

Quality of life 15 years after sex reassignment surgery for transsexualism

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Objective: To evaluate quality of life and patients' satisfaction in transsexual patients (TS) after sex reassignment operation compared with healthy controls.

Design: A case-control study.

Setting: A tertiary referral center.

Patient(s): Patients after sex reassignment operation were compared with a similar group of healthy controls in respect to quality of life and general satisfaction.

Intervention(s): For quality of life we used the King's Health Questionnaire, which was distributed to the patients and to the control group. Visual analogue scale was used for the determination of satisfaction.

Main Outcome Measure(s): Main outcome measures were quality of life and satisfaction.

Result(s): Fifty-five transsexuals participated in this study. Fifty-two were male-to-female and 3 female-to-male. Quality of life as determined by the King's Health Questionnaire was significantly lower in general health, personal, physical and role limitations. Patients' satisfaction was significantly lower compared with controls. Emotions, sleep, and incontinence impact as well as symptom severity is similar to controls. Overall satisfaction was statistically significant lower in TS compared with controls.

Conclusion(s): Fifteen years after sex reassignment operation quality of life is lower in the domains general health, role limitation, physical limitation, and personal limitation. (Fertil Steril® 2009;92:1685–89. ©2009 by American Society for Reproductive Medicine.)

Key Words: Quality of life, transsexuals, patients' satisfaction, sex reassignment operation, long-term results

Based on legal applications for sex change (1981–1990), the estimated prevalence over 10 years in the former Federal Republic of Germany is 2.4:100,000 male-to-female (MTF) transsexuals (TS) and 1.0:100,000 female-to-male (FTM) TS (1, 2). In other European countries higher prevalences have been reported such as The Netherlands with 8.4:100,000 MTF and 3.3:100,000 FTM TS (3).

Sex reassignment surgery has been part of the treatment of transsexuality for >70 years and is widely accepted as therapeutic (4).

Individuals considering surgery and medical staff who serve as advisor and gatekeeper still have little reliable information concerning general outcome and quality of life after surgery. Groups such as the Harry Benjamin International Gender Dysphoria Association, which promotes Standards of Care for the provision of sex reassignment surgery

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(SRS), lack empirical and scientific information to assess the validity of their recommendations (5).

Little information is available on quality of life and factors associated with satisfaction or regret following sex reassignment surgery. Lawrence (6) found in a study of 232 MTF TS that dissatisfaction was most strongly associated with unsatisfactory functional results of surgery.

There is a growing consensus that subjective criteria may provide a more meaningful basis for evaluating sex reassignment surgery than the use of so-called objective criteria such as employment, choice of "appropriate" sexual partners or anatomic aspects assessed by the medical professionals (6).

The visual analogue scale (VAS) is a validated tool to assess health and satisfaction in patients, and is widely used for the investigation of pain and for measuring attitudinal attributes and quality of life (7).

The King's Health Questionnaire is a validated tool to assess quality of life, and is widely used tool to assess quality of life in incontinence and is validated in several languages including German (8). The questionnaire assesses the domains general health, role limitation, physical and personal limitation, emotions, sleep, incontinence, and symptom severity.

TABLE 1			
Demographic data of transsexuals and controls.			
	Age (years; median, range)	BMI (median, range)	Number of previous operations (median, range)
TS	51 (39–62)	24 (18–31)	9 (6–23)
Controls	49 (37–60)	22 (19–34)	2 (1–5)
P value	ns	ns	P=.001

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The aim of the current study was to evaluate quality of life and patient satisfaction after sex reassignment surgery in MTF and FTM TS.

PATIENTS AND METHODS

The setting is a tertial referral center of the outpatient Department of Gynecology and Endocrinology of the University Hospital of Bern.

Between January 2005 and January 2008 we asked transsexual patients who received their hormonal replacement therapy in the Department of Endocrinology to fill out quality-of-life questionnaires. Patients and controls gave written and oral consent to participate in the study and to fill out the questionnaires.

Participants were asked to fill out the King's Health Questionnaire and to assess their general situation using a VAS adapted for transsexual patients.

For the latter, the exact wording was "How do you think your best friend would rate your satisfaction with your current general life satisfaction?," with 0 the greatest dissatisfaction and 10 as the greatest possible satisfaction.

The King's Health Questionnaire consists of the domains general health perception, incontinence impact, role limitations, physical limitations, social limitations, personal relationships, emotions, sleep/energy, and severity measures with scores between 0 and 5 and 1 and 5, respectively, and a change of at least five points is considered significant (8) (see Appendix).

As a control group, healthy female medical staff with at least one previous abdominal or pelvic operation was asked to fill in the King's Health Questionnaire and to rate their current situation using the VAS.

For statistical analysis, Graph Pad Prism version 5.0 for Windows was used (Graph Pad, La Jolla, CA). A Student's *t* test was used to compare groups and α was set .05.

RESULTS

Fifty-five TS patients and 20 controls could be included in the study. The TS and controls were similar in age and body mass index.

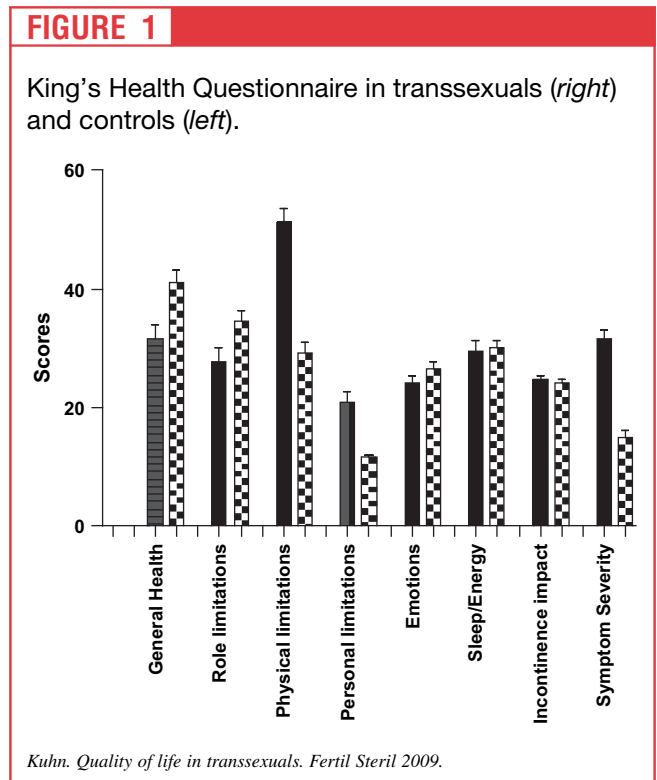


Table 1 shows demographic data and the number of previous operations.

Of the TS patients, 52 were MTF and 3 FTM. Of the latter, all three had had removal of their female organs and one had plastic surgery for penile reconstruction. Sex reassignment surgery had been 15 years previously in median (range = 8–23).

Concerning marital status, in the patient group, 13 were married, 12 were divorced, 25 were unmarried, and in 5 patients we have no data of the marital status. Of the controls, 13 were married, 5 were divorced, and 2 were unmarried.

Of the 37 divorced and unmarried patients, 9 were living in a stable partnership; in the control group, of the nine divorced and unmarried subjects five were living in a stable partnership.

Patients were significantly less married than controls ($P=.0019$; 95% confidence interval (CI) of the difference 0.15–0.57, Fisher's exact test), but the ratio of unmarried and divorced individuals differed not significantly from controls ($P=.106$; 95% CI of the difference 0.48–1.12, Fisher's exact test).

Figure 1 summarizes the quality of life as determined by the King's Health Questionnaire.

Table 2 summarizes the means, standard error of the mean (SEM) and statistical significances of each domain for TS and controls.

Figure 2 shows the results of the VAS for transsexuals and controls.

Transsexuals replied to the question how their best friends would rate their satisfaction with 4.49 ± 0.1 (mean \pm SEM)

TABLE 2**King's Health Questionnaire TS compared to controls.**

Domain	TS	Controls	P value
General health	31.7 +/-2.2	41.0+/-2.3	.019
Role limitation	27.8+/- 2.4	34.6+/-1.7	.046
Physical limitation	37.6 ± 2.3	20.9 ± 1.9	<.0001
Personal limitation	20.9 ± 1.9	11.6 ± 0.4	<.001
Emotions	24.2 ± 1.3	26.5 ± 1.6	.25
Sleep	29.6 ± 1.6	30.0 ± 1.4	.86
Incontinence	24.8 ± 0.6	24.2 ± 0.5	.49
Symptom severity	21.9 ± 1.2	15.1 ± 1.2	.125

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on the VAS, controls replied with a 7.35 ± 0.26 (mean \pm SEM) to the same question, and this was statistically significant ($P<.0001$).

DISCUSSION

To our knowledge, this is the first study with long-term data comparing various aspects of quality of life in TS to controls using validated tools.

The current study shows a similar quality of life in most of the domains in TS compared with a smaller group of controls who are similar in age.

General health was considered significantly lower, physical and personal limitations were significantly greater in TS, and general life satisfaction was significantly lower in TS compared with controls.

Role limitations were significantly lower in TS compared with controls, which could be a sign for good gender assimilation and well-being.

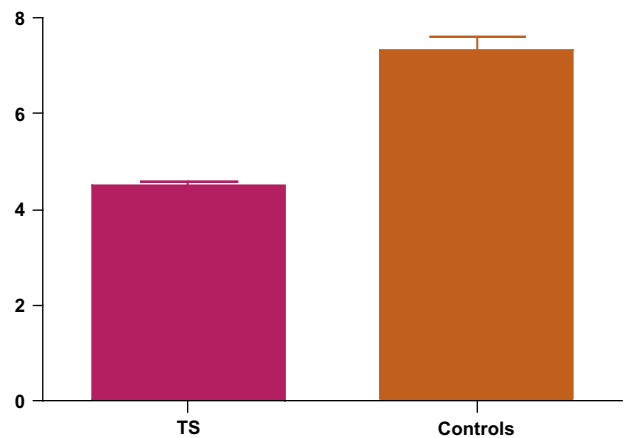
We did not analyze data for MTS and FTM TS separately, as this may imply differences; however, the number of FTM TS was small and we did not assume that we can draw conclusions out of three patients.

Patients were significantly less married than controls, which may add to general life satisfaction as described by Chiu et al. (9), who investigated quality of life among 1,250 elderly women in Asia and who determined marital status, age, and education as crucial factors influencing various domains of quality of life. However, marital status and its influence on quality of life is controversially discussed, as the marital status alone does not determine the quality of the relationship. A recent study (10) investigating the impact of marital status on blood pressure and mental health concluded

FIGURE 2

VAS Score

Visual Analogue Scale: TS *left*, controls, *right*.



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that marriage per se is not universally beneficial; rather, the satisfaction and support with such a relationship is important. In the current study, we have not evaluated the quality of the relationships and can rely on marital status only.

We used validated tools to assess quality of life and patients' satisfaction, but did not examine patients gynecologically or urologically; Kuiper and Cohen-Kettenis (11) expressed their viewpoint on that matter succinctly, stressing that an evaluation of sexual reassignment surgery can be made only on the basis of subjective data because SRS is intended to solve a problem that cannot be determined objectively. A lack of focus on patients' self-reported satisfaction limits the contemporary relevance of many early studies.

The use of validated tools is strength of the study; however, a weakness is that we have no validated data before SRS. During the study, patients reported anecdotally that their quality of life is better now than before SRS; however, VAS was significantly lower in TS compared with controls. In a study by Lawrence (6), 86% rated their satisfaction as 8 or higher on a 0–10 scale, and only 4% rated their satisfaction with results as 5 or less being asked directly about their satisfaction.

The control group with a history of past surgery may not be the most comparable group, as these individuals are unlikely to face societal and personal self-esteem issues as the study subjects.

In the future, we will obtain data from patients who have not yet undergone intervention or others seeking counseling for gender related issues causing dissatisfaction.

For VAS, we did not ask patients directly about their own assessment of life satisfaction but how their best friend would rate this using an open-ended question as suggested by van Doorn (12). We did this because from a previous study (13) we had the impression that TS patients were under pressure

to report well-being. In an open-ended interview setting, respondents are free to reflect on the attributions underlying their global self-assessed health; this way of interviewing is supposed to get more realistic answers. The wording has probably influenced the answers, which may explain the difference compared with other studies (6). We chose the King's Health Questionnaire to determine quality of life in incontinence because of this previous study (13): we had the impression that incontinence is a major issue in TS patients; however, in that study there was no control group so comparison of incontinence problems was only performed using global data. The current study shows that incontinence is an issue in some TS individuals, but this did not reach statistical significance compared with age-matched controls. Possibly another questionnaire aiming at quality of life in subjects with hormonal withdrawal symptoms would have given different results.

Self-ratings of health ratings are significantly influenced by the patients' psychologic, emotional, and spiritual characteristics, as described by Idler et al. (14). This study categorized patients' attitudes into health optimists, realists, and pessimists, depending on their verbal statements and their objective state of health. Optimists appeared to have several techniques that they use to maintain a positive view of their health despite having at least one serious health problem, and optimists were more positive in their health attributions, regardless of the content (e.g., health condition, attitude, mobility). This is one aspect that should also be taken into consideration rating quality of life; transsexuality is not the only quality that needs attention but also other characteristics that were not investigated in this study but may contribute to the results.

Another study of social comparison and self-rated health among middle-age women found that better health was a more complex construct than was worse health; whereas worse health was primarily physically based, better health included social and demographic advantages and self-image (15).

In the study of 40 transsexual patients, Zimmermann et al. (16) found high satisfaction rates with their new sex identity and operating result in 95% and 86%, respectively, in 40 TS 1.5 years after SRS without any differences between MTF and FTM TS; however, satisfaction referring to sexual function, job, family life, and financial aspects were substandard.

Using the Questions of life satisfaction module (FLZ), TS were significantly less satisfied in overall general life satisfaction than the general population. In overall FLZ scores for health-related life satisfaction, no differences were seen.

Particularly contradictory is the verbatim satisfaction with surgical results and the low level of psychologic satisfaction, which is considered as psychologic strategy of ignorance and negligence (17).

None of our patients reported outright regret with SRS, and only a few expressed even occasional regret. Lawrence (6) identified unsatisfactory physical or functional results as strongly associated with dissatisfaction in TS. In the current study, physical and personal limitations were statistically sig-

nificantly greater in TS than in controls; however, we did not correlate quality of life with objective anatomic findings, which is probably a weakness of the study.

Despite the significantly higher number of operations in TS patients, quality of life was similar to controls regarding general health, role limitations, emotions, and sleep.

Physical and personal limitations may be because of the high number of surgical interventions; it is difficult to compare SRS to other surgical interventions as most of the studies deal with either malignant diseases or chronic diseases, which may, additional to the operations themselves, impair quality of life (18, 19). In boys with surgery for hypospadias, quality of life is as well impaired as shown by Schönbucher et al. (20), and this comparison is probably more appropriate as this is surgery of the genital area.

To conclude, the current study shows 15 years after sex reassignment surgery quality of life is similar to controls except in the domains general health, role limitation, and physical and personal limitation. Physical and personal limitations were extremely significant lower compared with controls.

General satisfaction is lower than in controls if assessed by open-ended patients' self-reported questioning, but may also depend on patients' personal optimistic or pessimistic attitude toward life.

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1. How would you describe your health at the present?

Please tick one answer

- Very good
- Good
- Fair
- Poor
- Very poor

2. How much do you think your bladder problem affects your life?

Please tick one answer

- Not at all
- A little
- Moderately
- A lot

Below are some daily activities that can be affected by health problems.
How much does your health problem affect you?

We would like you to answer every question. Simply tick the box that applies to you

<u>3. ROLE LIMITATIONS</u>	1	2	3	4
	Not at all	Slightly	Moderately	A lot
A. Does your problem affect your household tasks? (cleaning, shopping etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Does your problem affect your job, or your normal daily activities outside the home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<u>4. PHYSICAL/SOCIAL LIMITATION</u>	1	2	3	4
	Not at all	Slightly	Moderately	A lot
A Does your problem affect your physical activities (e.g., going for a walk, running, sport, gym etc.)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Does your problem affect your ability to travel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. Does your bladder problem limit your social life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D. Does your problem limit your ability to see and visit friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<u>5. PERSONAL RELATIONSHIPS</u>	0 Not	1 Not at all	2 Slightly	3 Moderately	4 A lot
A. Does your problem affect your relationship with your partner?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Does your problem affect your sex life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. Does your problem affect your family life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<u>6. EMOTIONS</u>	1 Not at all	2 Slightly	3 Moderately	4 Very much
A. Does your problem make you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Does your problem make you feel anxious or nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. Does your problem make you feel bad about yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<u>7. SLEEP/ENERGY</u>	1 Never	2 Sometimes	3 Often	4 All the time
A. Does your problem affect your sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Does your bladder problem make you feel worn out and tired ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Do you do any of the following?	If so how much?			
	1 Never	2 Sometimes	3 Often	4 All the time
A. Wear pads to keep dry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Be careful how much fluid you drink ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. Change your underclothes because they get wet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D. Worry in case you smell?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

We would like to know what your bladder problems are and how much they affect you ? From the list below choose only those problems that you have at present. Leave out those that don't apply to you.

How much do they affect you?

FREQUENCY: going to the toilet very often

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

NOCTURIA: getting up at night to pass urine

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

URGENCY: a strong and difficult to control desire to pass urine

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

URGE INCONTINENCE: urinary leakage associated with a strong desire to pass urine

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

STRESS INCONTINENCE: urinary leakage with physical activity, for example, coughing, running

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

NOCTURNAL ENURESIS: wetting the bed at night

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

INTERCOURSE INCONTINENCE: urinary leakage with sexual intercourse

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

WATERWORKS INFECTIONS

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

BLADDER PAIN

1. A little	2. Moderately	3. A lot
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>