The effect of a group programme on women with the Mayer–Rokitansky–Küster–Hauser Syndrome

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Objective To evaluate the effect of a group programme on psychological distress in women with the Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome.

Setting Gynaecologic outpatient clinic.

Sample Seventeen women with MRKH syndrome participated in this study.

Method A semi-structured programme of seven sessions was offered dealing with themes of the MRKH syndrome. Psychological distress was measured at the first visit 3–6 month before the group programme was started (pre-test-0), at the first (pre-test) and then at the last group session (post-test).

Main outcome measure The Symptom Check List-90 was used to assess feelings of psychological distress.

Results The post-test subscale scores for anxiety, depression, interpersonal sensitivity and the total score for psychological distress were significantly lower than the pre-test-0 and pre-test scores ($P < 0.05$). No significant differences were found between the pre-test-0 and pre-test subscale scores and total score.

Conclusion A semi-structured group programme seems valuable in helping women with the MRKH syndrome to deal with their psychological stress.

INTRODUCTION

The Mayer–Rokitansky–Küster–Hauser syndrome, also known as Müllerian Agenesis syndrome, is characterised by congenital absence of the vagina, aplasia or hypoplasia of the uterus and hypoplastic fallopian tubes. Normal, functioning ovaries are present and external genitalia are normal. Affected women have a normal female karyotype (46XX) with female secondary sex characteristics. Failure in the canalisation of the Müllerian ducts during the embryonal phase of the development of the female fetus is thought to be the underlying process, although the real cause is unknown. Renal, skeletal and other congenital anomalies are frequently associated with the syndrome. The incidence is relatively rare.

After the first publications by Mayer, Rokitansky and Küster on this syndrome a hundred years ago, many studies have reported on numerous methods of creating a neovagina, surgical as well as nonsurgical. Only a few case reports have described the psychological, social and sexual consequences of the diagnosis and treatment of the MRKH syndrome.

Being born without vagina and uterus can induce feelings of being different from other women, leading to a sense of inferiority and doubts about female role and femininity. A genotypical and phenotypical woman may only be considered as a woman—both by herself and those around her—when she menstruates regularly, can have intercourse and is able to become pregnant and give birth to a child. Women with MRKH syndrome may feel ‘incomplete’. Even, when a woman has a vagina created by herself or the doctor, she still has to cope with all the other aspects of the anomaly. As support groups seem to help patients with different types of gynaecological problems, a semi-structured group programme for women with the MRKH syndrome has been developed at our department. The aim of this study was to evaluate the effect of the group programme on psychological distress using a waiting-list control period for comparison.

METHODS

Every two weeks a group session of two hours was provided, totalling seven sessions. The group sessions were conducted by a gynaecologist (first author) and a female social worker, a woman with MRKH syndrome herself. Six to eight women could participate in each group. A semi-structured programme was offered dealing with the themes presented in Table 1. At each session a theme...
Seven sessions of two hours every two weeks.

Table 1. The themes of a semi-structured group programme for women with Mayer–Rokitansky–Küster–Hauser syndrome. Seven sessions of two hours every two weeks.

<table>
<thead>
<tr>
<th>Session</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Introduction/getting acquainted with each other.</td>
</tr>
<tr>
<td>2.</td>
<td>How was the diagnosis made? What was your reaction? How are you coping with it now?</td>
</tr>
<tr>
<td>3.</td>
<td>What was the reaction of your parents, friends, brothers, sisters at that time? How are they dealing with it now?</td>
</tr>
<tr>
<td>4.</td>
<td>Medical information: what kind of method did you use to create your vagina? And why?</td>
</tr>
<tr>
<td>5.</td>
<td>Sexuality: can you have a satisfying sexual relationship? How do/ did you inform your (boy) friend?</td>
</tr>
<tr>
<td>6.</td>
<td>Infertility: how do you deal with it?</td>
</tr>
<tr>
<td>7.</td>
<td>Female role and femininity.</td>
</tr>
</tbody>
</table>

was introduced by one of the group leaders by informing the women about somatic and/or psychological aspects of the topic. Thereafter, the women in the group could ask questions and share their experiences and feelings.

Seventeen women were included in this study. They were self-referred or were referred by their gynaecologist. The only criterion to participate in this group programme was the diagnosis of MRKH syndrome made by a gynaecologist. The mean age of the women was 27-1 years (SD 10-0; range 17-54 years). Ten women were married or were living in an ongoing relationship. Two women reported sexual abuse in the past. The mean age of the women at the time the diagnosis of MRKH syndrome was made was 17-1 years (SD 1-5; range 15–20 years). The methods of treatment of creating a neovagina were diverse. Three women had decided not to create a vagina. One of these was 38 years old, and had never felt the need to (let) create a vagina. The other two women, seventeen and twenty-two years old, had the intention to create a vagina at some future time. Six women created a vagina themselves according to Frank’s method either by using moulds, or by ‘using’ a partner’s penis as a mould. The epithelium is widened and deepened by intermittent pressure on a vaginal dimple with a series of graduated dilators or partners’ penises. Eight women had undergone an operation to create a vagina, by different methods. All the 17 women completed the programme.

The Symptom Check List is a well-known, self-report questionnaire consisting of 90 items. It is scored on a five-point scale indicating the frequency with which the person is bothered by symptoms during the preceding week. The questionnaire consists of eight subscales: anxiety, agoraphobia, depression, insufficiency of thinking and acting, interpersonal sensitivity, somatisation, sleeping problems. The sum score of all items gives an index of psychological distress (possible score range 90–450). A higher score represents greater psychological distress. The SCL-90 was applied at the first visit to the department (pre-test-0). At this first visit, after taking the history of the MRKH syndrome, the woman was informed about the group programme. Thereafter she had to wait three to six months before the group programme started. The SCL-90 was also applied at the first (pre-test) and at the last group session (post-test). Because of too many missing items on two SCL-90-scores at post-treatment, only the results of 15 women could be used for the analyses. In this study the women were their own controls.

### RESULTS

As can be seen in Table 2, repeated-measure ANOVA revealed significant main effect for ‘time’ on four of the eight SCL-90 subscale scores and the total score.

Table 2. Means and standard deviations (in parentheses) of 15 women with the Mayer–Rokitansky–Küster–Hauser syndrome, with regard to subscale and total score on the Symptom Check List-90, 3–6 months before (pre-test-0), at the beginning (pre-test) and at the end (post-test) of a semi-structured group programme. Pre-0 = pre-test-0; pre = pre-test; post = post-test.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre-test-0</th>
<th>Pre-test</th>
<th>Post-test</th>
<th>F (time)</th>
<th>Post hoc analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>16.9 (6.7)</td>
<td>16.5 (6.7)</td>
<td>13.4 (3.7)</td>
<td>4.6*</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Agoraphobia</td>
<td>9.0 (4.1)</td>
<td>8.7 (2.9)</td>
<td>8.1 (1.7)</td>
<td>1.1</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Depression</td>
<td>32.5 (14.9)</td>
<td>29.1 (13.7)</td>
<td>23.2 (7.0)</td>
<td>5.9**</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Somatisation</td>
<td>17.6 (6.7)</td>
<td>17.2 (6.2)</td>
<td>14.8 (2.7)</td>
<td>2.4</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Insufficiency of thinking and acting</td>
<td>15.5 (6.0)</td>
<td>14.8 (4.9)</td>
<td>13.0 (3.4)</td>
<td>3.0</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Interpersonal sensitivity</td>
<td>31.1 (12.5)</td>
<td>28.9 (7.8)</td>
<td>24.6 (5.6)</td>
<td>7.1**</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Hostility</td>
<td>8.2 (2.3)</td>
<td>9.1 (3.2)</td>
<td>7.2 (1.3)</td>
<td>5.1*</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Sleeping problems</td>
<td>4.8 (2.6)</td>
<td>6.1 (3.6)</td>
<td>4.7 (1.8)</td>
<td>2.7</td>
<td>post &lt; pre-0 = pre</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>150.8 (55.11)</td>
<td>143.8 (47.0)</td>
<td>118.9 (22.9)</td>
<td>6.4**</td>
<td>post &lt; pre-0 = pre</td>
</tr>
</tbody>
</table>

*P < 0.05; **P < 0.01.
Post hoc paired t tests using the Bonferroni correction indicated that the women had lower scores for anxiety, depression, interpersonal sensitivity, and psychological distress at post-test in comparison with pre-test-0 and pre-test levels. The subscale score for hostility at post-test was decreased only in comparison with the pre-test score, and not with pre-test-0 score. No significant differences were observed between pre-test-0 and pre-test for SCL-90 subscale scores and the total score.

These results indicate that women with the MRKH syndrome felt less anxious, less depressed, and they felt less sensitive to interpersonal contact after a semi-structured group programme than before the programme. And they improved more during the group programme than during the waiting-list control period. (Table 2)

DISCUSSION

As far as we know, this study is unique by offering a group programme for women with the MRKH syndrome and quantifying the effect on the feeling of wellbeing by using SCL-90 scores.

From the first visit at the outpatient clinic up to the time the programme was started, it appears that the average levels of psychological distress of the women with the MRKH syndrome were higher in comparison with a normal population (mean score = 129)\\(^19\\)\(^19\). Especially the subscale scores for depression and interpersonal sensitivity were high and the subscale score for anxiety was above the mean in comparison with a normal population\(^19\). However, the average level of psychological distress of the women with the MRKH syndrome, was lower in comparison with a psychiatric population (mean score = 207)\(^29\). This result is in line with reports from others\(^11\)-\(^13\), although these authors only described different aspects of the psychological, social and sexual sequelae.

Our study also showed significant changes in SCL-90 scores after the group programme. On average the women felt ‘better’ after the programme. They felt less depressed, less anxious and less sensitive to interpersonal contact. The level of psychological distress after the programme was comparable with a normal population\(^19\). The women, however, did not improve significantly between the first visit to the outpatient clinic and the start of the programme. We may conclude that participating in a semi-structured group programme as described here can affect the general feeling of wellbeing. A possible explanation is that the women could get all the information they wanted to have and could share and recognise their experiences and feelings through interaction with others and, consequently ‘feel better’. Some women said they felt less ‘incomplete’ after the programme. Although this group programme was led by a woman with MRKH syndrome herself, we have the impression that it is not a necessity for the women in the group to take the opportunity to share their experiences and feelings with each other.

We may conclude that the effect of a group programme seems to surpass that of a waiting-list period. The present subject design however precludes conclusions about effective ingredients of change since the group programme consisted of several components, which may all have contributed to the effect in varied degree. Thus, there is the semi-structured programme itself, the nature of the group and their discussions or the fact that the programme was led by a woman with MRKH syndrome herself. As the women included in this study were heterogeneous with respect to biographic (age, relationship) and medical status variables (neovagina) and the level of psychological distress (SCL-90), there is an indication that this programme is effective for most of these women. Because only post-test measures were collected the maintenance of change in psychological distress in women with MRKH syndrome in the long term is unknown.

In conclusion, a semi-structured group programme seems valuable in helping these women to deal with their problems in ways clinicians are usually unable to do\(^71\).

References

5 Rokitansky C. Über die sogenannten Verdoppelungen des Uterus. (About the so called doubling of the uterus). Medizinisches Jahrbuch des österreichischen Staates 1838; 26: 39–77.


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