ABSTRACT

Background: As genital gender-affirming surgery (GAS) is a demanding and life-changing intervention, transmen should be able to make choices about the surgical treatment based on outcomes that are most important to them, while taking into consideration the concomitant risks involved.

Aim: Develop a decision aid (DA) for genital surgery in transmen (DA-GST) that can assist both transmen and health care professionals (HCPs) in making a well-informed decision about the surgical treatment.

Methods: A qualitative focus group study was performed. 5 Focus groups were organized with both HCPs and transmen. These were led by an independent professional moderator. Data collected during these focus groups were analyzed to provide content for the DA.

Outcomes: To develop content for a DA-GST.

Results: Data collected during the focus groups related to the treatment options, information deemed relevant by transmen, and the arguments for or against each treatment option. Collected items were divided into the following themes: outcome, quality of life, environment, sexuality, and beliefs.

Clinical Implications: The tool will be useful in assisting both transmen and HCPs in the shared decision-making process regarding genital GAS by exploring which domains are most relevant for each specific individual.

Strengths & Limitations: This DA was developed according to an iterative participatory design approach to fit the needs of both transmen and HCPs. Issues that transmen find important and relevant pertaining to genital GAS were translated into arguments that were incorporated in the DA-GST. The study is limited by the group that had participated. Not all arguments for or against specific surgical options may be covered by the DA-GST.


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Key Words: Transmen; Gender-Affirming Surgery; Decision Aid; Genital Surgery

INTRODUCTION

Gender dysphoria refers to the distress resulting from a marked incongruence between the assigned gender and experienced gender. In Western society, a rapidly growing number of people with gender dysphoria seeks treatment. Also, at the Center of Expertise on Gender Dysphoria in the VU University Medical Center, the number of new applications has grown exponentially over the last 10 years (Figure 1). The reason for this rise is unknown. Possibly this is partly due to increased exposure and acceptance of gender variance in society.
vidualized treatment and partial treatment requests.1 With regard to dysphoria, which is re outside of this spectrum. This changing paradigm has also influenced our approach toward the treatment of gender dysphoria among treatment options by providing information on the options and outcomes relevant to the person.19 This DA-GST will serve as a valuable tool to assist in shared decision-making (SDM) between the HCPs and the transman.

Aims
We aim to develop a DA for genital surgery in transmen (DA-GST). The purpose of the DA-GST is to facilitate transmen’s participation and to support them in making thoughtful choices among treatment options by providing information on the options and outcomes relevant to the person.19 This DA-GST will serve as a valuable tool to assist in shared decision-making (SDM) between the HCPs and the transman.

METHODS
A qualitative focus group study was performed. Focus groups with HCPs and transmen were selected as the best method to
collect information. In total, we organized 5 focus groups with both transmen and HCPs. Each focus group took between 3–4 hours. Participants were transmen (n = 12) who already underwent genital surgery, transmen who were considering undergoing surgery or who decided not (yet) to undergo genital surgery. Furthermore, HCPs (n = 9) involved in treatment of individuals with gender dysphoria (plastic surgeons, gynecologists, urologists, physician assistants, and psychologists) participated in the focus groups. The composition of the focus groups varied, but in all groups both transmen and HCPs were represented. Transmen were recruited via the transgender support group in The Netherlands and through their plastic surgeon. All HCPs involved were working at the Center of Expertise on Gender Dysphoria of the VU University Medical Center, Amsterdam, The Netherlands.

All focus groups were led by an independent professional moderator. The approach was to let all participants write down their “answers or issues” on a specific topic first, before letting everyone in turn share this in the group. This procedure prevented that some people in the group may be overshadowed, and it stimulated active participation of all group members. The suggestions were then translated into common Dutch language. The procedure was repeated until no new information could be collected.

The full process of DA development is illustrated in Figure 2. First, the scope of the DA-GST was charted. The first focus group was used to extensively map all possible issues and topics that should be covered. Data collected during this meeting were analyzed through thematic analysis in which subjects should be addressed were categorized into themes by the participants of the focus groups. This provided a so-called “map” for the DA, but without content. The next 2 focus groups were used to collect arguments for or against all possible treatment options with regard to the subjects/themes that were previously established as being important. Some adaptations of the structure and themes (ie, the map) were also discussed. Data collected during these focus groups were analyzed literally to provide content for the DA. Arguments for and against each procedure were established and clustered within the selected themes; these themes were then subdivided into specific subjects to cluster the arguments. Based on this subdivision, a first article design of the DA-GST was drafted. The last 2 focus groups were used to test the concept version of the DA-GST, with respect to content, comprehensiveness, clarity, language, and accuracy. Hereafter, the digital DA-GST was developed. After a testing period, where both patients and HCPs assessed the tool, final adaptations were made and the digital DA-GST was finalized.

RESULTS

Scope of the DA-GST

According to all attendants, the DA-GST should be designed to help transmen to think about what is most important for them as an individual when deciding for or against undergoing 1 or more surgical procedures. The DA-GST should not render 1 “best choice.” Its purpose is to facilitate participation in the SDM process and to support transmen in making specific and deliberative choices among treatment options. The information should encompass a broad spectrum of motives and possibilities for genital GAS. Within the group of HCPs and transmen it was agreed that the content of the DA-GST should focus primarily on desired outcomes and realistic expectations, and it should not aim to provide extensive medical information about the individual surgical procedures.

DA-GST Design

Taking the above into account, subjects and questions (items) that should be addressed in the DA were exhaustively collected during the first focus group. All items were noted during the meeting and categorized afterward. The items collected during the first focus groups were grouped into the following main themes: outcome, quality of life, environment, sexuality, and beliefs.

It was agreed by all focus group attendants that the DA-GST structure would be the clearest if it followed the multiple surgical options for GAS in transmen. During the second focus group all (combinations of) surgical options for removal of the native internal and external female genitals, and/or the construction of a masculine genital were established by the HCPs. The surgical options were categorized by gynecological procedures and (plastic-urological) reconstructive treatments provided in our clinic. The gynecological procedures included 5 options: (1) total laparoscopic hysterectomy and bilateral salpingo-ovariectomy (BSO) combined with top surgery, (2) robotic colpectomy and hysterectomy with/without BSO, (3) total laparoscopic hysterectomy only, (4) BSO only, and (5) colpectomy only. Reconstructive procedures included metoidioplasty and phalloplasty with scrotoplasty, both with or without urethroplasty. For all procedures, a short description was given to clarify what the procedure entailed. In addition, the requirements for undergoing a specific procedure were listed as well. Information collected in the first 2 focus groups rendered a map for the DA-GST (Figure 3).

DA-GST Content

Focus groups 3 and 4 were used to comprehensively collect arguments for and against each procedure. All items, which were collected during the first focus group were addressed, taking the defined main themes into consideration. Also, new items were put forward.

With regard to information about the procedures, it was decided to provide general information only. The treating HCPs should inform the patient about the details of the procedure, as these may change over time and depend on the individual situation. For instance, surgical reconstructive techniques of metoidioplasty and phalloplasty are evolving rapidly at this moment. Both procedures require tissue transfer from a donor site, but...
specific donor site locations may vary. Quantitative information on outcomes will also not be included in the DA-GST, because reliable evidence on clinical outcomes of GAS in transmen is currently insufficient. Instead, relative risks of complications are included, for instance, more problems with micturition are expected in phalloplasty with urethral lengthening compared with phalloplasty without urethral lengthening.

Completion of the DA-GST
Much effort was put into appropriate phrasing. Although not all individuals who opt for masculinizing genital GAS may identify as a “transman,” it was decided by the transmen participants (after deliberation with peers) that this was still the most appropriate term to use for the target population. It was also difficult to find appropriate common nomenclature for “metoidioplasty” and “phalloplasty,” without giving an inherent value judgment. The medical term “micropenis” (ie, a penis size smaller than 2.5 SD from the mean in a population) was dismissed by transmen. Instead we used “creation of a small penis” (metoidioplasty) and “creation of a large penis” (phalloplasty).

In order to facilitate implementation in decision-making and clinical practice, the digital DA-GST was developed in an online

Figure 2. A structured iterative process is used to develop the decision aid for genital gender-affirming surgery in transmen (DA-GST). Focus groups are held to collect qualitative data. Subsequently, these data are analyzed and processed to proceed to the next step in the development. HCP = health care professional. Figure 2 is available in color online at www.jsm.jsexmed.org.
format compatible with desktops, tablets, and handhelds as well as for several smartphone platforms (Figure 4). Both HCPs and transmen checked the final DA-GST for inaccuracies and hereafter the DA was finalized.

DISCUSSION

The aim of this study was to create a DA for transmen and HCPs to assist in the decision-making process for individuals considering genital GAS, the DA-GST. Transmen may opt for this surgery as part of their treatment to resolve the incongruence between their gender identity and their assigned gender. This DA-GST was created together with transmen, specifically aiming to integrate experiences of transmen into the decision-making process.21 Issues that transmen find important and relevant pertaining to genital GAS were translated into arguments that were incorporated in the DA-GST.

Over the past years, several developments have instigated a change in the treatment approach of individuals experiencing gender dysphoria, resulting in more individualized health care. Societal changes include legal changes as well as changes in general perceptions of gender (and transgender individuals). For the Dutch situation specifically, it has been possible to change sex registration on one’s birth certificate since 1985. However, the person was required to have undergone GAS and had to be made infertile. This legal requirement “naturally” resulted in uniform treatment requests in transmen (ie, removal of reproductive organs with/without the surgical creation of a penis). In 2014, following the European trend, the Dutch government adopted an updated version of this law,22 permitting people aged 16 years or above to change their legal sex without any treatment requirements and court procedures. As a result, genital GAS treatment requests—although not declining in number—are now primarily initiated by people’s intrinsic motives. However, the content of treatment requests has changed and the demand for partial treatments has grown as well.

Another factor contributing to changing treatment requests includes the evolving societal perspective on gender. The concept “gender” is shifting from a binary, ie, man or woman, toward a much broader concept in which gender is seen as a spectrum. New terms were introduced such as “gender fluidity,” “gender variance,” and “gender neutral.” In line with this, transgender individuals express more variance in how they experience and express their gender identity. Consequently, treatment requests are varying also. Individuals may not necessarily experience dysphoria with certain body parts and/or do not need certain
surgery to affirm their identity. This translates into partial treatment gaining popularity during all phases of treatment.\textsuperscript{13}

At the same time, transgender medicine evolves within a larger paradigm shift in health care: a system in which patients are more centered and decisions are deliberately taken with shared responsibility. In case of transgender health care, this development changes both the role of the health care provider and of the transgender individual. While HCPs offer treatment options to those applying for care, transgender individuals take a more active role within clinical contacts when developing and voicing their preferences. This ultimately leads to more autonomy during clinical encounters and ownership over one’s treatment (outcomes).\textsuperscript{23} In order to facilitate the process toward choosing the treatment policy that is best suited for the individual, SDM is often applied. SDM includes the notion of a medical encounter as a “meeting of experts”—the physician as an expert in medicine and the patient as expert in his or her own life.\textsuperscript{24} However, for such a “meeting of experts” to become effective, it is important that the physician obtains the relevant information about what the patient finds important in his/her life, while the patient needs to be informed about the relevant aspects of different treatment options. And subsequently, these 2 areas of information should be consolidated toward the available treatment options. The currently developed DA-GST is a tool that provides information based on experiences of transmen to assist in the SDM process with regard to genital GAS.\textsuperscript{25}

Returning to the criteria of feasibility, desirability, and risk and coping ability, as mentioned in the “Introduction” section, it is important for SDM to include all this relevant information. The method for developing the present DA-GST allowed for the inclusion of both surgically/medically relevant information, as well as information about the transman in a broader perspective. This resulted in the definition of 5 main themes to consider during decision-making: outcome, quality of life, environment, sexuality, and beliefs. While some subjects have been studied thoroughly, in relation to genital GAS (eg, clinical outcomes or quality of life), taking the patient-centered approach also addressed less frequently studied subjects such as one’s environment, sexuality, and beliefs. By using the DA-GST, clinicians are reminded to address these topics as well, while those applying for care are supported in overseeing all the consequences regarding their choices to facilitate the best (surgical) option for them. This again may provide individuals with insights on why they choose a certain option, rather than “just” what surgery. For SDM to be relevant, it is crucial that various treatment options are offered explicitly. The DA-GST provides information about general treatment options but does not provide information about each specific surgical technique, hence, responsibility for providing this specific information still lies with the treating surgeon. It is important to realize that not all surgical options may be offered at a single center. The HCP should be aware of the full spectrum of surgical treatments and techniques and discuss all options with the patient. When necessary, the patient should be referred to a center where alternative surgical treatments are offered.

While this study was designed and conducted in cooperation with transmen themselves, the study may be limited by the group that had participated. As they were mostly transmen who were somehow involved in health care facilities or support groups, and were willing to participate, the input for the DA-GST may not fully cover all associated arguments. Therefore, such a DA should constantly develop and re-iterate. Future studies might focus on the clinical effectiveness of the DA (eg, feelings of autonomy and ownership, and post-operative satisfaction and quality of life). In
addition, future research should focus on outcomes of GAS that transmen themselves find most important.

CONCLUSION

The present study describes the development of a digital DA for genital GAS in transmen. This online tool gives insight into arguments for or against each surgical option from a transman’s perspective. It is used to support SDM between the transman and the HCP.

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Corresponding Author: Müjde Özer, Department of Plastic, Reconstructive, and Hand Surgery, VU University Medical Center, De Boelelaan 1117, 1081 HV Amsterdam, The Netherlands. Tel: +31(0)204442965; Fax: +31(0)204440151; E-mail: m.ozet@vumc.nl

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STATEMENT OF AUTHORSHIP

Category 1

(a) Conception and Design
Müjde Özer
(b) Acquisition of Data
Müjde Özer; Garry L.S. Pigot; Mark-Bram Bouman; Tim C. van de Grift; Lian Elfering; Norah M. van Mello; Hoda H. M. Al-Ittewaiji; Marlon E. Buncamper; Margriet G. Mullender
(c) Analysis and Interpretation of Data
Müjde Özer; Mark-Bram Bouman; Tim C. van de Grift; Margriet G. Mullender

Category 2

(a) Drafting the Article
Müjde Özer; Tim C. van de Grift; Margriet G. Mullender
(b) Revising It for Intellectual Content
Müjde Özer; Garry L.S. Pigot; Mark-Bram Bouman; Tim C. van de Grift; Lian Elfering; Norah M. van Mello; Hoda H. M. Al-Ittewaiji; Marlon E. Buncamper; Margriet G. Mullender

Category 3

(a) Final Approval of the Completed Article
Müjde Özer; Garry L.S. Pigot; Mark-Bram Bouman; Tim C. van de Grift; Lian Elfering; Norah M. van Mello; Hoda H. M. Al-Ittewaiji; Marlon E. Buncamper; Margriet G. Mullender

REFERENCES


