SUMMARY

Human sex differentiation and (gender) identity development are possibly among the most complex processes in life. In case of atypical sex development and gender incongruence, the two subjects often intersect with health care. Many individuals in these groups may require mental health or medical care at a certain point in life. This thesis includes studies assessing:

- What are the body image and self-esteem of individuals with atypical sex development or with gender incongruence?
- How satisfied are individuals with the treatments they received?
- What (other) factors are important regarding these treatment outcomes?
- What can be concluded from these studies with regard to the effectiveness of the current treatments, post-treatment self-image and eventually quality of life?

KEY FINDINGS

In chapter 1, 660 individuals applying for medical care for gender incongruence participated in a study on gender-congruent appearance (as judged by clinicians) and experienced body (dis)satisfaction. Highest dissatisfaction was reported for primary and secondary sex characteristics. Gender-congruent physical appearance and higher body satisfaction were associated with female sex assigned at birth, earlier onset of gender dysphoria and sexual attraction to individuals of the same sex as the sex assigned at birth. The composition of body (dis)satisfaction of those applying for gender confirming treatment was analyzed in chapter 2 using network modeling techniques. Data of 485 individuals diagnosed with gender dysphoria showed that genital dissatisfaction was limitedly connected to dissatisfaction with other body areas. Socially gendered body parts were most important characteristics for overall body (dis)satisfaction. In a prospective study (chapter 3), 33 transmen were examined before and after mastectomy. Measures of cognitive, emotional and behavioral body image were used to study the effects of this intervention. Body image issues affect multiple areas of life. Mastectomy improved body image beyond chest-satisfaction only. Overall body satisfaction and more comfortable social participation were positively associated with better quality of life and self-esteem. In a multicenter study (chapter 4), a cohort of individuals with (prior) gender dysphoria was assessed up to six years after applying for medical care. The sample of 201 participants included persons without medical treatment, hormone treatment only and both hormone treatment and surgery. At follow-up, gender dysphoria scores had lowered in all groups, whereas body dissatisfaction decreased mostly in the persons who received medical treatments. Hormone therapy improved general body satisfaction, whereas genital satisfaction improved after surgery. Pretreatment body dissatisfaction and psychological symptoms at follow-up were positively associated with post-treatment body dissatisfaction. A prospective study on surgical outcomes and patient-reported satisfaction with aesthetics in individuals with gender dysphoria was described in chapter 5: 54 transmen undergoing mastectomy were studied before and after surgery to assess surgical decision-making and outcomes. It was found that despite being performed in favorable-quality breasts (e.g., better skin quality), concentric circular mastectomy yielded
poorer technical and experienced outcomes compared to mastectomy through inframammary skin resection. Experienced burden around surgery was associated with satisfaction with the result. In chapter 6, a cohort of individuals with (prior) gender dysphoria was assessed to examine (reasons of) satisfaction with surgery, psychological wellbeing and quality of life, up to six years after applying for medical care. The 136 participants who had received gender confirming surgery were included. Most individuals were satisfied with the surgical outcomes. Eight reported some degree of dissatisfaction/regret (6%), mostly related to the level of psychological symptoms and (experienced) complications. Disappointing outcomes were associated with unfavorable quality of life outcomes at follow-up.

The last two chapters present data on individuals with atypical sex development (intersex or DSD). Body image and self-esteem were assessed across the DSD spectrum in a European multicenter cross-sectional study including 1040 individuals (chapter 7). Data included questionnaire and medical data. Both outcomes were less positive compared to reference values and associated with atypical physical characteristics (e.g., body length or genital anatomy). Negative body image was associated with a higher BMI, sex hormone use, but also with lower sexual satisfaction, less openness about one’s condition, and higher anxiety and depression scores. The latter two also predicted lower levels of self-esteem. In the last chapter (chapter 8), the 500 individuals studied in the aforementioned study with past DSD-related surgery, were assessed through questionnaires and genital examination. Congruence between physician and patient evaluation was studied, as well as factors associated with patient evaluation. Less self-reported complications, more sexual activity, lower anxiety and depression symptoms and support group contact predicted positive (experienced) outcome of surgery. Participants were frequently less satisfied with outcome than physicians however, and a negative discrepancy (the patient being less satisfied than the physician) was associated with no sexual activity, body embarrassment and signs of depression.

DISCUSSION OF THE FINDINGS

Body image, self-esteem and treatment satisfaction are factors of importance in clinical outcomes and quality of life at large of people with atypical sex development or gender incongruence. We observed that body image and self-esteem in both groups relates to physical (e.g., appearance and functionality) as well as psychological characteristics (e.g., ideals of masculinity and femininity). Social factors were influential as well: passing, being able to act male or female-typical (e.g., during sexual activity) and openness were associated with body image, social participation and quality of life. Not unexpectedly, individuals with gender incongruence were least satisfied with primary and secondary sex characteristics before treatments. However, genital body image issues were not necessarily accompanied by overall body image issues. While gender-typical body parts were generally negatively evaluated, overall body image problems were reported much less. These more severe body image issues were mostly associated with co-occurring psychological problems.

Medical interventions were effective, judging from the improved levels of body image and self-esteem. Remarkably, satisfaction with both therapy responsive and
unresponsive body characteristics improved in individuals going through gender confirming medical therapies. Treatments not only assist to modify bodily features, but also support social participation and body evaluation in general. Not all participants benefitted from medical treatments to the same level: psychological symptoms before treatment (in gender incongruence, however this was not studied in the DSD population) and at follow-up (in both studied groups), and sexual satisfaction (in DSD, however this was not studied in the gender incongruence population) were strongly associated with the post-treatment levels of body image and self-esteem.

In both studies on gender incongruence and on DSD treatment, participants evaluated their treatment (fairly) positive. Gender confirming medical therapies are initiated by choice of the person involved, whereas individuals with atypical sex development may have had surgeries during childhood without their consent. In addition, the first group generally experienced significant dysphoria before treatments. These differences may have resulted in the limited number of participants reporting dissatisfaction or regret after gender confirming surgery, whereas people with a DSD condition were more often dissatisfied. Furthermore, when comparing patient-reported and physician-reported evaluation of surgical outcomes, it seemed that patients take different parameters into account than clinicians (e.g., sex-typical appearance or functional improvement). While this discrepancy generally does not have to imply that clinical care does not meet patients’ requirements, it is important for clinicians to be aware of the fact that patients may experience unexpectedly negative outcomes of surgery compared to routine clinical assessments. It is therefore important to actively assess expectations and assumptions, and associated subjects (e.g., sexuality).

Body image, self-esteem and treatment satisfaction are complex subjects that arise in the interplay between physical, psychological and social factors, and need hypothesis-generating studies in these groups. With regard to the clinical implications, several conclusions can be drawn from the present findings: (1) more attention needs to be paid to clinical follow-up (e.g., supporting people to adapt to their bodies and social situation) accommodating to phases of life, (2) clinicians should actively assess treatment expectations and factors that are known to influence satisfaction with treatment, (3) centers of expertise could better utilize certain disciplines that are currently underrepresented (mostly psychologists and sexologists, but also support group members). Findings in this thesis suggest that if these subjects are properly addressed, experienced outcomes of medical treatments of individuals with gender incongruence or atypical sex development (DSD) may further improve. It is, in addition, also important to consider that experienced outcomes of medical interventions also interfere with people’s lived experiences. These experienced may be improved by more social acceptance, more inclusive definitions of masculinity and femininity, and security of individuals’ rights.