

## Mini-Review

# Mayer-Rokitansky-Küster-Hauser Syndrome: Sexuality, Psychological Effects, and Quality of Life

E.J. Bean, MEd, LMSW<sup>1</sup>, T. Mazur, PsyD<sup>2</sup>, and A.D. Robinson, PhD<sup>3</sup>

<sup>1</sup>The MAGIC Foundation, Chicago, Illinois; <sup>2</sup>School of Medicine, State University of New York at Buffalo, New York, USA;

<sup>3</sup>School of Social Work, State University of New York at Buffalo, New York, USA

**Abstract.** Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome is a congenital condition in which a genetic female is born with vaginal agenesis and a rudimentary or absent uterus. This condition affects a woman's ability to menstruate, to engage in penile-vaginal intercourse, and to bear children. Much has been published about how best to create a neovagina in women with MRKH, but little has been written about the psychological impact of MRKH and quality of life outcomes for women with the condition.

A review of the extant literature published from 1955 to 2007 supports that (1) surgical or non-surgical creation of a neovagina alone does not ensure a successful psychological outcome, (2) psychological support at critical times can be helpful, and (3) how professionals use language to discuss the condition may positively or negatively influence a female's experience of MRKH. This article discusses the implications that existing knowledge has on future research and on clinical practice. Understanding how women with MRKH cope with and adjust to the condition will help healthcare professionals provide optimal care.

---

**Key Words.** Mayer-Rokitansky-Küster-Hauser syndrome—MRKH—Vaginal agenesis—DSD—Psychology—Sexuality—Quality of life

---

### Introduction

Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) is an uncommon, but not rare, congenital anomaly of the female genital tract, estimated to occur in approximately 1 in every 5,000 females.<sup>1</sup> Features include vaginal agenesis and uterine abnormalities that range from an absent uterus to rudimentary uterine remnants. Affected females usually have functioning

ovaries, normal external genitalia, and a female karyotype (46,XX). MRKH syndrome is the second most frequent cause of amenorrhea after gonadal dysgenesis<sup>1</sup> and is often discovered when a patient presents in adolescence due to primary amenorrhea.

MRKH syndrome is one of many Disorders of Sex Development (DSD). DSD refers to “congenital conditions in which the development of chromosomal, gonadal, or anatomic sex is atypical.”<sup>2</sup> DSD is a relatively new term and was proposed by international experts from the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology at the consensus meeting in October, 2005. DSD replaces out-of-date nomenclature like intersex and hermaphrodite. This review was undertaken partially in response to a request in the Consensus Statement on the Management of Intersex Disorders, a summary of the consensus meeting, that more attention be focused on the psychological aspects of DSD.<sup>2</sup> MRKH syndrome, like other DSD, poses challenges that go far beyond physical concerns. Since the publication of the Consensus Statement much dialogue has been generated. Often noted is the lack of long-term outcome studies for those with DSD.<sup>3</sup> 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.<sup>3</sup> This review supports this shift and the position that psychological issues as well as medical aspects must be addressed in order to provide optimal care.

A young woman's sense of well-being and quality of life are impacted by the condition. Affected individuals without treatment will find it difficult to engage in penile-vaginal intercourse, do not menstruate, and will be unable to carry a pregnancy. The discovery that sexual intercourse will not occur without medical intervention and the realization of loss of childbearing may be devastating to an adolescent who has not yet reached certain developmental milestones. Because of physical

---

Address correspondence to: Tom Mazur, PsyD, Women and Children's Hospital, 219 Bryant Street, Buffalo, NY 14222; E-mail: tamazur@buffalo.edu

and psychological challenges, it has been suggested that the management of MRKH falls into two categories: (1) the need to anatomically manage the anomaly so that young women may have the option to engage more easily in penile-vaginal intercourse and (2) the need to help young women cope with the psychological impact of the condition.<sup>4</sup> 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 aims of this article are three-fold: (1) to summarize the extant literature on the psychological effects of MRKH and QOL outcomes; (2) to identify existing gaps in the literature regarding the psychological effects of MRKH and QOL outcomes; and (3) to offer suggestions for future research and clinical practice for women with MRKH.

## Methods

A search of the databases Medline, Psyc INFO, PsycLIT, and CINAHL was conducted. The following keywords were used: Mayer-Rokitansky-Küster-Hausner syndrome, MRKH, vaginal agenesis, vaginal aplasia, psychological outcomes, gender identity, gender role, sexual orientation, sexual functioning, infertility, conception, marriage/cohabitation, social functioning, cognitive functioning, psychopathology, self-concept, career, spirituality, legal history, family response to MRKH, and individual adjustment to MRKH. From 36 articles collected, 31 were reviewed for this article.

## Inclusion

Articles were included that provided data on the psychological and psychosexual effects of MRKH as well as any information about a young woman's quality of life after diagnosis and treatment of MRKH. Data in the studies had to pertain to a diagnosis of MRKH. Only English manuscripts and those translated into English published between 1955 and 2007 were included. The year of 1955 was selected as the starting point for this review because this was the year that John Money published his now classic work on hermaphroditism,<sup>5,6</sup> now referred to as DSD.

## Exclusion

Data in which the results were not separated by specific diagnosis were excluded. For example, studies by Evans et al,<sup>7</sup> Hensle et al,<sup>8</sup> and Liao et al<sup>9</sup> were excluded because the data from those subjects who had MRKH could not be separated from the data of those participants who had other etiological reasons for vaginal malformations such as Androgen Insensitivity syndromes (AIS), Mixed Gonadal Dysgenesis, or cancer treatments.

## Results

The 31 articles reviewed were divided into several categories. There were 11 articles that focused primarily on how the condition of MRKH affects young women psychologically. Another 18 articles reviewed specific treatments to create a neovagina, and included varying amounts of information about how young women adjust psychosexually, emotionally, and/or psychosocially to the condition. In addition, two articles addressed the ability to achieve pregnancy through surrogacy.

The Centre for Health Promotion (2007) at University of Toronto conceptualizes QOL as the "degree to which a person enjoys important possibilities of his/her life"<sup>10</sup> taking into consideration a person's physical, psychological, social, and spiritual dimensions.<sup>10</sup> Having the condition of MRKH affects a woman's quality of life by placing limits on some of life's possibilities (like intercourse and childbearing) and may cause distress and an altered self-concept. For this article, attention was given to studies that reported on how women were functioning in regards to specific QOL domains. Also, there was a focus on how women were impacted psychologically by the limitations that MRKH imposes. The results are organized according to these dimensions of QOL and psychological effects.

## Quality of Life Outcomes

### Sexuality

Sexual functioning was addressed in 91% of the studies. The primary aim in most studies was to evaluate a specific treatment (either surgical or non-surgical) to create a neovagina. Because of the large number of articles that evaluated treatment techniques these data are reported in table format (see Table 1).<sup>11-31</sup> The focus of these articles ranged from the anatomical success of a neovagina to a more qualitative focus that included orgasm and natural lubrication. Additionally, by looking at the outcomes of these various treatments, data were also gathered about patients' psychosexual functioning and sometimes the emotional and psychosocial impact of the condition.

The literature suggests that after treatment, most women who underwent one of the many surgical or non-surgical techniques to create a neovagina were able to engage successfully in penile-vaginal intercourse; indicating that the vagina was long enough and wide enough to accommodate an erect penis. There were many reports of orgasm<sup>12-15,17,22,26,28,29</sup> and adequate natural lubrication<sup>13,18,19,21-24,29</sup> that indicated women with MRKH were actively participating in coitus. An affirmative response to the question, "Are you sexually active?" implied that



a woman was able to physically engage in the act of intercourse and *was* engaging in intercourse. However, in many of the studies that assessed treatment techniques, the terms “sexually active” and “satisfied” were not operationally defined. This left it unclear as to what was meant by these terms and just what was the quality of a woman’s sexual experience. Future studies should characterize terminology like “sexually active” and “satisfied” more definitively.

Much of the treatment focus and, hence, the research literature, has been on the remediation of a patient’s short vagina. However, approximately one third of the studies that addressed sexual functioning also looked more closely at the relationship between sexual functioning and psychological adjustment to MRKH. It was suggested that an anatomically intact vagina did not by itself ensure optimum sexual functioning. There needed to be healthy psychological functioning as well.<sup>9,11,16,31–33</sup> These studies suggested that psychological adjustment plus anatomical remediation ensured better sexual outcomes, and reinforces previous work on the complexity of female sexual response.<sup>34</sup>

### **Partner Reactions to Women Receiving Treatment**

Women with MRKH have been asked how their partners experienced their newly created vaginas. Partner responses were described as positive and reassuring. Several of these studies suggested that partners were satisfied with the neovagina and that partners experienced no negative reactions.<sup>12,26,27</sup> Partners could not tell that the neovagina was artificially created.<sup>11,35</sup>

### **Relationships with Partners**

Almost half of the studies reported on marriage and cohabitation. The studies demonstrated that a majority of study participants were either married or had a steady partner.<sup>11–13,15,26,27,32,36–38</sup> Poland and Evans wrote that “marital experiences of women with MRKH in western cultures do not seem unusual.”<sup>35</sup> However, this does not hold true for women from more traditional cultures where childbearing is expected and sometimes necessary to survival. It was reported that in Bangladesh a man may abandon a woman with a condition such as MRKH.<sup>25</sup> It was found that in India women did not seek medical help until the time of marriage arrangements. The families were counseled to marry their daughters to widowers who had already completed their families or to men who were physically challenged and wanted to adopt children.<sup>30</sup> These studies<sup>30</sup> highlight the necessity for cultural norms to be considered when assessing the impact of MRKH on a woman’s quality of life.

### **Fertility/Infertility**

An inability to bear children is very difficult news for women to hear. Studies reported a variety of painful reactions. Not only was infertility viewed as a personal loss<sup>32</sup> and anxiety provoking,<sup>24</sup> but some studies found that infertility was one of the hardest aspects of the condition to accept.<sup>11,35</sup> Other feelings that women with MRKH expressed were those of jealousy towards fertile women leading to isolation<sup>39</sup> and concern about how being unable to bear children would affect partner relationships.<sup>33</sup> Sharing the grief and loss associated with not being able to bear children in a support group helps to alleviate distress.<sup>40</sup> Both group interventions<sup>38,41</sup> included the topic of infertility in their programs.

### **Parenthood**

Women with MRKH have achieved parenthood through assistive reproductive technology (ART) and adoption. Two studies reported on successful pregnancies using ART.<sup>42,43</sup> Adoption was also documented in several articles.<sup>25,27,35–37</sup> In addition, it was found that all participants in another study expressed an acceptance of adoption as a means to create a family.<sup>33</sup>

### **Careers**

There were five articles that reported on career choices of young women with MRKH.<sup>12,32,33,35,36</sup> A variety of career choices and educational advancements were reported. Careers ranged from laundress to insurance agent. Selection of careers was found to be no different from that of other females in the general population.

### **Spirituality**

Spirituality was considered in two articles. In one study participants tried to make sense of their experience by searching for an explanation. This was viewed as a coping mechanism.<sup>39</sup> Religious affiliation was included in a table of demographic information in another study.<sup>33</sup> The majority of the participants identified a religious affiliation. One of these participants said that her faith helped her cope with partnership concerns related to MRKH.<sup>33</sup>

### **Psychological Effects**

#### **Diagnosis**

Women reported a variety of reactions, mostly negative, following a diagnosis of MRKH. These responses included reactive depression,<sup>36</sup> shock, feeling different,<sup>11,33,44</sup> and confused.<sup>12</sup> It was also learned that fear of partner rejection was common, as was isolation.<sup>35</sup> In yet another study, the reactions of women to a diagnosis of MRKH were likened to those reactions of persons experiencing trauma. The

women's sense of themselves and their worlds was shaken by the diagnosis.<sup>39</sup> A group cognitive behavioral therapy (CBT) intervention for women with MRKH was based on the belief that persistent psychological distress follows a diagnosis.<sup>38</sup>

### Individual Adjustment to MRKH

The reports of how women with MRKH adjusted to the condition offered conflicting data. An early and often cited study suggested that the condition of MRKH had an "overwhelming impact" on an individual and that women did not make a positive adjustment to the disorder.<sup>36</sup> Another study reported that 59% of their patients were generally well-adjusted and happy.<sup>11</sup> In addition, it was suggested in two studies that an important factor for determining successful outcome was the patient's psychological adjustment as it existed before knowledge of the MRKH.<sup>12,37</sup> Adjustment was reported to improve over time, especially when treated both medically and psychologically.<sup>19,35</sup> Following a supportive group psychological intervention, women with MRKH felt less anxious, depressed, and less sensitive to interpersonal contact.<sup>41</sup>

Women used a variety of strategies to cope with this diagnosis. Coping strategies that ranged from denial to compensation by accomplishment were reported in one study.<sup>32</sup> Working towards life goals were found to be a positive coping technique in another study.<sup>33</sup> Holt and Slade, using Interpretive Phenomenological Analysis, a method of qualitative research, analyzed the adjustment of seven women to MRKH. Participants used avoidance, search for meaning, resignation, and minimization as attempts to handle the stress of the diagnosis.<sup>39</sup> The CBT group intervention that helped women to process the diagnosis and to look at the situation differently was found to "improve psychological outcomes."<sup>38</sup>

### Psychopathology

Early reports<sup>36,37</sup> indicated that there could be psychopathology associated with MRKH, but these studies used only small samples and relied heavily on case reports. In contrast, other reports emphasized that although there can be severe distress at diagnosis, it may be alleviated by non-surgical or surgical treatment,<sup>19,22,24,26,35</sup> the passage of time,<sup>39</sup> counseling,<sup>35</sup> parent support,<sup>11,12</sup> and more recently, group interventions.<sup>20,38,41</sup>

### Family Response

Families varied in their responses to their daughters' diagnoses. Parental reactions were reported to range from guilty<sup>12,35,36</sup> and difficulty adjusting<sup>12,32,35</sup> to gentle and supportive.<sup>11</sup> It was found in several studies that parents encouraged their daughters to undergo

treatment to create a neovagina<sup>12,32</sup> and in one study that the parents pressured the medical staff as well to perform an operation so that their daughters would have an easier time finding a partner.<sup>32</sup> Parental support was helpful to a positive outcome<sup>12</sup> and it was recommended that parents be a part of counseling and decision-making.<sup>11,12,36,44</sup>

### Self-Concept

A discovery of MRKH appeared to be a threat to a woman's self-concept, especially immediately following diagnosis. Self-esteem and body image disturbances were reported in several articles.<sup>12,14,32,36,37,39</sup> In contrast, positive self-esteem, including a sense of achievement and self-confidence, was related to a successful treatment outcome.<sup>19,24,26</sup> One study reported that most participants had average levels of self-esteem.<sup>33</sup> Heller-Boersma et al used the Rosenberg self-esteem scale to measure self-improvement after a CBT intervention.<sup>38</sup> A trend for improved self-esteem in the CBT group was found.<sup>38</sup>

### Gender Identity

There were no reports of self-gender change or gender dysphoria. All participants had established female gender identity concordant with their gender assignment. Neither gender change nor gender dysphoria was a specific focus of any of the articles. Gender identity and gender change have been previously reported on for other DSD including congenital adrenal hyperplasia,<sup>45</sup> 5 alpha-reductase-2 and 17-beta-hydroxysteroid dehydrogenase-3 deficiencies,<sup>46</sup> AIS and micropenis,<sup>47</sup> and female-reared 46XY persons with penile agenesis, cloacal exstrophy of the bladder, or penile ablation.<sup>48</sup> This review documents that there are no reports of gender change for individuals with MRKH and adds another DSD condition to those already reviewed for this topic.

### Gender Role

There was one report of an adolescent who behaved as a "tomboy."<sup>36</sup> Additionally, women expressed concern that they would not be able to perform some of the typical tasks of a female gender role.

### Sexual Orientation

There were two reports of women with MRKH who identified as bisexual.<sup>33,44</sup> No women who identified as homosexual were noted. However, sexual orientation was specifically addressed in only one of the articles.<sup>32</sup>

### Self as Female

Many studies addressed how a woman's sense of herself as female was shaken after the diagnosis of MRKH. Doubts about female identity and a sense of

no longer feeling complete were reported.<sup>15,35,38,39</sup> In addition, early studies suggested that young women with MRKH experienced a markedly compromised “sexual identity”<sup>36</sup> and that young women felt different from other girls.<sup>11</sup> Some women believed that to be fully feminine one had to be able to reproduce.<sup>11</sup> Another study reported that one woman experienced “sexual identity problems” and advised that young women needed to be reassured about their female gender identity.<sup>44</sup> A CBT intervention was based on the concept that the core issue of MRKH was the threat to a woman’s sense of self as a fully-functioning, lovable adult woman. This intervention included an exploration of societal scripts regarding women’s roles and views of femininity.<sup>38</sup>

## Discussion

### Use of Language

What becomes clear from looking at the literature is the critical need to help women counteract negative perceptions and cognitive distortions that so easily accompany a diagnosis that has such profound effects. Both physicians and mental health professionals will be more effective if they are very intentional in the language used to explain and discuss MRKH. Two examples emerge from looking at the literature.

First of all, being unable to conceive children impacted women’s adjustment and how they perceived themselves. Many studies confirmed this difficult aspect of the diagnosis. The positive news is that there were two reports of pregnancies conceived with the eggs of women who have MRKH and carried by a surrogate.<sup>42,43</sup> This means that technically, a female with MRKH is fertile, but unable to conceive without ART and to carry the pregnancy herself. How a person is labeled affects self-concept, so this fact allows the physician or mental health professional to make an important distinction to a woman with MRKH: *She is fertile*. She can conceive a biological child, but will need a surrogate carrier for the duration of the pregnancy.

Secondly, one of the most troubling reactions reported from women with MRKH was the feeling that they were no longer full and functioning women. This belief was expressed in comments from women like “only part female”, “how much of a female am I?”, “incomplete.” If these comments are taken out of the context of the discovery of absent anatomical features, the comments may sound like those from individuals with gender identity disorder. As previously stated, there were no reports in the literature of women with MRKH who had changed gender. In fact, one article reported that the self-ideal of the young woman with MRKH showed traits of traditional femininity.<sup>32</sup> The studies that suggested markedly

compromised “sexual identity”<sup>36</sup> and doubt about “female identity”<sup>39</sup> should be interpreted cautiously. The above comments most likely do not mean that women with MRKH are dissatisfied with their female gender or female identity. The difficulty is that there is no existing terminology to adequately describe the feelings that women with MRKH reported. Perhaps, a more accurate term is *gender role insecurity*, a concern that an expected female gender role, one that includes menstruating, bearing children, and engaging in sexual intercourse, may go unfulfilled. It appears that women are questioning whether they can adequately perform the roles that biology typically equips them to fulfill and that society has historically expected them to perform. Data indicated that once a woman used her option to create a neovagina and was assured that there were alternative methods to creating a family, some of the questions about her sense of self as female dissipated. As a result of inadequate terminology, the language used to describe women’s attitudes about themselves was vague and left much room for interpretation.

### Recommendations

Many questions remain as how to best treat women with MRKH. At least half of the studies recommended psychological counseling, but very few made suggestions as to what types of psychological interventions are salient and when during the course of medical care they should take place. Because studies indicated that critical time periods include diagnosis,<sup>12,32</sup> treatment for a neovagina,<sup>16,32,35</sup> relationships with men,<sup>11,33,35</sup> and creation of a family,<sup>33</sup> it appears that these are the times when a woman may need more support. Also, women reported using several different strategies to cope with MRKH. If it can be determined more operationally how women are dealing with MRKH, these coping techniques may be incorporated into treatment plans and supportive group interventions for women with MRKH and other DSD. Furthermore, although the role of spirituality in adjusting to illnesses like cancer has been explored,<sup>49</sup> only two articles addressed spirituality and adjusting to MRKH. This is a QOL domain that deserves more investigation.

Additionally, no study looked at how a woman’s level of knowledge about her condition affected her ability to cope with it. Psychoeducation is frequently mentioned in the articles, but no recommendations were made for assessing the level of an individual’s understanding of MRKH. It would be helpful to evaluate how a woman’s knowledge of MRKH may contribute to her own health care self-efficacy.

Another gap in the literature was that there were only two reports<sup>35,39</sup> of how, when, and to whom young women might disclose the condition of

MRKH. Information management is an important topic that deserves consideration. Disclosure includes physicians informing patients about their diagnosis. Disclosure also includes patients and parents sharing information with family members and the wider community. Talking about a condition that involves the genitals and sexuality can be difficult for many adolescents and adults. No study offered any suggestions as to whom, when, and how to best disclose information about the condition. There is scant research on the disclosure of any DSD.<sup>3</sup> It would be helpful to explore just how much information is useful to patients and appropriate for others to know. How should the news of the condition be delivered and by whom?

Also, it is noteworthy that the majority of studies looked mostly at younger women. In 27 studies that reported age, only one study included women over 50 years and only four studies included women over the age of 40. How are older women doing? What is the quality of their sexual experiences? Have they adjusted to the condition? Prospective studies that follow women over time will help to answer these questions.

Finally, sexual orientation of women with MRKH was not thoroughly explored in any of the studies. It would be useful to determine whether or not a woman's sexual orientation has any bearing on her desire for a vagina. There are two reasons for wanting a vagina; to allow for penetration and to be like other females. Most reports indicated that women wanted vaginas and felt better once they had one. However, perhaps, a woman who is not going to engage in vaginal intercourse would not want one. This has never been investigated.

### Limitations

This entire area of research is limited by the paucity of studies that focus on psychological effects and quality of life outcomes. In addition, existing studies, in particular some of the older studies, used only case reports from a few patients to make general statements about women's reactions to the diagnosis of MRKH.<sup>36,44</sup> Few studies used standardized psychometric measurements, relying often on case reports, interviews, and questionnaires. Only two studies used quality of life measurements.<sup>19,26</sup> Valid and reliable measures designed for this population and others who have DSD are needed. In this review, no articles were excluded because of methodology. While it was noted that reports varied in their quality of investigation, all articles were included and given consideration.

### Conclusions

Optimal care for women with MRKH includes both medical and psychological support at important milestones throughout a woman's life span. A medical

approach to treating MRKH is necessary, but not sufficient. Physicians can further assist young women 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 mental health professionals and to support groups. Screening newly diagnosed patients for degree of psychological distress can help identify those individuals who may benefit from longer-term counseling. Further investigation into the factors that mediate and/or moderate the impact of MRKH will assist healthcare professionals in improving medical and psychological care for women with MRKH.

*Acknowledgements:* The authors would like to thank Abra Greer for her technical assistance and Armando Arroyo, MD, and Mary Ann Meeker, PhD, for their review of this manuscript. We are also grateful for the library assistance of Ms. Elaine Mosher, MLS, and Ms. Carolanne Kilichowski, AAS, Emily Foster Health Sciences Library of the Women and Children's Hospital of Buffalo.

### References

1. Fedele L, Bianchi S, Tozzi L, et al: A new laparoscopic procedure for creation of a neovagina in Mayer-Rokitansky-Kuster-Hauser syndrome. *Fertil Steril* 1996; 66:854
2. Lee P, Houk C, Ahmed F, Hughes I: Consensus statement on management of intersex disorders. *Pediatrics* 2006; 118:488
3. Hughes I, Nihoul-Fekete C, Thomas B, et al: Consequences of the ESPE/LWPES guidelines for diagnosis and treatment of disorders of sex development. *Best Pract Res Clin Endocrinol Metabol* 2007; 21:351
4. Edmonds DK: Congenital malformations of the genital tract and their management. *Best Pract Res Clin Obstet Gynaecol* 2003; 17:19
5. Money J, Hampson JG, Hampson JL: An examination of some basic sexual concepts: The evidence of human hermaphroditism. *Bull Johns Hopkins Hosp* 1955; 97:301
6. Money J, Hampson JG, Hampson JL: Hermaphroditism: Recommendations concerning assignment of sex, change of sex, and psychological adjustment. *Bull Johns Hopkins Hosp* 1955; 97:284
7. Evans TN, Poland ML, Boving RL: Vaginal malformations. *Am J Obstet Gynecol* 1981; 141:910
8. Hensle T, Shabsigh A, Shabsigh R, et al: Sexual function following bowel vaginoplasty. *J Urol* 2006; 175:2283
9. Liao LM, Doyle J, Crouch NS, et al: Dilation as treatment for vaginal agenesis and hypoplasia: A pilot exploration of benefits and barriers as perceived by patients. *J Obstet Gynaecol* 2006; 26:144
10. Renwick R, Brown I, Nagler M, editors. *Quality of life in health promotion and rehabilitation: conceptual approaches, issues, and applications*. Thousand Oaks, CA, Sage Publications, 1996

11. David A, Carmil D, Bar-David E, et al: Congenital absence of the vagina. *Clinical and psychologic aspects. Obstet Gynecol* 1975; 46:407
12. Hecker BR, McGuire LS: Psychosocial function in women treated for vaginal agenesis. *Am J Obstet Gynecol* 1977; 129:543
13. Raboch J, Horejsi J: Sexual life of women with the Kuster-Rokitansky syndrome. *Arch Sex Behav* 1982; 11:215
14. Smith MR: Vaginal aplasia: therapeutic options. *Am J Obstet Gynecol* 1983; 146:488
15. Freundt I, Toolenaar TA, Huikeshoven FJ, et al: Long-term psychosexual and psychosocial performance of patients with a sigmoid neovagina. *Am J Obstet Gynecol* 1993; 169:1210
16. Lappohn RE: Congenital absence of the vagina—results of conservative treatment. *Eur J Obstet Gynecol Reprod Biol* 1995; 59:183
17. Alessandrescu D, Peltecu GC, Buhimschi CS, et al: Neocolpoptosis with split-thickness skin graft as a surgical treatment of vaginal agenesis: retrospective review of 201 cases. *Am J Obstet Gynecol* 1996; 175:131
18. Borruto F, Chasen ST, Chervenak FA, et al: The Vecchietti procedure for surgical treatment of vaginal agenesis: comparison of laparoscopy and laparotomy. *Int J Gynaecol Obstet* 1999; 64:153
19. Kaloo P, Cooper M: Laparoscopic-assisted Vecchietti procedure for creation of a neovagina: an analysis of five cases. *Aust N Z J Obstet Gynaecol* 2002; 42:307
20. Robson S, Oliver GD: Management of vaginal agenesis: review of 10 years practice at a tertiary referral centre. *Aust N Z J Obstet Gynaecol* 2000; 40:430
21. Creatsas G, Deligeorgiou E, Makrakis E, et al: Creation of a neovagina following Williams vaginoplasty and the Creatsas modification in 111 patients with Mayer-Rokitansky-Kuster-Hauser syndrome. *Fertil Steril* 2001; 76:1036
22. Brun JL, Belleanne G, Grafeille N, et al: Long-term results after neovagina creation in Mayer-Rokitansky-Kuster-Hauser syndrome by Vecchietti's operation. *Eur J Obstet Gynecol Reprod Biol* 2002; 103:168
23. Graziano K, Teitelbaum DH, Hirschl RB, et al: Vaginal reconstruction for ambiguous genitalia and congenital absence of the vagina: a 27-year experience. *J Pediatr Surg* 2002; 37:955
24. Communal PH, Chevret-Measson M, Golfier F, et al: Sexuality after sigmoid colpoptosis in patients with Mayer-Rokitansky-Kuster-Hauser Syndrome. [see comment, *Fertil Steril* 2004; 81:1721]. *Fertil Steril* 2003; 80:600.
25. Del Rossi C, Attanasio A, Del Curto S, et al: Treatment of vaginal atresia at a missionary hospital in Bangladesh: results and followup of 20 cases. *J Urol* 2003; 170:864
26. Klingele CJ, Gebhart JB, Croak AJ, et al: McIndoe procedure for vaginal agenesis: long-term outcome and effect on quality of life. *Am J Obstet Gynecol* 2003; 189:1569
27. Frost-Arner L, Aberg M, Jacobsson S: Split skin graft reconstruction in vaginal agenesis: a long-term follow-up. *Scand J Plast Reconstr Surg Hand Surg* 2004; 38:151
28. Nadarajah S, Quek J, Rose GL, et al: Sexual function in women treated with dilators for vaginal agenesis. *J Pediatr Adolesc Gynecol* 2005; 18:39
29. Borruto F, Camoglio FS, Zampieri N, et al: The laparoscopic Vecchietti technique for vaginal agenesis. *Int J Gynaecol Obstet* 2007; 98:15
30. Kapoor R, Sharma DK, Singh KJ, et al: Sigmoid vaginoplasty: long-term results. *Urology* 2006; 67:1212
31. Ismail-Pratt IS, Bikoo M, Liao LM, et al: Normalization of the vagina by dilator treatment alone in Complete Androgen Insensitivity Syndrome and Mayer-Rokitansky-Kuster-Hauser Syndrome. *Hum Reprod* 2007; 22:2020
32. Langer M, Grunberger W, Ringler M: Vaginal agenesis and congenital adrenal hyperplasia. Psychosocial sequelae of diagnosis and neovagina formation. *Acta Obstet Gynecol Scand* 1990; 69:343
33. Morgan EM, Quint EH: Assessment of sexual functioning, mental health, and life goals in women with vaginal agenesis. *Arch Sex Behav* 2006; 35:607
34. Bancroft J, Loftus J, Long J: Distress about sex: A national survey of women in heterosexual relationships. *Arch Sex Behav* 2003; 32:193
35. Poland ML, Evans TN: Psychologic aspects of vaginal agenesis. *J Reprod Med* 1985; 30:340
36. Kaplan EH: Congenital absence of the vagina. *Psychoanal Q* 1970; 39:52
37. Coney P: Effect of vaginal agenesis on the adolescent: prognosis for normal sexual and psychological adjustment. *Adolesc Pediatr Gynecol* 1992; 5:8
38. Heller-Boersma JG, Schmidt UH, Edmonds DK: A randomized controlled trial of a cognitive-behavioural group intervention versus waiting-list control for women with uterovaginal agenesis (Mayer-Rokitansky-Kuster-Hauser syndrome: MRKH). *Hum Reprod* 2007; 22:2296
39. Holt RE, Slade P: Living with an incomplete vagina and womb: an interpretative phenomenological analysis of the experience of vaginal agenesis. *Psychol Health Med* 2003; 8:19
40. Dayus D, Rajacich D, Carty L: Promoting health among infertile couples through support groups. *Guidance Counseling* 2001; 16:110
41. Weijnenborg PT, ter Kuile MM: The effect of a group programme on women with the Mayer-Rokitansky-Kuster-Hauser syndrome. *Br J Obstet Gynaecol* 2000; 107:365
42. Van Waart J, Kruger TF: Surrogate pregnancies in patients with Mayer-Rokitansky-Kuster-Hauser syndrome and severe teratozoospermia. *Arch Androl* 2000; 45:95
43. Esfandiari N, Claessens EA, O'Brien A, et al: Gestational carrier is an optimal method for pregnancy in patients with vaginal agenesis (Rokitansky syndrome). *Int J Fertil Womens Med* 2004; 49:79
44. Neinstein LS, Castle G: Congenital absence of the vagina. *Am J Dis Child* 1983; 137:669
45. Dessens AB, Slijper FM, Drop SL: Gender dysphoria and gender change in chromosomal females with congenital adrenal hyperplasia. *Arch Sex Behav* 2005; 34:389
46. Cohen-Kettenis PT: Gender change in 46, XY persons with 5alpha-reductase-2 deficiency and 17beta-hydroxysteroid dehydrogenase-3 deficiency. *Arch Sex Behav* 2005; 34:399
47. Mazur T: Gender dysphoria and gender change in androgen insensitivity or micropenis. *Arch Sex Behav* 2005; 34:411
48. Meyer-Bahlburg HF: Gender identity outcome in female-raised 46, XY persons with penile agenesis, cloacal exstrophy of the bladder, or penile ablation. *Arch Sex Behav* 2005; 34:423
49. Laubmeier K, Zakowski S, Bair J: The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *Int J Behav Med* 2004; 11:48