and "family well-being" and "autism", using the Ebsco Host database and Google Scholar search engine. Additional papers were identified by reviewing the reference sections of included papers. Emphasis was placed on articles that examined the FQOL construct specifically, as opposed to those that addressed the more diversely defined 'family well-being' concept.

"This . . . makes our family closer" (Bayat, 2007, p. 709) is a quote taken from an interview with a mother who describes how the experience of raising a child with autism has brought her family together with a common purpose. In sharp contrast to this perspective, another family describes their feelings when they first realized the challenges that they were about to face: "We realized the truth, and by the end of the day we were distraught, because we knew the truth about it. It was actually the worst day of our lives, that was the day we came to terms with the fact that we had this problem" (Midence & O'Neill, 1999, p. 280). These quotes illustrate how families' responses to a child with DD may differ significantly. The quotes also reflect potential changes in a family's subjective experience at different developmental time points across the life cycle. After tackling challenging circumstances and thwarting negative outcomes a family may perceive value in the experience of raising a child with a disability. However, when the family is first faced with an unexpected diagnosis of DD the prospects may be daunting and the family may feel unprepared and concerned about what the future holds.

2. Evolution of the family quality of life construct

In recent years, the direction of disability research has shifted from a unitary focus on individual quality of life to a broadened examination of perspectives held by the entire family unit. The emergence of key theories, including Bowlby's (1969) attachment, Bronfenbrenner's (1979) ecological, and Turnbull, Summers, and Brotherson's (1984) family systems (as specifically related to families of a child with disability), have spurred a paradigmatic shift in the nature of family-related practice and policy. It is now understood that the family unit constitutes a dynamic, interconnected, and self-regulating

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[1] The terms 'developmental disability' (DD) and 'intellectual disability' (ID) will be used throughout the paper. It is important to note that these refer to unique circumstances, and are not interchangeable. The former is an overarching classification under which individuals with ID fall, although 'DD' refers to both those with and without intellectual impairment. ID, on the other hand, only includes those who have intellectual impairment (i.e., IQ at or below 70) as well as significant limitations in two or more areas of adaptive behaviour (e.g., daily living, communication, and social skills).

[2] The term 'autism' is intended to reference the full autism spectrum of disorders, as opposed to autistic disorder specifically.

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