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A new patient population for adult clinicians: Preterm born adults

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What if a single event could sway health, exercise capacity, learning style, social interactions, and even personal identities—yet individuals had no memory of the event? Adults born preterm are an under-recognized and vulnerable population. Multiple studies of individuals born prematurely, including our 35-year longitudinal study, have found important health concerns that adult healthcare providers should consider in their assessments. Concerns include increased rates of cardiovascular disease, metabolic syndrome, depression, anxiety and attention problems, lower educational attainment and frequency of romantic relationships.^{1,2} A Nordic study of over six million individuals found a linear relationship between gestational age and protection against early adult mortality, with preterm individuals showing 1-4 times increased likelihood of early mortality as full-term peers.³

At the same time, surviving premature birth has become increasingly common. For the last several decades, nearly one in nine U.S. babies is born early, and now more than 95% survive.² Global prevalence and survival data indicate more than 15 million preterm birth survivors annually reach adulthood.⁴ This suggests a new population of individuals with emerging healthcare needs for adult health providers.

Birth history should be part of every patients' medical record.⁵ Due to the varied risks and prevalence of premature birth, all healthcare practitioners should be aware of the potential for long-term effects. With one in ten 30-year-old patients born preterm, clinical specialists who treat long-term complications of prematurity (i.e., neurology, psychiatry, cardiology) may have more preterm-born patients. Recognizing preterm birth as a cumulative, lifelong risk factor is the first step.

As clinicians and researchers, we have observed the medical community, like society at-large, tends to view prematurity as a health event localized to infancy—something kids outgrow. Ironically, some pediatric providers report limited training and understanding of

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health complications for children born preterm, and little evidence exists regarding adult practitioners' knowledge to care for these adults.⁶ Preliminary adult primary care guidelines were recently created to screen and manage prematurity-related health complications.⁷

Health risks from prematurity are also risks to equality and justice. Women who bear social risk factors are more likely to give birth early. This includes Black women, those living in socio-economically depressed areas, and women with two or more Adverse Childhood Experiences.⁸ The many arms of racism and caste-based inequalities can complicate and worsen the health of people already at risk from preterm birth.

Attention also needs to be drawn to the prematurity research community. To date, research has focused on younger age groups and predominantly White populations. Future research needs to seek out ethnically diverse populations and comprehensively examine potential lifecourse complications of early birth. This is especially important when considering how socioeconomic factors may influence the allostatic load of individuals.

For many born preterm, prematurity is not just a health concern, it's a matter of who they are. Their perception of health over time, or health related quality of life (HRQL), is a critical outcome. To date, this evidence varies with age, degree of prematurity and reporter; clinicians and parents tend to rate HRQL more negatively than survivors.^{9,10} Preterm-born individuals may not have event memories but, early birth repercussions can reverberate through family narratives and unique life experiences. Some identify as typically developed individuals who happen to have been born early, others as functional and well-adapted "preemies", and others see prematurity as having colored their lives in negative ways.¹¹ As prematurity researchers, we aim to uncover and bring awareness to the health outcomes and risks from early birth. A critical need exists for more evidence about adult health following preterm birth and yet, how do we protect individuals with statistically increased risk without unnecessarily pathologizing them?

In clinical practice and research settings, we can take the opportunity to listen to people who were too young as patients to speak for themselves but have riveting and complex stories about preterm birth's effects. We are aware of just one other published qualitative study about the experiences of adults born preterm.¹² Because most adult healthcare providers have yet to acknowledge and factor this experience into patient care, individuals born preterm are finding alternative avenues to be seen. Adults born preterm report seeking online community and support, connecting globally with people over shared early life experiences, while simultaneously making their needs and identities known.

As a research team, we strive to avoid labels for people born early but have nonetheless found that they are, in often subtle ways, a special group. They beat the odds as infants. Their birth and subsequent survival affected their families and communities in unprecedented ways. As clinicians and researchers, we can attend to the health risks of those born premature while acknowledging and celebrating their unique strengths and perspectives, often resulting from their early life experiences.

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Declaration of interests

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