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| Sommario/riassunto      | <p>This Special Issue of the journal Children constitutes an opportune moment to reflect on the psychosocial needs of children living with rare diseases and of their families. As medical advances, treatments, and developments have enabled many of these children to survive infancy and to live into adulthood, progress brings with it concerns and opportunities to enhance the psychosocial quality of life of children living with rare diseases, and of their families. This Special Issue reflects the current state of psychosocial research, which is primarily qualitative in nature. There are no scientifically rigorous randomized clinical trials to create an evidence base of effective psychosocial interventions for the provision of care to children with rare diseases and to their families; nevertheless, the papers within this Special Issue provide a reflection on the state of the science, including ideas about future research and practice. In this next section we share observations about the contributions made by each of the 13 articles, which cover a diverse range of topics.</p> |