

ABSTRAK

Stres Pengasuhan Orang Tua dan Citra Tubuh Individu dengan Hiperplasia Adrenal Kongenital

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Latar Belakang: Hiperplasia adrenal kongenital (HAK) merupakan kelainan autosomal resesif akibat defisiensi enzim 21-hidroksilase yang menyebabkan kelebihan androgen, virilisasi, dan berbagai komplikasi psikososial jangka panjang. Perubahan fisik yang terjadi pada individu dengan HAK berpotensi mengganggu pembentukan citra tubuh, sementara kompleksitas tuntutan pengobatan seumur hidup dan ketidakpastian klinis memberikan beban emosional yang bermakna bagi orang tua sebagai pengasuh utama.

Tujuan: Penelitian ini bertujuan untuk menggambarkan dan mengeksplorasi dinamika stres pengasuhan orang tua serta citra tubuh individu dengan HAK secara komprehensif melalui pendekatan metode campuran.

Metode: Penelitian ini menggunakan desain *sequential explanatory mixed methods* (QUAN → qual). Fase kuantitatif dilakukan secara total sampling terhadap 53 individu dengan HAK (usia 6–32 tahun) dan pengasuh utamanya yang berobat di RSUP Dr. Kariadi dan RS Nasional Diponegoro Semarang pada periode Oktober 2025–Januari 2026. Citra tubuh dinilai menggunakan Children's Body Image Scale (CBIS) untuk usia 6–11 tahun dan Body Esteem

Scale for Adults and Adolescents (BESAA) untuk usia ≥ 12 tahun. Stres pengasuhan diukur dengan Parental Stress Scale (PSS). Fase kualitatif dilakukan melalui wawancara mendalam triadik terhadap 20 keluarga terpilih berdasarkan variasi skor PSS dan BESAA, dengan analisis tematik menggunakan *NVivo 12 Pro* (Braun & Clarke). Integrasi data dilakukan melalui *joint display* dan meta-inferensi.

Hasil: Sebagian besar subjek berjenis kelamin perempuan (79,2%), berdiagnosis *salt-wasting* (86,8%), dan terdiagnosis pada masa bayi. Pada kelompok usia 6–11 tahun, skor CBIS berkorelasi negatif kuat dengan IMT ($r_s = -0,736$, $p < 0,001$) dan berat badan ($r_s = -0,534$; $p = 0,005$). Pada individu usia ≥ 12 tahun, BESAA tidak berhubungan bermakna dengan karakteristik antropometri. Pada pengasuh, hanya usia yang berhubungan bermakna dengan stres pengasuhan ($r = -0,318$, $p = 0,020$), dan seluruh karakteristik demografi bersama-sama hanya menjelaskan 16,6% variasi skor. Hubungan citra tubuh dengan stres pengasuhan tidak ditemukan pada anak ($r = 0,157$, $p = 0,443$), sementara pada usia 12 tahun ke atas arah negatif ($r_s = -0,361$, $p = 0,065$). Analisis kualitatif menghasilkan dua domain dengan tema dominan berupa krisis persepsi tubuh, stigma dan menyembunyian diagnosis, beban finansial, serta pengalaman merendahkan dalam layanan kesehatan.

Simpulan: Stres pengasuhan dan citra tubuh pada keluarga HAK adalah fenomena dinamis yang dipengaruhi oleh faktor klinis (IMT, *late diagnosis*, jenis HAK), faktor pengasuh (usia, *bereavement*, *concealment*), dan faktor struktural (toksisitas finansial, *medical gaslighting*). Integrasi *mixed methods* diperlukan karena demografi kuantitatif hanya menangkap sebagian kecil varians. Penelitian merekomendasikan skrining neonatal HAK, prioritas intervensi psikoedukasi pada pengasuh muda, pelatihan kompetensi HAK bagi tenaga kesehatan layanan primer, dan pengembangan instrumen HAK-spesifik untuk dimensi yang belum terukur.

Kata kunci: hiperplasia adrenal kongenital, citra tubuh, stres pengasuhan, metode campuran, *medical gaslighting*, HAK, Indonesia

ABSTRACT

Parental Stress and Body Image in Individuals with Congenital Adrenal Hyperplasia

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Background: Congenital adrenal hyperplasia (CAH) is an autosomal recessive disorder caused by 21-hydroxylase enzyme deficiency, leading to excess androgens, virilization, and various long-term psychosocial complications. The physical changes experienced by individuals with CAH have the potential to disrupt body image formation, while the complexities of lifelong treatment demands and clinical uncertainty place a significant emotional burden on parents as primary caregivers.

Objective: This study aims to comprehensively describe and explore the dynamics of parental caregiving stress and the body image of individuals with CAH using a mixed-methods approach.

Methods: This study employed a sequential explanatory mixed methods design (quantitative → qualitative). The quantitative phase utilized total sampling of 53 individuals with HAK (ages 6–32 years) and their primary caregivers receiving treatment at Dr. Kariadi General Hospital and Diponegoro National Hospital in Semarang during the period from October 2025 to January 2026. Body image was assessed using the Children's Body Image Scale (CBIS) for ages 6–11 and the Body Esteem Scale for Adults and Adolescents (BESAA) for ages ≥12. Parenting stress was measured using the Parental Stress Scale (PSS). The qualitative phase was conducted through triadic in-depth interviews with 20 families selected based on variations in

PSS and BESAA scores, with thematic analysis using NVivo 12 Pro (Braun & Clarke). Data integration was performed through joint display and meta-inference.

Results: The majority of subjects were female (79.2%), had a diagnosis of salt-wasting (86.8%), and were diagnosed during infancy. In the 6–11-year-old age group, CBIS scores were strongly and negatively correlated with BMI ($r_s = -0.736$, $p < 0.001$) and body weight ($r_s = -0.534$; $p = 0.005$). In individuals aged ≥ 12 years, BESAA was not significantly associated with anthropometric characteristics. Among caregivers, only age was significantly associated with caregiving stress ($r = -0.318$, $p = 0.020$), and all demographic characteristics combined explained only 16.6% of the variation in scores. No association between body image and caregiving stress was found in children ($r = 0.157$, $p = 0.443$), while for children aged 12 and older, a negative correlation emerged ($r_s = -0.361$, $p = 0.065$). Qualitative analysis yielded two domains with dominant themes: body image crisis, stigma and concealment of the diagnosis, financial burden, and demeaning experiences in healthcare settings.

Conclusion: Caregiving stress and body image among families of individuals with HAK are dynamic phenomena influenced by clinical factors (BMI, late diagnosis, type of HAK), caregiver factors (age, bereavement, concealment), and structural factors (financial toxicity, medical gaslighting). The integration of mixed methods is necessary because quantitative demographic data capture only a small portion of the variance. The study recommends neonatal screening for CAH, prioritizing psychoeducational interventions for young caregivers, CAH competency training for primary care health workers, and the development of CAH-specific instruments for dimensions that have not yet been measured.

Keywords: congenital adrenal hyperplasia, body image, caregiving stress, mixed methods, medical gaslighting, CAH, Indonesia