Original article

Assessment of sexual relations in women with Mayer-Rokitansky-Küster-Hauser Syndrome after sigmoid neovaginoplasty (a mixed method analytical approach)

DYANA SAFITRI VELIES[1], SAWITRI SUPARDI SADARJOEN[2], EPPY DARMADI ACHMAD[1], BENNY HASAN PURWARA[1]

[1] *Faculty of Medicine Universitas Padjadjaran, Obstetric and Gynecology*
[2] *Universitas Padjadjaran, Faculty of Psychology*

Abstract: Objective: To evaluate sexual satisfaction and distress scale score of women with MRKH syndrome after sigmoid neovaginoplasty, and how it affects marriage life. *Method:* A mixed method study, using The Sexual Satisfaction Scale for Women (SSS-W) as the quantitative method, continued by focused interview as the qualitative method, on eight women with MRKH and sixteen normal women. The research was held in Hasan Sadikin hospital. Result: Quantitative method results with t test shows the mean score of sexual satisfaction and distress scale corresponding to the equivalent score of normal women, measured by contentment, communication, compatibility, relationship and personal distress factors with p value: 0.083, 0.496, 0.056, 0.971 and 0.266 respectively. Qualitative method shows analysis of seven themes which are described under the following headings: sexual relations, partner's reaction to women with MRKH, relationships with partners, patients' concerns, motivations to have operation, family support, and self esteem as female. Participants who underwent neovaginoplasty were able to engage successfully in sexual intercourse. Partners of our patients could accept the MRKH condition and were satisfied with the neovagina. Participants have good relationship with partner. Participants' current concern related to the inability of bear children. Motivations to have operation were to have better sexual relations. Family support is very important. Positive self-esteem, including self-confidence, was related to a successful treatment outcome. *Conclusion:* Sigmoid neovaginoplasty is an effective technique to improve sexual relationship and help to alleviate distress of women with MRKH.

Key words: Distress; Mayer-Rokitansky-Küster-Hauser syndrome; Mixed Method analytical approach; Sexual relations.

INTRODUCTION

Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome is one of many Disorders of Sex Development (DSD), characterized by a normal female phenotype with congenital aplasia of the uterus and the upper part (2/3) of the vagina with functional ovaries, normal development of secondary sexual characteristics and a normal 46, XX karyotype.[1-3]

A woman's sense of well-being and quality of life are impacted by the condition.4 The incidence of MRKH syndrome has been estimated as 1 in 4500 female births, but need special attention due to the impact on patient's life.[2]

The management of MRKH falls into two categories: the need to anatomically manage the anomaly so that women could engage more easily in sexual intercourse and the need to help women cope with the psychological impact of the condition.[4] The ideal surgical technique for neovaginoplasty is the one that can provide the patient with a vaginal vault of sufficient size, adequate introitus and an acceptable cosmetic external appearance.[5] Many methods of vaginal reconstruction were reported, including the non operative (Frank procedure) and operative technique (including McIndoe and Sigmoid neovaginoplasty), but the chosen method needs to be tailored to the individual needs, motivation of the patient and the options available.[6]

Since 1990-2009, the urogynecology subdivision of Obstetrics and Gynecology Department in Hasan Sadikin Hospital Bandung are using McIndoe procedure which involves insertion of a mold covered with split thickness skin or amnion graft into the created neovaginal space followed by postoperative vaginal dilation.[7] High percentage of vaginal stenosis was reported after 1 year. Moreover, this modality requires long term vaginal dilatation and stenting by a vaginal mold which affects the patient`s psychological condition.[5]

Since 2009 we have started using sigmoid for vaginal replacement. The use of isolated bowel segments has been shown to provide excellent results, circumventing the need for regular dilatation. Long term evaluation shows minimal complications and low risk of stenosis.[8] The sigmoid neovagina shows a good anatomic result, but it's also important to evaluate how it affects patient's sexual relations.

Treatment of MRKH syndrome, poses challenges that go far beyond physical concerns. Additionally, it has been recommended that a shift in emphasis takes place from the physical aspects of DSD to how individuals adjust to the conditions. Consensus Statement on the Management of Intersex Disorders suggested that more attention be focused on the psychological aspects of DSD.[1]

Genital surgery on one side, is typically presented as an obvious solution, but on the other hand, genital surgery can itself be stigmatizing and shaming.[9] The centrality of surgical correction in care delivery may have inadvertently sidelined the development of quality care that targets psychological adaptation, and more commitment from service providers will be needed to make this a primary focus in clinical management. Shame and fear of repercussions may continue to render personal communications about DSD too challenging for some individuals. So perhaps the most important collaboration between professional and user communities, ultimately, is a long-term social project to improve public understanding of DSD.[10]

Although the outcomes of surgical treatments to create a new vagina have been reported, there have been few reports addressing the psychological impact of the condition and quality of life (QoL) outcomes. There was no previous research aimed to evaluate the result of sigmoid neovaginoplasty in Hasan Sadikin Hospital. The aim of this study is to evaluate patient's sexual relations after sigmoid neovaginoplasty and how it affects marriage life.

Quantitative research is not an appropriate paradigm for psychotherapy research. Qualitative research or clinical observation should be the evidence source.[11] This study supports the consensus statement that psychological issues as well as medical aspects must be addressed in order to provide optimal care, using qualitative-quantitative method.

SUBJECTS AND METHODS

Subjects

This study included women with MRKH syndrome who underwent sigmoid neovaginoplasty as their surgical treatment from 2009 to 2012. All women with current partners were offered to participate in the study together. Subjects chosen for focused interview by stratified purposive sampling.

Normal women were chosen from the outpatient gynecological clinics of Hasan Sadikin Hospital, which had primary infertility, and have matched qualities of the control group. The ratio between MRKH patients and normal women was 1:2.

Methods

This is a mixed method study using explanatory sequential design. The primary method chosen as the quantitative method was The Sexual Satisfaction Scale for Women (SSS-W) questionnaire to measure patients' sexual relations, followed by focused interview as the qualitative method.

The quantitative method was cross sectional, whilst the qualitative method was descriptive ethnographic.

The study was approved by the Committee on the Ethics of Human Research.

The Sexual Satisfaction Scale for Women (SSS-W)[12]

The SSS-W was developed to provide a comprehensive measure of sexual satisfaction and sexual distress that would benefit researchers and clinicians interested in further understanding what constitutes sexual satisfaction in women and how it relates to levels of sexual functioning. The SSS-W is a brief, 30-item measure of sexual satisfaction and sexual distress, composed of five domains supported by factor analyses: contentment, communication, compatibility, relational concern, and personal concern.

Quantitative data analysis

All statistical analysis was performed using SPSS version 18.0 (SPSS Inc, Chicago, IL). Questionnaires were assessed using published standardized scoring systems. Comparison of mean score from questionnaires between MRKH patients and control group were analyzed using t test on the normally distributed data.

Statistical significance test results are determined based on the value of $p < 0.05$.

Qualitative data analysis

Each interview was analyzed using a number of steps, which starts with coding, categorization, defining themes, and interpretation. The validity of this study is not compromised despite the small sample size because of the different assumptions which underlie the philosophy of qualitative inquiry. The validity of a qualitative study should not be judged with reference to sample size and selection or statistical power, but rather in terms of the applicability of the concepts for describing similar experiences in other situations.

RESULTS

From 2009 to 2012, there were 15 potential samples of participants diagnosed with MRKH syndrome from outpatient gynecological clinics of Hasan Sadikin Hospital, who underwent sigmoid neovaginoplasty. Potential participants were contacted directly by the researcher. One patient did not have contactable address. Three patients declined to participate. Three patients were abandoned by their husbands after the surgery; only 1 of the women was willing to be interviewed. Eight patients indicated they were interested in participating.

Informal telephone contact was carried out with all interested participants who were encouraged to ask any questions about the study, following which they and their partner were asked to come to Hasan Sadikin Hospital for the research participation. They were asked to give written confirmation if they wished to take part and so eight MRKH patients and sixteen normal women agreed to fill in the questionnaires.

Quantitative result

Table 1 shows that our MRKH patients have a matched characteristic with the control group.

Figure 1 shows that both groups have equal mean sexual satisfaction score, with p value for contentment, communication, and compatibility was 0.083, 0.49, and 0.056 respectively.

Figure 2 show that both groups have equal mean distress scale score, with p value for relational concern and personal concern was 0.971 and 0.266 respectively.

TABLE 1. – Characteristics of MRKH patients after sigmoid neovaginoplasty and control group.

Characteristics	MRKH		Control		p*) value
	n	%	N	%	
1) Total subject	8	100	16	100	
2) Age (years)					
< 25	2	25	2	12.5	0.682
25-34	3	37.5	8	50	
> 35	3	37.5	6	37.5	
3) Occupations					
Not working	4	50	9	56.3	1.0
Working	4	50	7	43.8	
4) Education					
Low	5	62.5	6	37.5	2.727
Middle	0	0	4	25	
High	3	37.5	6	37.5	
5) Family income					
< min. rate	4	50	6	37.5	0.673
≥ min. rate	4	50	10	62.5	

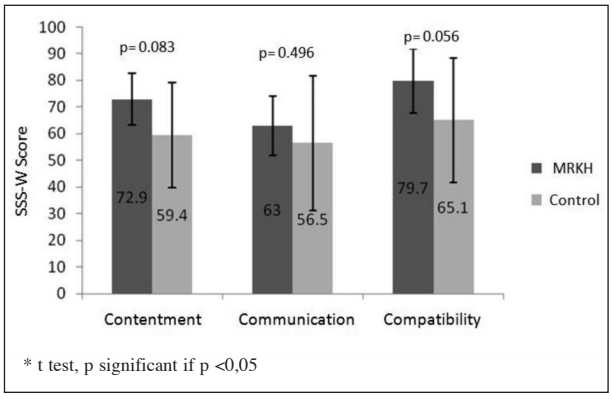

Figure 1. - Comparisons of Sexual Satisfaction mean score between MRKH patients after sigmoid neovaginoplasty and control group.

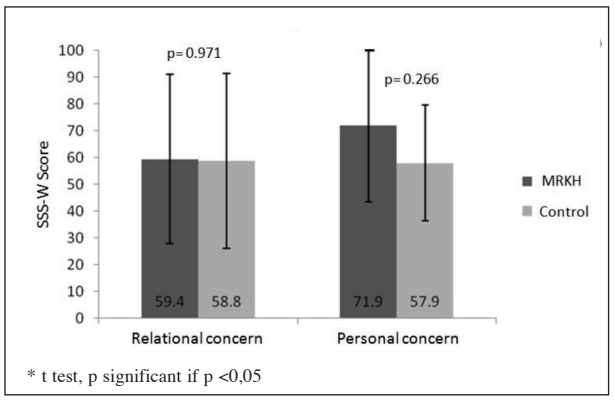

Figure 2. - Comparisons of distress scale mean score between MRKH patients after sigmoid neovaginoplasty and control group.

Qualitative result

Five patients and three with their partners were chosen for focused interview. Seven themes emerged from the analyses which were: sexual relations, partner's reaction to women with MRKH, relationships with partners, patients' current concerns, motivation to have operation, family support, and self esteem as female.

1. Sexual relations

Participants and partners complained difficulties to engage penile-vaginal intercourse due to short vagina.

"After we were married, we found it difficult to engage a sexual intercourse. Then we went to a doctor and were told that I didn't have a vagina" (patient E)

They admitted better sexual relations after patients underwent sigmoid neovaginoplasty due to longer neovagina.

"After the operation, we had a better sexual relations. and it's not painful anymore, for both of us" (patient A)

2. Partner's reaction to women with MRKH

Partners show different reactions to patient's MRKH condition. They feel disappointed by the inability to have normal sexual relations and infertility, but generally accepted the condition. They gave support for patients to have operation.

"Well I think it's normal to feel disappointed, especially when I realized I couldn't have children with her. But I'm grateful enough to have children from my previous wife so I tried to accept her for what she is.." (husband A)

One patient was abandoned after she was diagnosed MRKH actually never got any support from her husband.

"I didn't know my condition before we were married. After I was diagnosed MRKH and suggested to have operation, my husband didn't agree.." (patient F)

3. Relationships with partners

Partners support patients to have a better life, thus the decision to have operation was a result of their discussion. Most of the participants have a good communication with their partners especially related to difficulties in sexual relations and how to deal with it.

"We actually often discuss about our difficulties in engaging sexual intercourse.. He encouraged me to consult to a doctor and supported me when I had to underwent surgery.." (patient A)

Divorced patient admitted to have a poor relationship with her husband since they were married, before she was diagnosed MRKH.

"We never had any communications in our marriage. Maybe because our marriage were arranged by our parents.. We were divorced two.. three months after the operation.. I think the reason of our separation was the arrangement of our marriage." (patient F)

4. Patients' current concerns

Patients' most concerns related to their inability to bear children because they consider it's very important in their marriage life.

"I actually expected to have children... just like a normal woman... I wish I could menstruate... and pregnant… " (patient E)

The other concern was the possibility of being cheated by their partner due to their condition.

"Of course I was afraid of being cheated. I only have an artificial vagina... what if he's not satisfy enough? so I'm grateful enough he's still loyal to me until now..." (Patient D)

Our divorced participant lost her self confidence after being abandoned by her husband and still afraid to get involved in a new relationship.

"Now… I just try to live my life... but if anyone ask me whether I want to have a new husband or not, I must say that I'm not confident enough..." (Patient F)

5. Motivations to have operation

Their motivation to have operation is to improve their sexual relations, also to please their partner.

"I was afraid to have the operation. But I tried not to think about it because I really wanted to please my husband… I feel guilty because of my flaw.." (Patient B)

6. Family support

Patients suggested that family support is very important to help patients to cope with their condition.

"Family support is very important to me… they really helped me to get through everything..." (Patient C)

7. Self esteem as female

Participants felt devastated when they found out about their MRKH condition. Their inability to engage sexual relations before surgery, inability to menstruate and to bear children made them feel incomplete as a woman.

"I didn't feel sad when I knew I didn't have vagina... but I was very disappointed and devastated when I realized I also didn't have a womb which means I won't be able to get pregnant... I always think a complete woman is those who can get pregnant... to have children... so I felt really sad... so incomplete.." (Patient E)

They also feel ashamed, disappointed and felt sorry for their partner because feel not normal.

"I'm so disappointed... so sad... I'm angry but don't know what to do... I feel sorry for my husband to have a flaw wife..." (Patient A)

DISCUSSION

Although the outcomes of surgical and non-surgical treatments to create a new vagina have been reported, there have been few reports addressing the psychological impact of the condition and quality of life (QoL) outcomes.

The aim of creating a neovagina is to enable satisfactory sexual activity and thus to achieve a physical and psychological equilibrium.[13] The results of this study show no significant differences between sexual relations of MRKH patients and normal women (Figure 1).

Sexual relations measured by sexual satisfaction score of SSS-W are highly affected by good sexual communication. Effective communication between partners could con-

tribute to sexual satisfaction by facilitating closeness and intimacy, and by informing partners about sexual desires and preferences that, in turn, could lead to enhanced arousal and orgasm.[12]

Mean score of contentment domain from SSS-W questionnaire in MRKH patients are relatively higher than normal women, as suggested by the literature; probably because of higher communication and compatibility mean score. This supported by the result of interview that patients and their partner could have a frank discussion about their sexual difficulties, before and after surgery. This suggested good communication and relationship between patients and their partner that could enhance their sexual relations after neovaginoplasty.

Participants stated that they had a better sexual intercourse after neovaginoplasty, as suggested by a study that a longer vagina could improve sexual satisfaction.[14] Many studies suggested MRKH syndrome patients could have a normal sexual function after neovaginoplasty. Sexual satisfaction is an important component of sexual function assessment. Psychological adjustment plus anatomical remediation are aimed in this improvement. Considering each domain mean score, women with MRKH syndrome treated by sigmoid neovaginoplasty could be considered ''normal'' in terms of global sexual satisfaction.[4,13,15]

There was a statistically significant correlation between sexual satisfaction and relationship satisfaction and between sexual satisfaction and commitment. There was a significant positive correlation between commitment and the pro-relationship sexual behaviours. Commitment was most highly correlated with emotional bond, followed by motivation to satisfy partner, and disclosure. The three pro-relationship sexual behaviour scales were also correlated with one another. These results indicate that women who reported being more committed in their relationship also reported an increased use of the three pro-relationship sexual behaviors.[16]

The result of this study shows that our patients have a strong commitment which proofed in marriage, motivation to satisfy partner as the reason to have surgery, and disclosure about their sexual difficulties, could improve their sexual relations after sigmoid neovaginoplasty.

Patients' distress concerning their sexual difficulties was measure by distress scale in SSS-W questionnaire. Those who answered questions number 19-30 are patients who admit difficulties in their sexual relations. Figure 2 shows no significant difference between MRKH patients compared to normal women. All of our MRKH patients admitted their sexual difficulties but no longer as their concern after surgery.

Interview result shows that patients' concern related to their artificial vagina was admitted by the patients, but not as important as the inability to bear children. They were worried to be abandoned because they could not give children to their partners more than sexual intercourse difficulties.

MRKH gives a significant and lasting negative psychological impact on women with this condition, with levels of psychological distress being high and self-esteem impaired even after successful creation of a neovagina.17

Our patients stated in the interview about how MRKH affected their self esteem as female. They found it difficult to engage in sexual intercourse before surgery, unable to menstruate, and unable to carry a pregnancy. These challenges compromised their emotional well-being and no longer feeling complete.

Neovaginoplasty have been proven to improve sexual relations, but the infertility remains a problem. Our patients stated having jealous feelings towards women who could have children but found it hard to accept these difficult feelings as part of themselves, as suggested in a qualitative study that this condition led patients to a sense of isolation and an accompanying sense of insecurity about their own self worth.[18]

This study also discuss about partner's reactions to the MRKH condition. They felt sorry for the patients and disappointed due to the desire to have a perfect wife. They described positive and reassuring reactions to the neovagina. Several other studies suggested that partners were satisfied with the neovagina and that partners experienced no negative reactions.[4]

Good relationship and strong support from their partner could affect patients' self confidence and help patients to cope with their condition. Our patient lost her confidence and found it difficult to continue her life after being abandoned by her husband. Luckily she had supportive family that helped her to deal with her condition. All participants stated that family support is very important.

This entire area of research is limited by the rarity of case also the paucity of studies that focus on psychological more than the clinical aspect only. In addition, this is a cross sectional study that focused only to the conditions after surgery, therefore in the future, it's better to also study the condition before surgery and the differences.

CONCLUSIONS

Our experience shows that sigmoid neovaginoplasty is an effective technique to improve sexual relationship and help to alleviate distress of women with MRKH, although infertility remains the hardest aspects of the condition to accept. Physicians can further assist patients by being very thoughtful and deliberate in the manner that they reveal the diagnosis of MRKH. Frank discussion about how MRKH affects the physical aspects of sexual intercourse as well as acknowledging its impact on a patient's psychological well-being will be important. Physicians can also provide information about the condition and provide referrals to support groups.

Further investigations about the psychological impact and quality of life will assist healthcare professionals in improving medical and psychological care for women with MRKH.

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Correspondence to:

Dyana Safitri Velies
E-mail: dyana.safitri.v@gmail.com