MedERA - Journal of CMH LMC MedERA 2022, 4: 1
ISSN(e) 2789-3081 ISSN (l) 2521-0106 https://doi.org/10.5281/zenodo.6942991

Original Article

Role of Hypogonadotropic Hypogonadism in Psychosocial Deprivation among Females Patients

Shaista Aslam[1], Riffat Iqbal [2], Rida Fatima Saeed [3], Iqra Yousaf [4], Rana Khurram Aftab[5], Erum Monis[6]

[1]Assistant Professor, National University of Medical Sciences Rawalpindi, Pakistan
[2]Assistant Professor, Government College University Lahore, Pakistan
[3]Assistant Professor, National University of Medical Sciences Rawalpindi, Pakistan
[4]PhD Scholar, University of Vienna, Centre for Microbiology and Environmental Systems Science
[5]Additional Medical Superintendent, Punjab Institute of Cardiology, Lahore, Pakistan
[6]Deputy Director, National University of Medical Sciences Rawalpindi, Pakistan

***Corresponding Author:** Dr Shaista Aslam, Department of Biological Sciences, National University of Medical Sciences, PWD Campus, Rawalpindi, Pakistan
E-mail. shaista_aslam@numspak.edu.pk

Received: June 12, 2022; *Revised:* June 31, 2022; *Accepted:* July 25, 2022; *Published:* July 26, 2022
How to cite: Aslam S, Iqbal R, Saeed RF, Yousaf I, Aftab RK, Monis E. Knowledge, Role of Hypogonadotropic Hypogonadism in Psychosocial Deprivation among Females Patients. MedERA-Journal of CMH LMC and IOD. 2022;4(1).

ABSTRACT

Background: Patients with rare diseases such as congenital hypogonadotropic hypogonadism (CHH) are often challenged to be isolated, lack proper medical care and face negative social consequences. Furthermore, pubertal development is the period of rapid and nearly simultaneous transformation of biological, physical, social, and psychological domains of an individual. Hence, the process of personal transformation is also affected in children with pubertal delay. Due to delay in the growth process, the individual looks different from her or his peers and may have negative consequences on the psychological and social interactions. **Objective:** The disparities in the growth and development may cause an increase in psychosocial problems and negative peer relationship. Hence, this study was designed to observe psychosocial consequences of delayed puberty in female with CHH. **Design:** Cross sectional study. **Place & duration of study:** The data were collected from CHH patients visiting public sector hospitals over a period of 18 months. **Patients & Methods:** The demographic information, complete medical history, psychological and psychosocial symptoms of the 52 female CHH patients were recorded on the questionnaire. **Results:** The present study demonstrated that most of the patients were frustrated due to poor body image, low self-esteem, feeling themselves behind the peers, and were with complaints of depression and anxiety. The other psychological symptoms include anger, irritability, loneliness, eating and sleeping disturbances. **Conclusion:** It was concluded that the delayed sexual maturation has resulted in frustration, low self-esteem and increased anxiety and depression in cohort of local females with CHH.

Key Words: Delayed sexual maturation, Congenital hypogonadotropic hypogonadism, psychosocial

Introduction

Congenital hypogonadotropic hypogonadism (CHH) is a rare, endocrine and genetic disorder characterized by absent or incomplete puberty in the settings of low concentration of sex steroids and gonadotropins in both gender.[1] Globally, CHH is underdiagnosed rare medical condition without knowing prevalence in both males and females.[2] The biochemically evaluation of CHH is low levels of gonadotropins in the setting of sub-optimal, undetectable or inappropriately normal serum levels of gonadotropins (follicle stimulating hormone and luteinizing hormone.[3] The incidence of congenital hypogonadotropic hypogonadism is difficult to estimate as the condition manifests by way of incomplete or absent puberty with infertility. However, the estimated incidence of CHH is approximately 1-10:100,000 live births.[3] Like other rare disorders, the CHH patients experience a delay in diagnosis due to the diversity and complexity of molecular basis of the CHH.[4] Furthermore, the absence of sexual development becomes more apparent in CHH patients, when they remain at pre-pubertal state while their peers and youngsters are going through puberty. There are very meagre data available on the psychosocial stresses faced by the females with delayed sexual maturation. This situation may result in severe emotional and psychological experiences.[5] Indeed, the previous studies have shown that delayed puberty and small stature may result in severe psychological consequences such as poor body-image, depression, strained interpersonal relationships and increased denial of sexuality.[6] A previous study reported hostile rejection by age-mates and social introversion in patients with Kallmann syndrome. However, no significant increase in personality pathology and decreased intellectual functioning was witnessed in these patients.[7] Patients affected with rare diseases face a variety of challenges in their daily life, which have been brought to light by the European Organization for Rare Diseases (EURORDIS) in 2009.[8] This includes delayed diagnosis, lack of specialized healthcare, negative social consequences, psychological and psychosocial constrains.[9] The main reason of these constraints is the obstacles in disease management, health disparities and feeling of marginalization in patients and their families.[9,10] The rarity of the condition may result in deleterious effects on quality of life and psychosocial consequences such as isolation, feelings of powerlessness and perception of invisibility.[11] Therefore, the aim of the present study was to examine the psychosocial stressors faced by the female CHH patients in our local population.

Methodology

We conducted a cross-sectional study at public sector hospitals of Islamabad and Lahore over a period of 18 months. The female CHH patients were categorized on the basis of criteria, including absent or incomplete puberty by age of 16 years, low serum estradiol (E2) level in association with low levels of serum gonadotropins and otherwise normal pituitary function.

Inclusion criteria: The female patients diagnosed with CHH including both Kallmann Syndrome and isolated hypogonadotropic hypogonadism and consented to participate in the study.

Exclusion criteria: The delayed puberty patients with hypothyroidism, panpituritism, systemic diseases, nutritional deficiencies and Turner Syndrome were not included in the study.

Data collection: The demographic information, complete medical history, health-seeking behaviour, psychological and psychosocial interventions of the patients were recorded through a questionnaire.

Data analysis: The rates in terms of percentages were calculated for the overall study population using SPSS version 16.0.

Ethical consideration: The study was approved by institutional research ethics committee of Government College University Lahore. The informed consent was taken from all participants. All information obtained or used in the study was kept confidential.

Results

During the study period a total of 52 female CHH patients were enrolled and cross-examined. The socio-demographic information about the patients is presented in Table I. These participants varied in age from 17 to 27 years (mean 18.91+1.98, median 19). The majority of respondents were between the ages of 15 and 20 years (86.54%), single (90.38%), students (61.54%), and had received qualification or was studying for Secondary School Certificate (61.54%). Different psychosocial symptoms experienced by female patients of CHH are presented in Table II. The significant behavioral concerns faced by patients include frustration due to poor body image (pre-pubertal genitalia and breast development) (57.7%), low self-esteem (37%), feel that they are behind the peers (29.4%) and depression and anxiety (80.8%). Furthermore, 38.5% patients told that the diagnosis of disease and hormone replacement therapy for treatment of condition provoked anger in them. The increased irritability and loneliness after diagnosis of the disease was observed by 20.4% and 18.4% patients respectively. The eating and sleeping disturbances were reported by 23.5% and 13.7% patients respectively.

Table 1. Socio-demographic information of the CHH patients.

Socio-demographic Characteristics	Number (%age)
Age	
17-22	45 (86.54)
23-27	7 (13.46)
Employment Status	
Student	32 (61.54)
Employed	3 (5.76)
Unemployed	17 (32.69)
Relationship Status	

Single	47 (90.38)
Married	4 (7.69)
Divorced	1 (1.92)
Education	
Upto Secondary School	32 (61.54)
Higher Secondary School	13 (25)
College/University	7 (13.46)

Table 2. Psychosocial Characteristics of the CHH patients.

Psychosocial Characteristics	**Number (%age)**
Frustration due to body image	30 (57.7)
Low self-esteem	28 (54)
Behind the peers	15 (29.4)
Depression & Anxiety	42 (80.8)
Anger	20 (38.5)
Irritability	11 (20.4)
Loneliness	9 (18.4)
Eating disturbances	12 (23.5)
Sleeping disturbances	7 (13.7)

Discussion

The present study demonstrated increased levels of depressive and psychological symptoms in CHH patients. In line with observations, a study conducted in African American and Caucasian girls showed that late maturing girls experienced the greatest increase in depressive symptoms.[12] Furthermore, body esteem significantly mediated the relationship between pubertal timing, peer victimization, and depressive symptoms in girls of both races. Hence, patients suffering from a rare disease experience health disparity.[10]

The study further demonstrated that body esteem is an important mechanism that contributes to increased depression among girls in adolescence.[13]

The psychological and behavioural consequences of delayed puberty are not fully known in adolescents, whereas, the higher rates of depressive symptoms, dysfunctional eating patterns and victimization has been reported in late maturing boys. However, the medical facilities in terms of hormone replacement therapy are adequate for CHH patients and helps to improve mood and disease conditions. Even though, the physical, emotional and psychological components of the disease are usually ignored.[14,15] Therefore, there is a need of appropriate mental and behavioural health counselling for the patients and their parents to meet the challenges related to rare diseases.[16]

Our findings in female subjects are in consensus with the previous studies which showed lower self-esteem and body satisfaction, heightened feelings of inferiority, inadequacy and social rejection in late maturing boys.[17] The earlier studies demonstrated that both early and late pubertal development affects the psychological well-being and social adjustment of an individual. Moreover, increased risk of depression is reported in the children with early or late puberty[18] and may persist during adolescence and early adulthood.[19] The surrounding environment plays a significant role in the psychological well-being of the individual with pubertal delay. The depressive symptoms were more common in late maturing children with problematic peer relationships than those with harmonious friends.[18]

The psychosocial prospective suggested that the early or late maturation in the children of both genders is an aberrant position during critical stages of development, which may be psychologically distressing for them. It is believed that social comparisons diminish self-esteem and triggers other problematic outcomes.[20] In biological perspective, the cortisol and salivary alpha amylase (SAA) concentrations are reported to be higher in late matures and is exhibited by more rule-breaking and is stronger in boys than girl.[21] Nevertheless, higher levels of cortisol are correlated with social withdrawal and may help to explain the interaction with peers at pubertal transitions.[22]

The present study demonstrates that the unmet medical needs, uncertainty of health conditions and helplessness provokes anxiety and depression among the CHH patients. It is suggested that the psychotherapy should be included in the treatment protocol of the patients with CHH. The psychotherapy will help the patients to utilize the positive aspects of their personality and become the productive individual of the society.

Conclusion

The present study reported an alarming situation among CHH patients. A noteworthy fraction with delayed sexual maturation which resulted in frustration, low self-esteem and increased anxiety and depression. Furthermore, special approaches involving family members and/or digital communication can be used to deliver information related with common problems and coping strategies, which may help in proper psychosocial development.

Funding

No funding of any kind was taken for this study.

Conflict of Interest

The authors declare no conflict of interest.

References

1. Young J. Approach to the male patient with congenital hypogonadotropic hypogonadism. The Journal of Clinical Endocrinology & Metabolism. 2012 Mar 1;97(3):707-18.

2. Ross A, Bhasin S. Hypogonadism: its prevalence and diagnosis. Urologic Clinics. 2016 May 1;43(2):163-76.
3. Boehm U, Bouloux PM, Dattani MT, De Roux N, Dodé C, Dunkel L, Dwyer AA, Giacobini P, Hardelin JP, Juul A, Maghnie M. European consensus statement on congenital hypogonadotropic hypogonadism—pathogenesis, diagnosis and treatment. Nature Reviews Endocrinology. 2015 Sep;11(9):547-64.
4. Stamou MI, Cox KH, Crowley Jr WF. Discovering genes essential to the hypothalamic regulation of human reproduction using a human disease model: adjusting to life in the "-omics" era. Endocrine reviews. 2015 Dec 1;36(6):603-21.
5. Smith N, Quinton R. Kallmann syndrome. BMJ. 2012 Dec 3;345.
6. Pfeffer PE, Pfeffer JM, Hodson ME. The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults. Journal of Cystic Fibrosis. 2003 Jun 1;2(2):61-8.
7. Bobrow NA, Money J, Lewis VG. Delayed puberty, eroticism, and sense of smell: A psychological study of hypogonadotropinism, osmatic and anosmatic (Kallmann's syndrome). Archives of Sexual Behavior. 1971 Dec;1(4):329-44.
8. EURORDIS AK, Faurisson F. The voice of 12,000 patients. experiences and expectations of rare disease patients on diagnosis and care in Europe. EURORDIS-Rare Diseases Eu; 2009.
9. Dwyer AA, Smith N, Quinton R. Psychological aspects of congenital hypogonadotropic hypogonadism. Frontiers in endocrinology. 2019:353.
10. Holtzclaw Williams P. Policy framework for rare disease health disparities. Policy, Politics, & Nursing Practice. 2011 May;12(2):114-8.
11. Cohen JS, Biesecker BB. Quality of life in rare genetic conditions: a systematic review of the literature. American Journal of Medical Genetics Part A. 2010 May;152(5):1136-56.
12. Holden KB, Bradford LD, Hall SP, Belton AS. Prevalence and correlates of depressive symptoms and resiliency among African American women in a community-based primary health care center. Journal of health care for the poor and underserved. 2013 Nov;24(4 0):79.
13. Hamlat EJ, Shapero BG, Hamilton JL, Stange JP, Abramson LY, Alloy LB. Pubertal timing, peer victimization, and body esteem differentially predict depressive symptoms in African American and Caucasian girls. The Journal of early adolescence. 2015 Apr;35(3):378-402.
14. Aydogan U, Aydogdu A, Akbulut H, Sonmez A, Yuksel S, Basaran Y, Uzun O, Bolu E, Saglam K. Increased frequency of anxiety, depression, quality of life and sexual life in young hypogonadotropic hypogonadal males and impacts of testosterone replacement therapy on these conditions. Endocrine journal. 2012:EJ12-0134.
15. Dwyer AA, Quinton R, Morin D, Pitteloud N. Identifying the unmet health needs of patients with congenital hypogonadotropic hypogonadism using a web-based needs assessment: implications for online interventions and peer-to-peer support. Orphanet journal of rare diseases. 2014 Dec;9(1):1-1.
16. Georgopoulos NA, Armeni AK, Stamou M, Kentrou A, Tsermpini EE, Iconomou G, Hyphantis T, Assimakopoulos K. Gonadotropin-releasing hormone (GnRH) deficiency under treatment: psychological and sexual functioning impacts. Hormones. 2018 Sep;17(3):383-90.
17. Benjet C, Hernández-Guzmán L. A short-term longitudinal study of pubertal change, gender, and psychological well-being of Mexican early adolescents. Journal of Youth and Adolescence. 2002 Dec;31(6):429-42.
18. Conley CS, Rudolph KD. The emerging sex difference in adolescent depression: Interacting contributions of puberty and peer stress.

Development and psychopathology. 2009 May;21(2):593-620.
19. Graber JA, Seeley JR, Brooks-Gunn J, Lewinsohn PM. Is pubertal timing associated with psychopathology in young adulthood?. Journal of the American Academy of Child & Adolescent Psychiatry. 2004 Jun 1;43(6):718-26.
20. Mendle J, Turkheimer E, Emery RE. Detrimental psychological outcomes associated with early pubertal timing in adolescent girls. Developmental review. 2007 Jun 1;27(2):151-71.
21. Susman EJ, Dockray S, Granger DA, Blades KT, Randazzo W, Heaton JA, Dorn LD. Cortisol and alpha amylase reactivity and timing of puberty: Vulnerabilities for antisocial behaviour in young adolescents. Psychoneuroendocrinology. 2010 May 1;35(4):557-69.
22. KLIMES–DOUGAN BO, Hastings PD, Granger DA, Usher BA, ZAHN–WAXLER CA. Adrenocortical activity in at-risk and normally developing adolescents: Individual differences in salivary cortisol basal levels, diurnal variation, and responses to social challenges. Development and psychopathology. 2001 Sep;13(3):695-719.

Contributions of the Authors

SA, RI did literature research, data collection and manuscript writing

RFS conceptualized the project, did drafting and revision

IU, RKA did data collection and article writing

EM, SA did drafting and revision and manuscript writing