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Merging the person and the illness: The lived experience of emerging adults with childhood onset chronic illness

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Chronic illness is emerging as major health problem in the developed world. The increased prevalence of childhood chronic conditions such as asthma and diabetes coupled with the successful management of childhood onset disease has altered the landscape of chronic illness among young people. This study explored the lived experiences of emerging adults who have grown up and live with chronic illness since childhood. The health of emerging adults (18 to 25 years) has received far less attention in the literature compared to adolescence. Yet they often fare worse than adolescents in many areas including adherence to treatment and are more likely to have social, emotional and behavioural problems than their healthy counterparts. Emerging adults tend to grouped with adolescents and are often not studied as a separate group in the nursing literature. The paucity of research on this particular developmental group living with chronic illness will hinder policy makers in the future planning of chronic illness care. Exploring the lived experience of this specific age group, emerging adults, from a qualitative philosophical and developmental perspective is critical because of the challenges young people face moving to adulthood with illness. Drawing on the philosophy of van Manen's lifeworld existentials the lived experiences of 15 emerging adults aged between 18 and 25 years who had a self-reported chronic illness since childhood. Findings reveal eight emergent themes: Transitioning to the adult world with illness, Living with unanswered questions, Visibility of chronic illness, Fitting in: the desire for normalcy, Developing a sense of self, Hopefulness, Sense of connectedness with peers and the overarching theme of Merging the person and the illness. Emerging adults struggle to achieve a sense of identity which is often sabotaged by illness.

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