

# Mayer-rokitansky-kuster-hauser syndrome

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Depression, anxiety and low self-esteem in woman with Mayer-Rokitansky-Kuster-Hauser syndrome (MRKH) Abstract Mayer-Rokitansky-Kuster-Hauser syndrome (MRKH) is a rare syndrome that not only causes physical conditions but emotional. The psychological effects of woman diagnosed with MRKH have never been fully discovered. The hypothesis and or purpose of this study is to evaluate self-report measures of psychological distress in woman with MRKH syndrome compared to woman without MRKH syndrome.

A group of woman with MRKH will be assessed through anxiety, depression, and self-esteem scales to determine any psychological distress MRKH had on them when they first received the diagnosis up until later on in life. Similar studies and theories believe that coping with infertility can be taxing and cause psychological issues throughout a woman's life. I believe observing woman when diagnosed with MRKH as well as following up with woman after dealing with the initial shock of this syndrome will give insight to being able to give proper coping skills to not only woman with MRKH syndrome but woman with infertility issues.

Keywords: MRKH, anxiety, depression, infertility, menstrual disorders

Introduction MRKH is a rare condition found in approximately 1 in 5000 female births, and it is typically diagnosed in mid-adolescence (Leidolf, 2006). The psychosexual development and the identity, femininity, body image and self-esteem of the patients can be significantly impaired by receiving this type of information about their bodies (Laggari, et al. , 2009). Mayer-Rokitansky-Kuster-Hauser syndrome is a condition that involves congenital absence of the vagina, fallopian tubes, cervix and/ or uterus.

Some women have uterine remnants, or horns. External genitalia are normal. Chromosome karyotype is 46XX(normal female). The incidence rate is approximately one in 5000. Other symptoms involved to varying degrees are kidney abnormalities, skeletal problems and hearing loss. The cause is somewhat unclear, but the Syndrome occurs during the 4th-6th week of fetal development (Heller-Hoersma, Schmidt, Edmons, 2009). MRKH syndrome is divided into two types; type I Rokitansky sequence and type II MURCS association.

Isolated utero-vaginal aplasia is referred to as Rokitansky sequence or to type I (isolated) MRKH syndrome. Incomplete aplasia and/or associated with other malformations, is generally referred to as MURCS association (or type II MRKH syndrome) (Camborieux, Guerrier, Morcel, 2007). Many components go into each case found with MRKH syndrome. Surgery may be in order to have a correctly functioning vagina in many cases. There are many different elements that can affect woman with MRKH syndrome physically and psychologically.

Menstruation is considered to be one of the archetypal symbols of femininity and thus constitutes a phenomenon of great significance in the nature of woman (Laggari, et al. , 2009). Living in a world where fertility is a virtue can cause many confusing thoughts for those who are infertile. Adolescent girls struggle when trying to figure out who they are as kids and as women. Magazines, Television and Role Models stress the importance of becoming a mother and giving birth.

Seeing pregnant women on a day-to-day basis as well as displayed as beautiful in the media shapes a certain image in girls' minds. When

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diagnosed with MRKH many women feel confused, angry, and hurt. Adjusting to the diagnosis of MRKH is a difficult and traumatic process for these women, leading them to question their identity as women and to experience a sense of confusion regarding their gender, their bodies, and their social and sexual roles (Leidolf, 2006). Being diagnosed as abnormal can lead to many questions about one's identity.

Many women who struggle with infertility difficulties struggle with psychological difficulties. MRKH syndrome is a rare disorder and has been limitedly studied. Looking at the connection between psychological stress with women who have MRKH and those who do not will give insight to many syndromes that deal with infertility issues for example polycystic ovary syndrome. Studies that have been taken have shown a strong connection between anxiety and depression with women with MRKH syndrome. Limited sample sizes have caused strain in the past studies.

A past study states; “very little is known about the short and long-term psychological impact of MRKHS in females, but several clinicians have suggested that the physical malformations, absence of menstruation and infertility and the subsequent surgical intervention may all contribute to narcissistic damage in these patients” (Laggari, et al. , 2009). Finding out this information can help doctors prepare in helping women cope with the struggles of infertility. In women with MRKH is it not only the struggle with infertility but also the conflict of identity.

Many of these patients may also become depressed questioning themselves over their gender and doubting their ability to fulfill the female role as adults in the future. They report that infertility is the most difficult part of the

condition for young woman to accept (Laggari, et al. , 2009). Doing two personal interviews with patients with MRKH syndrome really helped get into the eyes of how one dealt with the overwhelming feelings of being diagnosed with this syndrome as a teen, and dealing with and living with MRKH as an adult.

This interview will help in the preparation for the study we hope to perform for the future. Having such a rare disorder makes it not only difficult to study but difficult to find participants. Finding those with MRKH syndrome around the world willing to participate in this interview was very helpful. A set of interview questions was produced to ensure the best quality answers. Fake names were used to ensure the privacy of patients. Interview Questions 1. How old were you when you found out you had MRKH syndrome 2. How did you find out you had MRKH syndrome . What were the feelings/emotions you felt when you found this out? 4. Was there anything that doctors could have improved on? 5. Was there a support system available? Or something you would have liked to see? 6. Was there anything that would have made finding out and dealing with having MRKH easier? I asked two participants of different ages. Both women were asked the same questions; Alicia fifty years of age, and Jessica twenty-two years of age. Alicia was diagnosed with MRKH at the age of fifteen, she found out due to “ not having a normal size vagina. “ Only a dimple sized vagina. ” When she found out she was devastated, the doctors were poking and prodding at her not having a support system treating her like some kind of experiment. “ Today I am very thankful and try to be of any help to girls who are struggling with what I went through, never wanting a girl to have to go through it alone like I did. I know how hard it can

be and believe a strong support system is very important. " Jessica is only twenty-two years of age and found out she had MRKH at fourteen years of age due to a lack of menstruation.

Jessica said she was very confused, she thought something was wrong with her because she was different from all of her friends. After she found out she had MRKH she was overwhelmed but glad she didn't feel so lost and alone. Jessica said she still went through a great deal of depression and grieving but it was great having a support group and having many girls that were going through the same thing. I found it very interesting to see the differences in answers between Alicia and Jessica due to their difference in age.

Even though MRKH syndrome is still a very rare syndrome the doctors dealing with this syndrome are trying to improve on the support systems to keep improving on the psychological effects that this emotional syndrome can have on women. Methodology Section Recent studies have been performed trying to evaluate self-report measures of psychological distress in woman with MRKH syndrome compared to woman without MRKH syndrome but have none have fully succeeded. Past studies have struggled with finding a significant sample size.

I plan to contact woman with MRKH syndrome not only in the United States but also the United Kingdom. Having a bigger range will help get a more significant sample size. The four main MRKH doctors will be contacted in hope they will participate in this study. Helping find patients through this source will not only be helpful but more successful. I hope to find a central location to perform this study. Boston, Massachusetts is one of the central

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hubs for the MRKH community and believe it would be a great location for the experiment to take place.

Before the experiment was to start I believe all the woman should be informed that there is a support system available at all times, if they are in any way uncomfortable they do not need to feel pressured to answer any questions, and or can return as they please not having a time limit. I believe that this is a very difficult subject and should be treated with the utmost care. Dealing with infertility and identity issues can cause great psychological stress on a woman. I believe looking at anxiety, depression and self-esteem would be a good start to looking at the psychological effects MRKH syndrome has had on women.

Using The Beck Depression Inventory (BDI), which is a widely used questionnaire and is the depression rating scale that is most often used with adolescents. BDI consists of 16 items, designed to assess the cognitive behavioral effective and somatic components of depression, and the severity or self-reported depressive symptoms (Laggari, et al. , 2009). The State-Trait Anxiety Inventory (STAI), which is used extensively to assess global anxiety that varies across situations and anxiety that is stable across time and situations. The STAI is composed of two separate self-report scales (Laggari, et al. 2009). Rosenberg Self-Esteem scale is 10 items being rated strongly agrees to strongly disagree. This questionnaire observes how one views one's own worth. Using these scales will let us observe the difference between woman with MRKH and woman without MRKH. Because MRKH is such a stressful syndrome the belief is the results will show significantly higher ratings in depression, anxiety, and self-esteem in woman with MRKH

syndrome. It is important to following up with the woman who participated in the study years after the diagnosis.

Looking to see the hopeful progress a woman has made in dealing with the diagnosis is important to helping women in the future. Using similar scales to assess their psychological state would be beneficial to track their progress. Reviewing and comparing both scales will then give an accurate depiction of the psychological effects that MRKH syndrome can have on a woman. I believe it is very important to make sure that a woman is stable enough to participate in these studies after being diagnosed with MRKH.

Many women have been known to go through severe depression and even attemptsuicideafter dealing with infertility issues, needing time to go through a proper grieving process. We want to get accurate measures, but want to make sure that participants are emotionally stable after leaving the experiment. References Laggari, V. , Diareme, S. , Christogiorgos, S. , Deligeorglou, E. , Chrisopoulos, P. , Tsiantis, J. , & Creatsas, G. (2009). Anxiety and depression in adolescents with polycystic ovary syndrome and Mayer-Rokitansky-Kuster-Hauser syndrome. *Journal of Psychosomatic Obstetrics and Gynecology*, 30(22). 3-88. Laure Camborieux, Daniel Guerrier, Karine Morcel. (2007). Mayer-Rokitansky-Kuster-Hauser (MRKH) syndrome. *Orphanet Journal of Rare Diseases*. 13. Leidolf, E. (2006). The missing vagina monologue...and beyond. *Journal of Gay Lesbian Psychotherapy*. 10(2), 77-92. Heller-Boersma, J. G. , Schmidt, U. H. , & Edmons, D. (2009). Psychological distress in women with uterovaginal agenesis (Mayer-Rokitansky-Kuster-Hauser Syndrome. MRKH). *Psychosomatics; Journal of*



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