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Shared decision-making in transgender healthcare

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VRIJE UNIVERSITEIT

Shared Decision-Making in Transgender Healthcare

Ethical and Conceptual Challenges and the Co-Creation of an Ethics Support Tool

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op gezag van de rector magnificus
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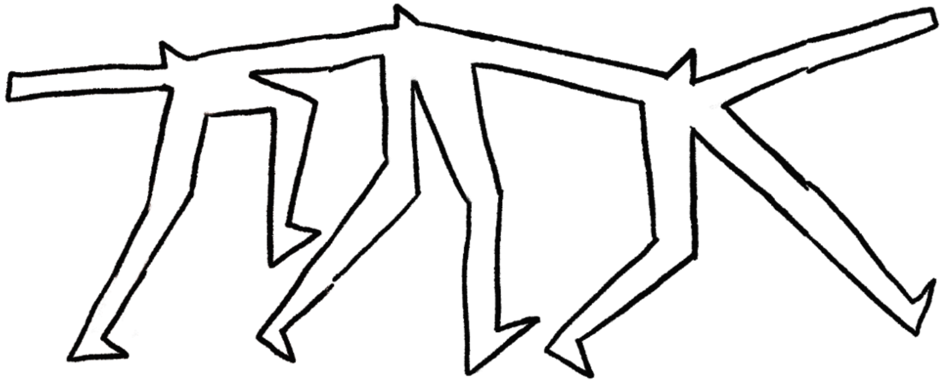

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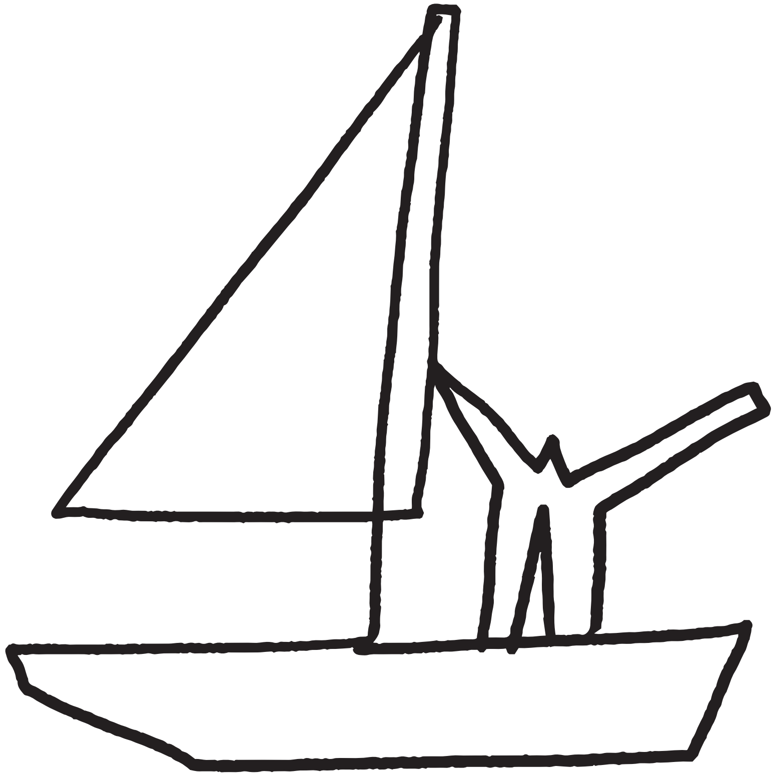

Chapter 1

General introduction

General introduction

> *A 19-year-old trans man presents at a gender identity clinic requesting masculinizing hormone therapy. Assigned female at birth, he experiences distress related to the mismatch of his bodily characteristics to his male gender identity. His healthcare professional (HCP) suspects gender dysphoria but wants to establish the impact of a possible co-occurring autism spectrum disorder on his gender identity development, psychosocial functioning, and capacity to consent to treatment. The client, however, refuses the proposed autism assessment as he 'just needs hormones.' He also wonders whether he should tell her about his past depressive episodes, fearing it will further delay the decision-making process. The HCP, too, is at a loss: Is the client truly gender dysphoric and stable enough for hormone treatment? Should I respect his self-determination and refer him to my colleague to get started on hormones, or put my foot down regarding the autism assessment? (Case vignette from Gerritse et al., 2018)*

Worldwide, an exponentially increasing number of transgender (trans*)[1] individuals turn to gender identity clinics for gender-affirming medical care (GAMC) (Goodman et al., 2019): interventions such as feminizing and masculinizing hormones and surgeries to aid the affirmation and expression of their experienced gender and improve their quality of life (Javier et al., 2022; Wilson et al., 2021). Those providing and receiving GAMC may face ethical challenges: situations in which they do not know, are uncertain, or disagree with each other about what is good or right (Molewijk et al., 2015). A central question such challenges appear to center on is: How should stakeholders go about making and sharing medical decisions? In other words: What does *good* shared decision-making (SDM) in GAMC entail? The literature on these challenges is sparse, systematic empirical work is absent, and stakeholders indicate a need for support.

This thesis aims to (1) gain insight into and better understand the moral and conceptual landscape of GAMC, particularly concerning SDM. Furthermore, to (2) co-create an ethics support tool to foster *good* SDM and aid HCPs and trans* clients in recognizing and handling related ethical challenges. In this introduction, we describe the field of GAMC and SDM in GAMC. Next, we focus on stakeholders' ethical challenges, emphasizing those concerning SDM. Subsequently, we introduce clinical ethics support (CES) and the efforts to integrate CES in GAMC. Finally, we present this thesis's research aims, methodology, and outline. We also share some words on reflexivity.

Gender-affirming medical care

"Transgender" is an umbrella term and refers to various forms of gender identities, roles, and expressions that differ from those normatively expected of one's sex assigned at birth. In medical practice, this difference may be classified as Gender Incongruence (GI) (World Health Organization [WHO], 2018) or Gender Dysphoria (GD) (American Psychiatric Association [APA], 2013). According to the 11th version of the *International Classification of Diseases* (ICD-11), GI is characterized by a marked and persistent incongruence between a person's experienced gender and sex assigned at birth (WHO, 2018). As outlined in the fifth version of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), a GD diagnosis requires clinically significant distress or impairment in functioning due to the experienced incongruence (APA, 2013). Although not all trans* individuals indicate a need for it, GAMC is available to aid one's gendered embodiment goals, alleviate distress and improve well-being (Javier et al., 2022; Wilson et al., 2021).

For adults, GAMC chiefly consists of feminizing/de-masculinizing or masculinizing/de-feminizing hormone and surgical treatment (Coleman et al., 2022; Hembree et al., 2017). Feminizing hormone treatment typically consists of estrogens and androgen-lowering agents leading to changes in body composition, breast growth, skin softening, and decreased body hair growth and libido. Surgical options include breast augmentation, vaginoplasty or vulvaplasty with orchiectomy, and facial feminization surgery. Masculinizing hormone treatment is comprised of testosterone which brings about voice lowering, increased muscle mass and body hair growth, and the cessation of menses. The most frequently performed masculinizing surgery is mastectomy. Transmasculine clients may also seek gonadal gynecological and genital surgeries such as hysterectomy (with or without oophorectomy), colpectomy, phalloplasty, or metoidioplasty. Many of these interventions require expertise from different medical and mental health professionals (MHPs) and are often provided in multidisciplinary cooperation and/or specialized multidisciplinary gender identity clinics (Coleman et al., 2022).

Various organizations make available clinical guidelines to structure the provision and organization of care, criteria for GAMC, and visions for decision-making. The most widely adopted guidelines are the *Standards of Care* (SoC) of the World Professional Association for Transgender Health (WPATH) (Coleman et al., 2012, 2022). In many countries, the SoC are implemented in local guidelines. The SoC7[2] stipulate that clients must engage with a (MHP) to receive a formal diagnosis of GD and to determine whether they meet the eligibility criteria for GAMC. The authors of SoC7 hold that MHPs are best suited to assess these criteria, given that medical treatment is intensive, often life-long, and irreversible. For example, although very few regret GAMC (Bustos et al., 2021), the SoC7 speak of trans* clients who received hormone therapy and genital surgery and later regretted their inability to parent genetically related children (p. 196). Another rationale for the central role of MHPs in decision-making is that prevalence rates of co-occurring mental health concerns (e.g., depression, substance abuse, autism spectrum disorder, and suicidality) in the trans* community vastly outnumber those in the general population (Dhejne et al., 2016). The SoC7 state that MHPs should "[make] sure that gender dysphoria is not secondary to, or better accounted for, by other diagnoses" and assess the potential impact on clients' capacity to give informed consent for GAMC (Coleman et al., 2012, p. 180).

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[1] Transgender (trans*) is an umbrella term referring to various gender identities, roles, and expressions differing from those (normatively expected from) one's sex assigned at birth.

[2] WPATH recently put out the SoC8. In this thesis, we mostly refer to SoC7, as these were in place during the research. We consider some of the changes from SoC7 to SoC8 in relation to our findings in the General Discussion section.

Shared decision-making in gender-affirming medical care

In medical decision-making, paternalistic models are usually contrasted with informative ones. In between, we find SDM models emphasizing the importance of personalized care, client-clinician partnership and dialogue, shared ownership in the decision-making process, and responsibility for choosing (or deferring) treatment (Charles et al., 1997, 1999).

According to Stiggelbout et al. (2015) and Elwyn (2016, 2021), two lines of thinking paved the way for SDM: practice variation and ethics. The work of Wennberg in the 1980s demonstrated how HCPs' preferences or practice style, rather than the client or client-related factors, often determined the outcome of medical decisions with a high preference sensitivity, i.e., those decisions where risk-benefit ratios are equivocal. To counter the dominance of clinicians' values and to ground such decisions more on those of the client, SDM programs were introduced. The second route toward SDM is ethics. From the 1970s onward, the physician's decisional hegemony was questioned. The dominant discourse shifted from "doctor knows best" to acknowledging that healthcare is not solely about saving lives at all costs but also the patient's quality of life and autonomy. The relationship between clients and clinicians increasingly became the object of debate and research. Veatch (1972), Beauchamp and Childress (2013), and others laid the groundwork for the pivotal 1992 paper by Emanuel and Emanuel outlining the informative, interpretative, paternalistic, and deliberative model: four ways in which clients and clinicians may relate to each other to make medical decisions, with the latter model seen as a precursor of SDM.

Two publications by Charles et al. (1997, 1999) realized a breakthrough in harmonizing concepts of SDM. To them, a defining characteristic distinguishing SDM from informative and paternalistic modes is the two-way exchange of information, values, and decision-making preferences. They stipulated the following four elements as necessary criteria for SDM:

1. At a minimum, both clinician and client are involved in the treatment decision process;
2. Both clinician and client share information with each other;
3. Both clinician and client take steps to participate in the decision-making process by expressing treatment preferences;
4. A treatment decision is made, and both clinician and client agree on the treatment to implement.

Although the central tenets of SDM are widespread and generally agreed upon, myriad interpretations have been put forward (see Makoul & Clayman, 2006). Notwithstanding the absence of a definitive or universal SDM model, SDM is often operationalized as a deliberative and sequential process consisting of the (1) introduction of choices and elucidation of goals, (2) comparison of the relevant options, and (3) discussion of decisional role preferences and decision-making (Elwyn et al., 2016; Stiggelbout et al., 2015). Over time, particularly the three-talk SDM model of Elwyn et al. (2017) gained momentum. Today, SDM is becoming ever more prominent in healthcare (policy) and is considered the preferred decisional model, especially for so-called preference-sensitive decisions, i.e., decisions where more than one reasonable treatment option is available (Elwyn et al., 2016; Montori et al., 2017).

The gradual and successive changes to WPATH's SoCs evidence a similar development in the field of GAMC (Bakker, 2018; shuster, 2021). For example, SoC6 relinquished the mandatory psychotherapy requirement and SoC7 the need for a so-called "real-life test" to gauge "readiness" for GAMC, in effect removing barriers to SDM (shuster, 2021). The expansion of treatment options and the notion that treatment requests are inherently tied to an individual's gendered identification and experience (Beek et al., 2015; Huisman et al., 2022) make GAMC a preference-sensitive care practice *par excellence.* Hence, the growing appeal for SDM in GAMC (Clark et al., 2021; Coleman et al., 2022) is not surprising. However, the call of experts, clients, and HCPs for more SDM in GAMC risks bypassing fundamental questions that ought to be addressed: Given its conceptual and normative ambiguity, what *is* SDM? And what should SDM involve in the specific context of GAMC?

Indeed, the field of GAMC has some unique characteristics that impact the decision-making process. First, GAMC's growing but still limited biomedical evidence base (Coleman et al., 2012, 2022; Hembree et al., 2017; Wilson et al., 2021) leaves many clinical questions (e.g., regarding its long-term effects and risks) unanswered but also complicates the weighing of potential harms and benefits in decision-making (Vrouenraets et al., 2015). Second, the sequential and multidisciplinary organization of GAMC (Coleman et al., 2012, 2022) challenges the idea of the one-off client-clinician SDM moment and prompts the question as to who should carry responsibility for (what aspect of) the decision-making process (Budge & Dickey, 2017; Karasic & Fraser, 2018). Third, the convoluted history of (psychopathologization in) GAMC (Bakker, 2018; shuster, 2021) and current ambiguities as to the clinical conceptualization of gender incongruence (APA, 2013; WHO, 2018) reflect ongoing shifts in clinical and cultural understanding of gender diversity (Beek et al., 2016). Consequently, assessing GI/GD can be clinically but also ethically challenging (shuster, 2016). For example, which treatment requests are ethically permissible under the rubric of GI/GD (see, e.g., Notoni et al., 2020)?

Against the background of these empirical complexities and uncertainties, divergent normative views on (the organization of) decision-making in GAMC abound. Indeed, the discourse concerning how to serve the best interests of trans* people in decision-making in GAMC is polarizing. On the one hand, a group of clients, clinicians, and advocates argue that the "gatekeeping" role of HCPs—especially MHPs—in decision-making recommended in the SoC forms an unjust barrier to trans* clients' self-determination (e.g., Ashley, 2019; Cavanaugh et al., 2016; Schulz, 2018). For example, some (Ashley, 2019, 2022; Schulz, 2018) hold that the inherent subjectivity and epistemic inaccessibility of GI/GD challenges HCPs' ability and expertise in establishing its presence and warrants more laissez-faire approaches to decision-making. Consequently, the last decade has seen an increase in local guidelines for hormone therapy that fall under the rubric of the so-called "Informed Consent Model" (ICM) for GAMC (Deutsch, 2012; Schulz, 2018). The ICM emphasizes clients' right to self-determination and minimizes the role of MHPs in assessing eligibility for GAMC.

Others (e.g., Evans, 2021) maintain that non-maleficence is insufficiently safeguarded in current (Western) GAMC decision-making practices. Often mentioning the exponential increase (Goodman et al., 2019) and changed sex ratio (Aitken et al., 2015) of those seeking GAMC[3] and the risk of "regret" and "detransition,"[4] they argue for more rigorous assessments and paternalism in decision-making. This normative position is echoed in the justification for recent legislation and policy changes in various European countries (e.g., Sweden, Finland, Norway, the United Kingdom) and the United States (e.g., Alabama, Texas, Arkansas, Arizona, Florida) restricting, halting, or criminalizing the provision of GAMC to especially trans* youth and young adults (Turban et al., 2021).

These differing normative views and clinical guidelines appear to presuppose a *different* object of care. Indeed, in these discourses, GI/GD takes on various shapes and forms and is enacted as something (ontologically) different. For example, proponents of self-determination in decision-making stress how GAMC ought to be treated akin to other clinical practices, e.g., by drawing parallels between GAMC and abortion, and GI/GD and diabetes (Ashley, 2019). Clarifying how the ICM and SoC7, but also stakeholders in practice, "enact" GI/GD may inform and facilitate normative discussions on and analyses of what *good* SDM in GAMC entails.

Furthermore, these clinical guidelines appear to be underpinned by divergent conceptualizations and normative assumptions of decision-making and client autonomy that often remain implicit. For example, the SoC7 recommend MHPs "assist clients with making fully informed decisions (Coleman et al., 2012, p. 181), and the ICM stresses the value of "client autonomy" (Reisner et al., 2015). The specific interpretation of these notions remains ambiguous: When is a decision *fully* informed? What interpretation of "client autonomy" is invoked and how should HCPs do justice to it? Elucidating these questions could aid in better understanding stakeholders' ethical challenges in practice.[5]

Ethical challenges in gender-affirming medical care

Indeed, the above-described background gives rise to myriad ethical challenges in practice. Literature on these challenges strongly centers on those opined or expressed by HCPs (e.g., Budge & Dickey, 2017; Drescher & Pula, 2014; Wren, 2019). Likewise, the mainstay of empirical research focuses on the challenges experienced by HCPs, especially in GAMC for trans* children and youth. For instance, some have focused on the ethical complexities of providing puberty suppression (Vrouenraets et al., 2015) or fertility preservation (Chen & Simons, 2018). The empirical literature on ethical challenges in GAMC for adults is sparse, and, as of yet, no systematic work has investigated the ethical challenges arising in decision-making. Those tangentially exploring such challenges frequently highlight the fundamental ethical dilemma of weighing respect for clients' self-determination against an experienced duty to non-maleficence (Dewey, 2015; MacKinnon et al., 2020; shuster, 2021), particularly preventing regret (MacKinnon et al., 2021).

This empirical research describes how HCPs face ethical challenges such as: How should we share responsibilities for medical decision-making when a client suffers from (severe) mental health concerns or cannot consent to treatment? In the context of the multidisciplinary organization of GAMC, who may decide whether a "non-standard" treatment request is permissible? How should we go about dissensus regarding the latter? These questions highlight that the ethical framework for decision-making in GAMC remains ambiguous. To illustrate, a qualitative study showed that HCPs in GAMC often used the rhetoric of informed consent and SDM while reverting to a more paternalistic model of care in practice (shuster, 2019). While HCPs in GAMC express a preference for SDM, in practice, they find it ethically challenging to establish their role and responsibility in the decision-making process: should this role be protective, autonomy-promoting, or something else altogether (Dewey, 2015; MacKinnon et al., 2021; shuster, 2021)?

Similarly, there is a dearth of empirical research into the ethical challenges of adult trans* clients. The literature offers good reasons to assume that they, too, have to navigate unique complexities and decisional ethical challenges. The ethnographic findings of MacKinnon et al. in Canadian GAMC (2020) illustrate how some trans* clients concealed co-occurring mental health conditions and faced a balancing act in presenting enough distress to receive GAMC without being deemed too "mentally unstable" by their HCPs. In the European context, an online survey conducted in Germany found that 96,5% of trans* individuals desired more involvement in decision-making (Eyssel et al., 2017). Furthermore, most respondents wished to share decisional responsibility with their HCP and strengthen their role in the decision-making process. Recent reports issued by the Dutch Ministry of Health, Welfare, and Sport echo these German findings (Zorgvuldig Advies, 2020). They note how the current organization of Dutch GAMC impedes a personalized and shared approach to care and decision-making.

Together, the literature indicates that ethical challenges related to decision-making in GAMC are ubiquitous, relevant, and urgent but remain understudied. Notably, studies seeking to understand how HCPs and trans* clients experience and reflect on these ethical challenges are absent. Such systematic and empirical studies may help identify needs, barriers, and facilitators concerning SDM. They may also provide empirical grounds for the dialogue on and moral inquiry into what good SDM in GAMC should entail. Ultimately, these insights and dialogues may improve current decision-making practices.

Attuning clinical ethics support to decision-making in gender-affirming medical care

Increased attention toward ethical challenges necessitates structures and methods to handle them. CES offers stakeholders support in dealing with ethical issues they face in

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3. Currently more birth assigned females than birth-assigned males seek GAMC
4. Discontinuing and/or reversing GAMC
5. Throughout this thesis, "ethical challenges in practice" are also referred to as "clinical ethical challenges"

clinical practice, thereby improving the quality of care, cooperation, and moral competencies (Rasoal et al., 2017). CES may be provided through different services with varying aims, methods, and theoretical backgrounds. In the Netherlands, CES often refers to the following three activities: (1) clinical ethics consultation, (2) clinical ethics committees, and (3) moral case deliberation (MCD) (Dauwerse et al., 2014). To clarify: MCD is a facilitator-led collective moral inquiry in which professionals reflect on an ethical challenge. MCDs often last 60-90 minutes, take place on the ward, and can be structured according to different conversation methods. Rather than offering normative guidance, the role of the ethicist/facilitator in an MCD is to foster joint investigation and moral reflection (De Snoo-Trimp, 2020; Molewijk et al., 2008).

Increasingly, CES is offered in GAMC (de Snoo-Trimp et al., 2022; Feldman et al., 2022; Mabel et al., 2019; Vrouenraets et al., 2020). Some of the benefits of CES in GAMC identified in the literature include (1) making HCPs more aware of the moral dimensions of their work; (2) improving their ability to respond to similar ethical challenges in the future; (3) addressing ethical challenges proactively, and preventing more serious ones; and (4) promoting mutual respect and open communication (Feldman et al., 2022; Hartman et al., 2019b; Mabel et al., 2019). In their scoping review of CES in GAMC, Feldman et al. (2022) identified various services, including ethics consultation and committees. The mainstay of CES in GAMC, however, is described as “embedded” or “integrative.” In these models, rather than providing ad hoc advice on ethical challenges, CES staff work regularly and collaboratively with (multidisciplinary) GAMC teams to provide tailor-made CES through diverse activities. Such integrative or embedded approaches aim to foster HCPs’ abilities to identify and address ethical challenges in their practice and bolster CES staff’s expertise in GAMC (Feldman et al., 2022).

The Center of Expertise on Gender Dysphoria (CEGD) of the Amsterdam UMC is one such clinic with an integrative approach to CES. At the CEGD, CES was introduced in the form of MCD in 2013 (Hartman et al., 2019b, 2020). While HCPs positively evaluated MCD sessions, they also expressed a desire for CES that is more attuned to the (organizational) context of GAMC. Over time, an iterative and responsive evaluation process led to the co-creation of more integrative CES (activities) interwoven in CEGD’s daily work processes (Hartman et al., 2019b, 2020). These activities included joint ethics/CES research, presenting and using CES together at conferences, steering group meetings, CES staff joining team meetings, contributions to policy changes and guideline development, and keeping an “ethics logbook” (Hartman et al., 2019b). Another way to integrate CES into daily practice is by co-creating theme- and practice-specific ethics support tools (Hartman et al., 2018; van Schaik et al., 2022). For instance, Hartman et al. (2018) developed an ethics support tool for dealing with dilemmas concerning client autonomy in long-term care. An example of such a tool in GAMC is the “Competence Consultant,” which aims to help HCPs recognize and handle ethical challenges around decisional competence in GAMC for adolescents (de Snoo-Trimp et al., 2022).

What ethics support tool can aid HCPs and trans* clients in realizing good SDM in GAMC and recognizing and handling ethical challenges regarding SDM? To address this question, it could prove fruitful to include end-users. Indeed, including stakeholders throughout the development process may address their needs more adequately, facilitate implementation (Goodyear-Smith et al., 2015), and empower them (Abma et al., 2019). While integrative CES and ethics support tools are usually developed with and aimed at HCPs, such a co-creation process could greatly benefit from the participation of both HCPs and trans* clients (Eijkholt et al., 2022). Involving both HCPs and trans* clients in the development and eventual use of CES is both promising and arguably indispensable given the theme of SDM and considering how the relationship between HCPs and trans* clients in GAMC is historically strained (Bakker, 2018; shuster, 2021). Empirical and theoretical grounds to involve trans* clients in CES identified by Eijkholt et al. (2022) include procedural and epistemic justice (Abma et al., 2019), balancing perspectives (Reiter-Theil, 2003), addressing power differentials (Neitzke, 2009), and avoiding paternalism (Newson, 2009).

Furthermore, the development of such a tool necessitates a thorough understanding of the moral and conceptual landscape of SDM in GAMC: What ethical challenges (pertaining to SDM) are stakeholders confronted with when providing or receiving GAMC? How do these challenges relate to care models and clinical guidelines? What is the impact of stakeholders’ conceptual and normative assumptions regarding GAMC and GD/GI? To reiterate, research into these questions is sparse yet vital, not only to inform the co-creation of a theme and practice-sensitive CES tool but also to further the dialogue on what good SDM in GAMC entails.

Research aims and questions

This thesis has two central aims. First, to (1) gain insight into the moral and conceptual landscape of GAMC for adults, specifically concerning SDM. Second, to (2) co-create an ethics support tool that fosters (a joint reflection on) *good* SDM and aids HCPs and trans* clients in recognizing and handling concomitant ethical challenges. These central aims will be investigated with the following research questions:

- What ethical challenges do HCPs working in a multidisciplinary GAMC center in the Netherlands experience? (Chapter 2)
- What are the ethical challenges and norms concerning SDM of adult trans* clients who received GAMC in the Netherlands? (Chapter 3)
- What are the ethical challenges and norms concerning SDM of HCPs providing GAMC to adult trans* clients in the Netherlands? (Chapter 4)
- What are the conceptual assumptions regarding decision-making and client autonomy in two care models for GAMC, and what are their key ethical challenges? (Chapter 5)
- How do HCPs in GAMC “enact” Gender Dysphoria in daily practice, and what normative assumptions concerning GD do these enactments reflect? (Chapter 6)

- What ethics support tool can foster (a joint deliberation and reflection about) *good* SDM in GAMC and help stakeholders to recognize and handle its concomitant ethical challenges? (Chapter 7)

Setting

The CEGD and the department of Ethics, Law, and Humanities of the Amsterdam UMC jointly initiated this research. One of the world's oldest and largest GAMC clinics and research institutes, the CEGD started treating trans* adults[6] in 1972 (Bakker, 2021). The CEGD is one of three current university medical centers in the Netherlands where psychologists, psychiatrists, endocrinologists, plastic surgeons, urologists, gynecologists, nurse specialists, and other HCPs offer GAMC in close multidisciplinary collaboration. We studied and collaborated with HCPs and trans* clients in Dutch GAMC. Dutch GAMC guidelines largely follow WPATH's SoC—version 7 during this project (Coleman et al., 2012, cf. 2022)—and are adapted to the local infrastructural, legal and professional context. Adult trans* clients are referred to an MHP for a diagnostic phase after an initial screening. Those diagnosed with GD may start gender-affirming hormone therapy or surgical interventions if deemed eligible (Wiepjes et al., 2018). Our respondents included HCPs and MHPs from the CEGD and a nonacademic mental healthcare center, as nonacademic mental healthcare centers are increasingly working in partnership with UMCs and other somatic healthcare providers to offer GAMC. The participating trans* adults received GAMC in various Dutch GAMC settings.

Design, theoretical background, methodology, and methods

This research studies ethical challenges and ethics support in SDM in GAMC through an emerging research design. An emerging research design allows for adaptation to changing circumstances and new ideas or findings that arise during the research (Abma et al., 2019). As such, this research is "designed in the doing" (Abma et al., 2019): findings from one interview, group discussion, and research phase provide input for the next and are iteratively interpreted, analyzed, and reflected on, often with stakeholders.

Ontologically, this research is broadly concerned with the morality of specific actors (HCPs and adult trans* clients) who engage in the (social) process of decision-making in GAMC. In line with Hartman et al. (2019a), we understand morality as a broad web of what these stakeholders consider morally important (i.e., values), and their corresponding ethical rules (i.e., norms) and responsibilities. It takes ontological elements such as experiences, beliefs, views, interactions, and social relations as manifestations of, or at least relevant to, said morality (Widdershoven & Molewijk, 2010). We used various methodologies and qualitative research methods to probe into these elements. Qualitative research explores diverse dimensions of the (social) world and highlights its richness, complexity, and depth. As such, it has "an unrivaled capacity to constitute compelling arguments about *how things work in particular contexts* [emphasis in original]*"* (Mason, 2017, p. 1). Methodologically, the research in this thesis falls under the rubric of descriptive ethics (Chapters 2-4), (empirical-) conceptual analysis (Chapters 5, 6), and dialogical empirical ethics (Chapter 7).

Part A (Chapters 2-4) elucidate what Kon (2009) called the "Land of the lay," i.e., the ethical challenges, norms, and intuitions of HCPs and trans* clients, particularly concerning SDM. Theoretically, these three chapters are informed by a hermeneutic and pragmatic take on (clinical) ethics and ethical challenges (Hartman et al., 2020; Inguaggiato et al., 2019; Widdershoven & Molewijk, 2010). Chapter 2, a focused ethnography (Cruz & Higginbottom, 2013), probes into the ethical challenges of HCPs through observations of multidisciplinary meetings and individual consultations but also uses MCD as a data collection method. Chapters 3 and 4 employ semi-structured interviews (Mason, 2017) to study the ethical challenges and norms concerning SDM of trans* clients and HCPs, respectively.

Part B (Chapters 5, 6) employs (empirical-)conceptual analysis to get a fuller appreciation of the issues at hand. Chapter 5 uses theoretical work on decision-making (Emanuel & Emanuel, 1992) and client autonomy (Agich, 1990; Dworkin, 1988; Verkerk, 2001) to make the conceptual and normative assumptions in the SoC7 (Coleman et al., 2012) and ICM (Deutsch, 2016; Reisner et al., 2015) more explicit. In Chapter 6, we draw from Material Semiotics (Law, 2007; Moser, 2005) to clarify how HCPs, but also SoC7 (Coleman et al., 2012) and DSM-5 (APA, 2013) *enact* GD in practice.

Finally, Part C (Chapter 7) consists of a participatory development study theoretically grounded in empirical ethics, an "activity in which empirical social scientific analysis is integrated with ethical analysis in order to draw normative conclusions" (Ives et al., 2018, p. 1). Although numerous strategies toward such integration have been described, our approach in this chapter is best characterized as "dialogical" empirical ethics. Drawing from hermeneutic ethics and responsive evaluation, dialogical empirical ethics aims to address ethical issues and reach normative conclusions through dialogue with stakeholders in practice (Widdershoven et al., 2009). Through homogenous and heterogenous co-creation workshops (Abma et al., 2019; Ørngreen & Levinsen, 2017), we seek to arrive at normative conclusions shared by HCPs and trans* clients regarding the development, content, and design of the envisioned ethics support tool. See Table 1 for an overview of the methodologies, theoretical backgrounds, methods, and data. More details can be found in the Methods sections of the individual chapters.

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[6] This thesis focuses on trans* adults. In Chapter 2, we studied HCPs providing GAMC to both trans* adults and children/youth. For an overview of care for trans* children/youth, see Coleman et al. (2012, 2022).

Table 1. Overview of methodologies, theoretical backgrounds, methods, and datasets

Chapter	Study	Theoretical background	Methodology	Methods	Data
2	Focused ethnography	Hermeneutics and Pragmatism	Descriptive ethics	• Observations of multidisciplinary meetings • Observations of individual consultations • MCDs	• 12 observational notes • 12 observational notes • 7 transcripts • 22 reports • 4 observational notes
3	Qualitative Interview study	Hermeneutics and Pragmatism	Descriptive ethics	Semi-structured interviews	10 transcripts
4	Qualitative Interview study	Hermeneutics and Pragmatism	Descriptive ethics	Semi-structured interviews	11 transcripts
5	Conceptual study	Theories on decision-making and client autonomy	Conceptual analysis	Documents	• SoC7 • ICM
6	Empirical-philosophical study	Material Semiotics	Conceptual analysis	• Semi-structured interviews • Documents	• 16 transcripts • SoC7 • GD Chapter DSM-5
7	Participatory development study	Hermeneutics and Responsive Evaluation	Dialogical empirical ethics	Workshops	• 6 observational notes • 6 member checks • >100 participant notes on Google Jamboard

The importance of reflexivity while executing reflective research

Qualitative social science presupposes that researchers are not neutral, objective, or detached from the practice they are studying and the knowledge and evidence they gather (Mason, 2017). Consequently, as researchers, we have to account for how our various identities, positions, and perspectives impact our decisions, methods, and findings; in other words, to be reflexive. Mason writes: "Reflexivity … means thinking critically about what you are doing and why, confronting and often challenging your assumptions, and recognizing the extent to which your thoughts, actions, and decisions shape your research and what you see" (2017, p. 5). This entails acknowledging how our personal and professional roles impact our approach and normative presuppositions to (studying) SDM in GAMC.

The research team—a white, Dutch group with different genders and sexualities—consisted of a trained ethicist, qualitative health researcher, and Ph.D. candidate who was also a junior M.D. working in GAMC at the time of research (KG), a healthcare consultant and community advocate (CM), two senior researchers and psychiatrists, one working in GAMC for adults (MB) and one with trans* children/youth (AdV), a senior researcher in medical psychology focusing on gender identity development and (outcomes of) GAMC (BK), an expert in qualitative health research (FdB) and an ethicist and senior researcher with experience in providing and researching CES in GAMC (BM). Throughout the project, we reflect on the impact of our roles and positions on the research and potential biases. We elaborate on this in the Epilogue.

Outline

Part A: Mapping stakeholders' ethical challenges and norms

Chapter 2 presents a focused ethnography descriptively mapping the ethical challenges of HCPs working in a specialized multidisciplinary GAMC center in the Netherlands. Our dataset consists of participant observations of multidisciplinary team meetings and individual consultations. We also include transcripts, reports, and observational notes from MCDs. **Chapter 3** and **Chapter 4** present two studies on the ethical challenges and norms of trans* clients and HCPs regarding SDM, respectively. We analyze semi-structured interviews with adult Dutch trans* people who formerly engaged in GAMC and HCPs working in two distinct GAMC settings.

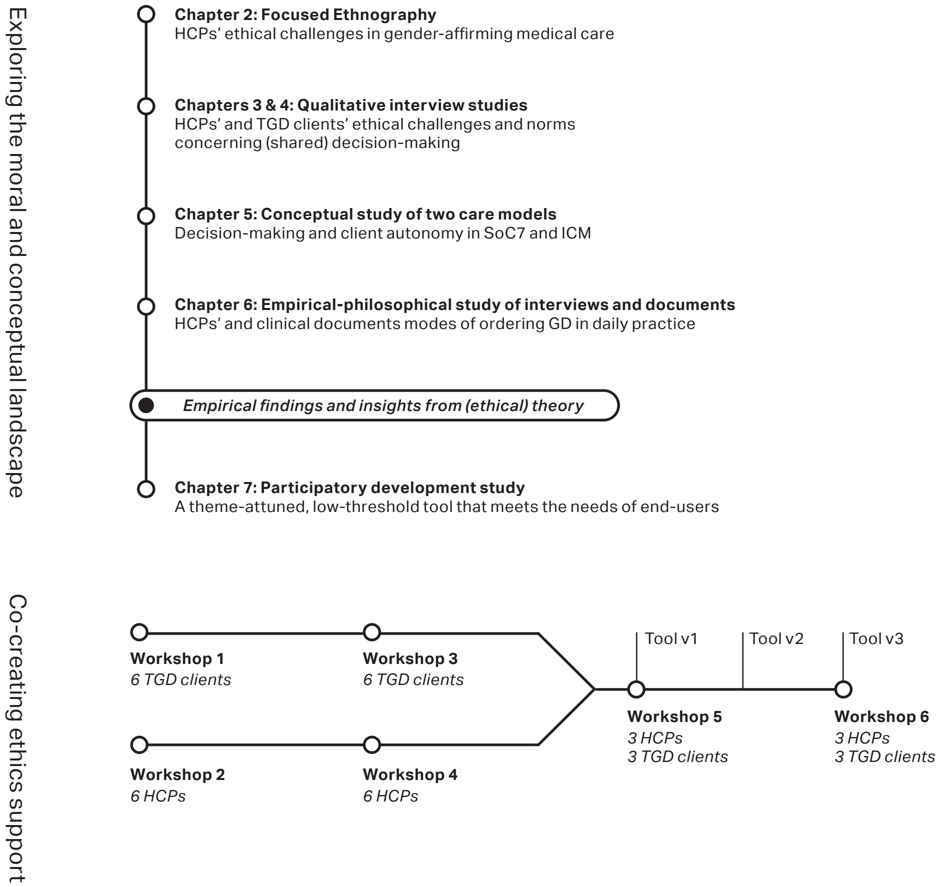
Part B: Elucidating conceptual and normative assumptions

Chapter 5 aims to clarify the conceptual and normative assumptions regarding decision-making and client autonomy in the SoC7 and the ICM and to illustrate how this clarification aids in better understanding stakeholders' decisional ethical challenges. In **Chapter 6**, we probe into the object of care by elucidating how HCPs *enact* GD in daily practice. We do so by means of semi-structured interviews with MHPs working in Dutch trans* mental healthcare. Furthermore, the dataset includes interview transcripts of Chapter 4, relevant fragments from SoC7, and Dutch clinical GAMC guidelines.

Part C: Developing an ethics support tool

Chapter 7 describes and reflects on the development process of "GenderJourney," an ethics support tool for the consultation room to foster *good* SDM in GAMC. We employ a participatory development design and include trans* clients and HCPs throughout the study in homogenous and heterogenous co-creation workshops. In an iterative process—informed by a dialogical approach to empirical ethics—we establish needs; reach a consensus on the aims, content, and design; and develop, test, and present successive versions of the tool. **Chapter 8** presents the discussion section of this thesis. After summarizing the main findings and discussion points of the individual chapters, we reflect on GAMC in light of SDM and vice versa. Subsequently, we reflect on (dialogical, pragmatic-hermeneutic) CES and ethics support tools based on our experiences with developing the GenderJourney. We end each section by outlining practice implications and avenues for future research. See Figure 1 for a visual overview of the research project.

Figure 1. Overview of the research project



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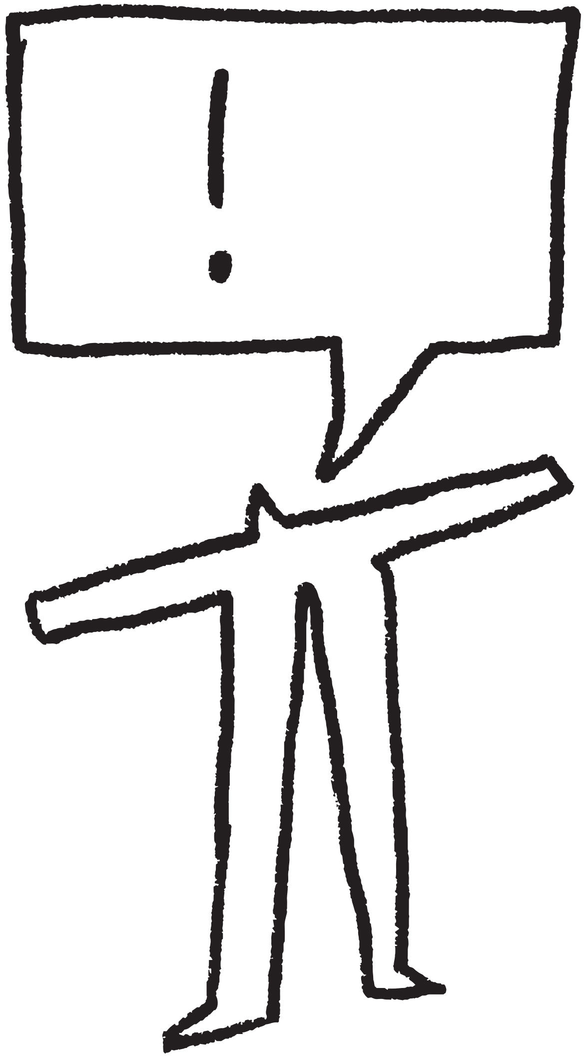

Chapter 2

Moral and ethical challenges in transgender care: A thematic analysis based on a focused ethnography

Gerritse, K., Hartman, L. A., Antonides, M. F., Wensing-Kruger, A.,
de Vries, A. L. C., Molewijk, A. C. (2018). *Archives of Sexual Behavior 47, 246-257.*

Abstract

Treatment teams providing gender-affirming medical care (GAMC) face various moral and ethical challenges. These are becoming even more pressing due to increasing referrals and public attention to GAMC. There is little knowledge concerning what moral and ethical challenges manifest in clinical practice. The present research aimed to map such challenges of healthcare professionals working in a specialized multidisciplinary GAMC center. Over a period of 7 months, during a focused ethnographic study, we collected data through participant observation of multidisciplinary team meetings and individual psychodiagnostic assessment sessions with clients. Furthermore, we included transcripts and reports from moral case deliberations. Through a thematic content analysis of the data, we identified the following six themes: (1) assessing eligibility; (2) the content of treatment; (3) the sequential order of the treatment steps; (4) the role of clinical guidelines; (5) differing notions regarding gender identity and assessing Gender Dysphoria, and (6) decision-making. Our research provides a detailed insight into how healthcare professionals experience these moral and ethical challenges and how they relate to (local) guidelines, the multidisciplinary character of GAMC, and its implicit and explicit (gender) norms. Our findings suggest that good GAMC may profit from ongoing multidisciplinary deliberation and sensitivity toward its inherent moral and normative dimensions. The paper ends with recommendations for clinical ethics support mechanisms in GAMC.

Introduction

In countries where healthcare professionals use the Diagnostic and Statistical Manual of Mental Disorders (DSM), those who experience distress due to an incongruence between one’s experienced gender identity and sex assigned at birth may meet the criteria for a diagnosis of Gender Dysphoria (GD) (American Psychiatric Association, 2013). Gender-affirming treatment may aid individuals in exploring their gender identity and coping with their distress (Hidalgo et al., 2013). Sometimes, gender-affirming treatment includes bodily alterations to help clients in expressing their experienced gender: Sequentially, such gender-affirming medical care (GAMC) options include puberty suppression (in youth), feminization, or masculinization through hormone therapy and surgery (Coleman et al., 2012).

The practice of diagnosing and treating GD is complex (Drescher & Byne, 2012; Stein, 2012), and moral and ethical challenges are ubiquitous (Swann & Herbert, 2008). In line with Hartman et al. (2019a), we delineate the concept of “morality” as a moral background consisting of an intricate web of norms, values, and responsibilities. We use the term “ethics” for the actual discussion of or reflection on these values and norms (Dewey, 2002). We define moral challenges as situations where stakeholders are uncertain or disagree about what is morally right to do. Conversely, ethical challenges are related to dealing with or solving a moral challenge (see Molewijk et al., 2015, for a typology of moral and ethical challenges).[7] The literature on GAMC describes various moral and ethical challenges: theoretical and taxonomical, but also more practical and clinical. The latter include challenges such as: How should we go about informed consent issues in the case of transgender clients suffering from co-occurring mental health concerns such as autism (Shumer & Tishelman, 2015)? Or, is it ethically permissible to offer puberty suppression to adolescents, given that its medical and psychosocial risks have not been fully established (Vrouenraets et al., 2015)?

When providing care to clients, clinicians may draw from international guidelines and standards such as the Standards of Care (SoC) of the World Professional Association for Transgender Health (WPATH) (Coleman et al., 2012) and the Endocrine Society Guidelines (Hembree et al., 2017). These guidelines are purposefully flexible to meet various transgender healthcare needs and service providers. Multidisciplinary GAMC clinics often develop local clinical based on the infrastructural, legal, and practical context.

However, these guidelines offer rough guidance based on expert consensus statements and lack robust empirical evidence. The extent to they can aid clinicians in grappling with the contingencies giving rise to moral and ethical challenges in practice is equivocal. For example, cases involving parental apprehension toward transitioning (Bernal & Coolhart, 2012) or severe co-occurring psychopathology (Vrouenraets et al., 2015) can leave clinicians morally divided on how to act. There is little explicit support for clinicians to cope with moral challenges in GAMC. A deliberative handling of these challenges may not only support

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[7] Throughout the rest of this thesis, we do not differentiate between moral challenges and ethical challenges, and use the overarching term “ethical challenges.”

professionals in their practice but also establish a reference to what "good" care is. Attention and sensitivity toward these dimensions are essential, especially in light of the distress experienced by clinicians when facing opposing (multidisciplinary) values from colleagues or clients (Entwistle & Watt, 2016).

Against a backdrop of increasing numbers and decreasing age of referrals for GAMC (Aitken et al., 2015), these moral challenges become even more pressing. Indeed, they have been the subject of various publications. Some authors used composite case narratives based on their working experience with the transgender community (Bernal & Coolhart, 2012; Swann & Herbert, 2008; Tishelman et al., 2015). Others drew retrospectively from case histories without systematic data collection (Giordano, 2008; Wiseman & Davidson, 2012) or did not use empirical data to support the moral challenges they raised (Drescher & Pula, 2014; Pomora et al., 2015). However, moral challenges are intricately linked to the context in which they arise (Molewijk et al., 2008). Notably, studies investigating how clinicians in GAMC experience moral challenges in the embedded context of everyday clinical practice are missing.

This study aims to systematically map the moral and ethical challenges experienced in everyday clinical practice by professionals working in multidisciplinary GAMC (i.e., during team meetings, outpatient services, and specific clinical ethics support (CES) sessions). We conducted a qualitative, focused ethnography (Cruz & Higginbottom, 2013), which allowed us to add an experiential, clinical, and context-sensitive account to the existing literature. Our overall research question was: What are the moral and ethical challenges of clinicians working in a multidisciplinary GAMC center in the Netherlands?

We emphasize that this descriptive study is a first step in revealing and making explicit such clinical moral and ethical challenges. Based on our theoretical viewpoints on clinical ethics and integrative CES (Hartman, Metselaar, et al., 2019; Widdershoven et al., 2009), we did not intend to normatively settle these challenges in this paper. By publishing these findings, we seek to start an (international) dialogue and pave the way for both tailor-made CES and normative analysis.

Methods

Setting

In Amsterdam, GAMC is provided by the Center for Expertise and Care for Gender Dysphoria (CEGD), a multidisciplinary gender identity clinic. The CEGD's guidelines largely follow WPATH's SoC (Coleman et al., 2012) but are adapted to a local (infrastructural, professional, and legal) context. For example, while closely mimicking the eligibility criteria mentioned in the SoC, the local guidelines include health determinants such as body mass index (BMI), smoking, and age requirements as eligibility criteria for medical interventions, while stating that a case-by-case decision is always possible.

From 2013 onward, the CEGD received structural and integrated clinical ethical support (CES) from the medical humanities department of VU University Medical Center (VUmc). CES aims to support clinical practitioners in reflecting on the quality of care by elucidating their moral challenges and stimulating reflection and dialogue (Hartman et al., 2019b). At the CEGD, CES was introduced through moral case deliberation (MCD) (Molewijk et al., 2008). To clarify, MCD is a facilitator-led collective inquiry by healthcare providers into a moral question connected to a real clinical case. In this study, we used MCD as a data collection method.

Research team

We collected data during the winter of 2015–2016. The research team consisted of a medical and bioethics student (KG, MD), a clinical ethics researcher (LH, Ph.D. candidate), a child and adolescent psychiatrist (AdV, M.D., and Ph.D.), a medicine student (MFA, B.Sc.), a medical psychologist (AWK, M.Sc.), and an ethicist and senior researcher (BM, Associate Professor). Participant observations were carried out by KG (MCDs, multidisciplinary and individual consultations), LH, and BM (multidisciplinary team meetings and both facilitators of MCDs). MFA helped during data analysis.

Study design

This research combined various data collection methods (see Table 1 for an overview):

(1) Observations of multidisciplinary team meetings. In these meetings, complex and (potentially morally or ethically) challenging treatment decisions are discussed and made based on the consensus of attending psychologists, psychiatrists, endocrinologists, pediatricians, and plastic surgeons. KG carried out ten observations (five children/adolescent and five adult team meetings); LH and BM were present at four out of ten.
We took detailed field notes on (moral and ethical) content during the observations.

(2) Observations of individual psychodiagnostic sessions between clinicians and transgender individuals (10x). We identified preliminary themes and used these to determine a purposeful selection for the observation of individual consultations.

(3) This research made use of analyses of (a) transcripts of seven MCDs; (b) 22 MCD reports, written by the facilitator and member checked by the MCD participants; (c) field notes taken during four MCDs. During data collection, LH, BM, and a colleague facilitated four MCDs which KG observed. We took field notes and wrote reports of all four MCDs, and three out of four MCDs were audio-recorded and transcribed verbatim (duration +/- 90 min). We derived the remainder of MCD data from a dataset used in a larger study context into the role of MCD in dealing with moral dilemmas in GAMC by LH and BM.

Table 1. Overview of the dataset

Data collection method	Type of data	Amount	Sample
Moral case deliberation	Transcripts	7x	Convenience
	Reports	22x	Convenience
	Field notes	4x	Convenience
Multidisciplinary meetings	Field notes	12x	Convenience
Individual consultations	Field notes	10x	Purposive

Analysis

We conducted a thematic content analysis (Green & Thorogood, 2014), a systematic method to map content and topics across a dataset. We coded the data inductively in MAXQDA 12.0, which entails that we coded all potentially relevant textual fragments. Chronologically, the coding process took place as follows.

First, KG inductively coded all data and compared codes with MFA, who coded two MCDs, two interviews, and four observational reports. The latter author was hitherto not involved with the team and unfamiliar with GAMC and thus able to offer an independent perspective. Their comparison resulted in an initial code list. KG and MFA reached consensus/resolved discrepancies by examining and determining which code fitted best the content of a particular textual fragment.

Next, KG, LH, and BM independently coded one transcript, compared and discussed codes, and developed a coding tree. The coding tree consisted of codes–subcodes–segments. KG applied this coding tree to the field notes while still adding new codes. KG also used this coding tree to go back to the data analyzed earlier. Throughout this process, KG checked and rephrased specific codes, and developed new hierarchies.

During the third phase, KG, LH, and BM reconvened to discuss and reach a consensus on the initial themes that emerged from the hierarchical coding tree. They grouped the codes (based on the textual fragments) based on the emerging themes and subthemes while checking for interpreter consensus concerning this assignment.

Through this procedure, we identified six themes of moral and ethical challenges. In our analysis, we identified explicit and implicit moral and ethical challenges and an overarching moral question for every main theme that summarizes its moral content. Explicit moral and ethical challenges are those experienced and verbalized by healthcare professionals, whereas implicit ones remain largely under-discussed and are made explicit by us as authors. In our study, through identifying implicit moral and ethical challenges and confronting team members with them, e.g., during the member check, we sought to bring about—in a non-directive manner—moral reflection onto specific themes and challenges that members of the team potentially overlooked.

This is in keeping with our theoretical and normative assumptions: this research is part of a movement within CES that views experience as the source of morality (Molewijk et al., 2008; Widdershoven et al., 2009) and stresses the value of fostering ethical reflection together with healthcare professionals in the context of daily practice rather than a detached moral or ethical judgment. Our role as researchers in this study was to identify, extract and describe the moral and ethical challenges experienced by clinicians, and foster moral reflection on challenges that healthcare professionals potentially overlooked.

Quality procedures

In qualitative research, data saturation usually dictates sample size (Cruz & Higginbottom, 2013). Due to practical considerations, we conducted a set number of observations. We reached data saturation in the analysis of MCDs and multidisciplinary observations. We did not reach data saturation in the analysis of individual consultations due to the heterogeneity of client-clinician dyads. We conducted a member check with the participating clinicians of the CEGD in the form of a presentation and discussion of our preliminary results. The analysis and findings reported below are based on triangulation (Mays, 2000) of three data types (transcripts and reports of MCD, detailed field notes on multidisciplinary and individual meetings).

Ethical considerations

We submitted this study for review to an officially accredited IRB/REC, the Medical Ethics Committee of the VUmc, which declared that a full ethical review was unnecessary under Dutch law (IRB00002991, January 21, 2016). The management team, partaking clinicians, and those present during individual consultations gave oral informed consent for the research. We informed all participants in the study that their participation was voluntary and that they could withdraw from the study at any moment without providing motivation. We preserved anonymity in this writing by anonymizing quotes and altering participant characteristics. To safeguard the sensitivities and vulnerabilities of the multidisciplinary team, we edited some primary expressions and responses by clinicians or omitted them from the manuscript without changing the specific moral theme or content at hand.

Results

We identified six main themes of moral challenges in GAMC (see Table 2): (1) assessing eligibility; (2) content of treatment; (3) the sequential order of the treatment steps; (4) the role of clinical guidelines; (5) notions regarding gender identity/GD, and (6) decision-making process. We discuss, illustrate and substantiate the themes and their subthemes below. Rather than providing an all-encompassing overview of the dataset, the quotes and field notes serve as a means to demonstrate the moral relevance of the themes in clinical practice and are selected based on significance and methodological clarity. It is important to note that the quotes from individual employees and observations do not necessarily reflect the views of the CEGD.

Table 2. Frequency and percentages of coded segments per (sub)theme

Theme	Frequency	Percentage
Assessing eligibility	415	26%
The Content of treatment	222	13.9%
The sequential order of the treatment steps	154	9.6%
The Role of the (local) Guidelines	144	9%
Notions regarding gender identity/GD	175	11%
The decision-making process	486	30.5%
Total:	1596	100%

Assessing eligibility

The process through which clinicians assess transgender individuals' eligibility for GAMC is intricate. We identified four subthemes leading to moral and ethical challenges: (1) determining distress to diagnose GD, (2) overseeing the consequences of treatment, (3) estimating one's ability to cope with the effects of treatment, and (4) the influence of health determinants. The overarching moral question within this theme is: Under what circumstances should transgender individuals be rendered ineligible for GAMC?

How should we go about determining distress?

At the CEGD, to commence treatment, clients have to meet the criteria of a formal DSM diagnosis of Gender Dysphoria (GD) (American Psychiatric Association, 2013). An essential criterion is the existence of clinically significant distress, i.e., distress related to a marked incongruence between one's experienced/expressed gender and primary or secondary sex characteristics. However, some children and adolescents under discussion showed only minimal suffering, leading to a discrepancy between eligibility for medical treatment and a formal diagnosis. This proved to be ethically difficult for some members of the multidisciplinary team: "And at the same time, what is relatively odd is that there hasn't been any distress. … Based on this story, we can't really diagnose, but I do feel that we should treat, so it's complicated" (transcript MCD). This quote raises the following moral question: Should we treat children and adolescents even though they show little distress?

Should clients oversee all relevant consequences of treatment before we start?

Hormonal treatment for GD is usually a life-long commitment and only partially reversible, while surgical treatment is fully irreversible. Team members found it essential to assess whether those opting for GAMC could envision the consequences (i.e., medical risks/side effects). Sometimes, in case of an intellectual disability, co-occurring mental health concerns, or when a client was especially young, this raised doubt: "Can she [i.e., the client] envision the consequences of a decision that will span multiple years?" (Transcript MCD). Consequently, a moral question for some of the team members is whether one should start treatment when the implications are not fully understood. Take this case involving a 17-year-old trans boy:

> *Participant 1: That IQ test makes it problematic. What is our responsibility in making this treatment decision when he has an intellectual disability? Then we should make it, right?*
>
> *Participant 2: Are we not overthinking? Intellectually disabled or not, he should be able to choose.*
>
> *Participant 3: Well, then he should be able to understand what he chooses. (Transcript MCD)*

In the quotes above, and more generally during observations of team meetings dealing with co-occurring mental health concerns such as autism, caretakers were weighing respect for autonomy with sufficiently informed consent regarding the consequences of treatment.

Should we know that someone can cope with treatment before we start?

We observed three criteria colloquially used by clinicians to determine clients' expected coping with treatment effects: having a stable home situation, personal resiliency, and a successful social transition. However, using these criteria led to moral and ethical questions.

Regarding the criterion of personal resiliency, one team member expressed apprehension when discussing a client who showed dysfunctional coping skills in other life domains. The clinician was unsure whether her client would be resilient enough to cope with the (side)effects of GAMC. She believed the client would benefit from psychological training to ameliorate her coping skills. During an MCD, she shared the following: "Will she be resilient enough when complications occur? I'm worried about psychological suffering" (transcript MCD). When made more explicit, her ethical question could be formulated as: Should we offer treatment if we are not entirely sure whether the client can cope with the treatment's (side)effects?

Regarding the criterion of a successful social transition, clinicians discussed the following case during a team meeting. In this case, some of the client's family members did not accept her transgender identity. Consequently, she expressed her experienced gender to some, but not all, family members. To some clinicians, the client's ability to cope with a social transition indicates to what extent they may cope with GAMC. In effect, some clinicians use it as an informal means to gauge eligibility for treatment. This case laid bare that it may be unclear what a social transition should entail. One of the clinicians asked: "What does that actually entail, a full social transition?" A discussion ensued regarding whether a "proper" social transition entails being open to all family members or just a few. This ambiguity also raises the implicit moral question of whether clinicians should use the notion of a successful social transition to establish eligibility for GAMC.

When should health determinants become exclusion criteria?

The CEGD refers to health determinants such as substance use and BMI in their local guidelines. For example, a high BMI is an exclusion factor for specific surgical options to prevent or minimize the chances of surgical complications. The BMI criterion is lenient for low-risk surgeries (e.g., mastectomy) and stringent for high-risk surgeries (e.g., phalloplasty*)*. It also leads to moral and ethical challenges, for example, when used to determine eligibility for preceding treatment steps such as gender-affirming hormone treatment (where medical risks related to an elevated BMI are unknown). Quoting a psychologist during a team meeting: "He has been trying to lose weight, but unsuccessfully, so it's very complicated. Are we going to start [hormone] treatment?" In other words, the psychologist seemed unsure whether an elevated BMI is a morally and scientifically permissible exclusion factor for gender-affirming hormone treatment. Here, we identified the following implicit moral questions: Based on what (scientific, experiential) knowledge may a health determinant become an exclusion criterion? Who should decide whether and when an increased risk warrants an exclusion criterion?

Content of treatment and care

The moral and ethical challenges in this theme concerned (1) variations from a "complete" GAMC trajectory and (2) (scientific) evidence and uncertainties. The overarching moral questions were: What non-standard treatment requests are ethically permissible? How should we deal with scientific evidence and uncertainties? What risks may be carried by clients, and against what risks should clinicians protect them?

Which variations from a complete GAMC trajectory should be permissible?

A "complete" GAMC trajectory roughly consists of puberty suppression (in adolescents), followed by gender-affirming hormonal and (genital) surgical treatment. However, some clients only request specific treatment steps. Such "partial" requests may be at odds with the traditional male/female dichotomy. As such, some gave rise to moral and ethical challenges. For example, at a team meeting, a clinician asked whether a transman who did not have gender-affirming hormone treatment should be eligible for mastectomy, as she feared the client may not have "fully experienced living as a man." To us as researchers, this raised the question based on what normative assumptions clinicians deem some requests permissible and others not.

What are appropriate implications of (scientific) evidence and uncertainties?

Moral and ethical challenges concerning (scientific) evidence and uncertainties were myriad. To illustrate, during an MCD, it appeared unclear to the team members what the evidence for a BMI criterion for gender-affirming hormone treatment is. A surgeon stated: "The difficult thing is that I cannot put the complication risk into a percentage." (Transcript MCD) In another team meeting, a pediatrician asked: "How strict should we be regarding the BMI criterion for hormone treatment?" Here, we identified the following implicit moral questions: How should caretakers extrapolate general (scientific) evidence, e.g., regarding risk factors and complications, to procedures specific to GAMC? Who should determine what counts as valid evidence? More generally, how should clinicians cope with uncertainties in scientific evidence?

Sequential order of the treatment steps

Although the individual treatment steps are officially separate entities, they appear to be sequential and interconnected in clinical practice. For example, gender-affirming hormone treatment functions as a prerequisite for surgical interventions, and if clients desire surgery without hormone treatment, local guidelines recommend a "thinking" period of the same duration. The interconnectedness of the various treatment steps gave rise to moral and ethical difficulties. We identified two subthemes: (1) the multidisciplinary character of transgender care and (2) the sequential order of the treatment steps. The overarching moral question was: To what extent should the sequential order and interconnectedness of GAMC play a role in establishing eligibility for individual treatment steps?

Should a lack of multidisciplinary consensus lead to taking a step back in treatment?

Although intricately connected at the CEGD, a distinction is made between the medical and psychological aspects of GAMC, leading to moral and ethical questions concerning multidisciplinary consensus. For example, an MCD report described the case of a client who requested gender-affirming surgery without a social transition due to an unaccepting environment. In this MCD, participants found it essential to reach multidisciplinary consensus within the team, noting how "it can be important to take a step back to retain consensus." Here, we identified the implicit ethical challenges of determining when and why multidisciplinary consensus may necessitate taking a step back.

Should we take potential future treatment steps into account at the start?

Some clinicians struggled to decide whether they should consider potential future GAMC steps in determining eligibility at the start of medical treatment. For example:

"suppose that due to his BMI, he will never get to the surgeries, there is a risk that someone will become even unhappier, by being in a masculinized body with breasts" (Transcript MCD). This clinician is concerned that the client may suffer adverse sequelae if they start gender-affirming hormones while ineligible for gender-affirming surgery due to the BMI criterion. This evokes the ethical question of whether a criterion for treatment B (i.e., surgery) may also hold for treatment A (i.e., hormone treatment). A normative argument in favor was to prevent false expectations: "It could give someone the idea that he is on his way to masculinization whereas [with this BMI] he will potentially never be eligible for surgery" (Transcript MCD). However, weighing these arguments against the potential alleviation provided by gender-affirming hormones on its own is challenging.

The role of clinical guidelines

CEGD's clinical guidelines provide guidance but also give rise to moral and ethical challenges, particularly in those cases that do not neatly fit. Clinicians experienced ethical challenges concerning: (1) biological and calendar age and (2) determining the guidelines' strictness. The main ethical question is: Since the guidelines are flexible, what individual exemptions are permissible?

Should we go by biological or calendar age?

The local guidelines recommend that adolescents must be 12 years old and in Tanner stage 2–3 to be eligible for hormonal puberty suppression. However, as some reach puberty earlier, a case-by-case analysis is opted for in those under 12. The use of calendar age led to an exemplary moral dilemma in a 10.5-year-old girl with early puberty. A psychologist in a team meeting shared: "[S]he's too old for the children's guidelines but too young for the adolescent's guidelines." To the team, it was unclear whether the biological age and need for puberty suppression outweighed the precedent and the client's limited abilities to oversee the consequences. As such, it illustrates the difficulties involved in the balancing act between the guidelines, their flexibility, and individual treatment needs.

How strict should the clinical guidelines be?

We also identified moral and ethical challenges relating to the strictness or lenience of the guidelines. In the following case, for example, a discussion arose as to whether smoking marijuana should be a firm exclusion criterion for surgery:

> *Is it bothering you that the guidelines on this topic aren't clear? I think they shouldn't be too strict because every client is different. … There are always particularly upsetting cases where you think: what a sad story. There are just so many reasons why a person might use these substances. (Transcript MCD)*

The quote above shows that some team members stress how a more lenient and individual interpretation of the guidelines is more appropriate when striving for good care. However, other team members deem the guidelines ambiguous and call for

clarification and stricter usage. For example, "Well, for me, it would be pleasant if we'd be a bit more unambiguous about these guidelines [i.e., on smoking marijuana as an exclusion criterion for surgery]" (Transcript MCD). These quotes question the aim, (moral) status, limits, and ultimately the efficiency of the guidelines. We identified the following moral question: When is it right to deviate from the guidelines?

Notions regarding gender identity and assessing GD

In some cases, assessing the presence of GD turned out to be a challenging endeavor. We identified two subthemes: (1) strategies for assessing GD and (2) questions regarding the authenticity of GD. The main moral questions were: What is the normative status of advice regarding gender expression? And how should we go about doubt regarding GD and its authenticity?

What strategies may be used to assess GD?

Clinicians described various transgender clients who were unable to express their experienced gender (i.e., verbally, in their demeanor, or otherwise) or who could not verbalize their feelings, desires, convictions, and experiences of distress. In these cases, clinicians were often at a loss as to how to proceed in diagnosing GD and assessing eligibility for GAMC. Clinicians may refer such clients for psychological or social support services to ameliorate their resiliency and ability to express or verbalize their experienced gender. Sometimes, however, this approach led to moral challenges. During a team meeting, clinicians discussed a case of a transman who appeared to suffer from GD but did not dare to transition socially and was not amenable to receiving psychological care. The clinician shared her trepidations about diagnosing and considering this person eligible for GAMC. In response, another clinician asked more generally: "How should we actually deal with these kinds of vulnerabilities?"

Similar questions arose in an MCD where a client disregarded the advice to seek psychological care for resiliency and gender expression. During this MCD, a clinician shared: "You can always tell people that they should explore [their gender expression] further, but if they don't, how forceful should that advice be?" This question evoked the following questions from another clinician: "What is our role as advisers? When people fail to follow up on our advice, and we don't draw consequences, then what are we doing?" (Transcript MCD). These fragments illustrate how the normative status of clinicians" advice is opaque and beg the moral question of what the consequences should be when clients fail, or do not want, to follow up on it. We identified the following implicit moral question: Should clients express their experienced gender to be rendered eligible for GAMC?

How should we deal with questions relating to authenticity?

As some GAMC interventions are invasive and (partly) irreversible, the clinicians we observed sought to determine the "authenticity" of GD to minimize the chances of regret. However, this endeavor led to moral challenges, especially in prepubescent children.

Consider the following MCD case:

> *They [i.e., the parents] have layed it [i.e., GD] on this child from three onwards … which makes me doubt whether this is indeed the child's calling. … He told me memories of early childhood that I knew were not his but the mother's. … Then you're dealing with a complex case. (Transcript MCD)*

This clinician struggled to distinguish between parental influence and the child's authentic feelings, complicating the decision of whether to start puberty suppression.

Relatedly, caretakers assessed authenticity by considering the temporality with which clients experienced their GD feelings and expressions. They deemed the GD of clients presenting with a persistent, life-long, or "early-onset" narrative more authentic. However, the usage of this "early-onset narrative" as a means to assess authenticity was not without its moral challenges, for sometimes caretakers feared that: "Maybe they [i.e., clients] are telling this story, because they think it increases [their] chances of getting treatment" (Team meeting).

The (shared) decision-making process

The final theme concerns moral and ethical challenges related to the roles, characteristics, and values of the various stakeholders in decision-making. We identified two main categories: (1) parents/caretakers and (2) the clinician's role. The central question is: What is the right balance between protecting transgender individuals and promoting their autonomy?

What role should parents/caretakers have in reaching treatment decisions?

According to Dutch medical decision-making law, parents are responsible for children under 12 and share responsibility with adolescents between 12 and 16 for signing informed consent. Furthermore, the guidelines state that children/adolescents should have a stable support system. Contextual factors impacting these legal and social roles of parents/caretakers give rise to moral challenges for clinicians. For example, during a team meeting, a clinician shared:

> *It's a case where parentification manifests in socially desirable behavior [in the client]: 'I'll do whatever my parents think is good for me.' As her father did not believe the diagnosis [of GD], the adolescent was unsure whether to continue treatment. (Team meeting)*

This case was complicated further by the fact that the child was 16 years old and thus legally allowed to continue GAMC without parental support. However, if doing so, she would risk a deterioration of her home situation, potentially leading to the absence of the parental support necessary for GAMC. In this situation, the clinician found herself morally weighing the adolescent's parental relationship and support against the potential benefits of GAMC.

What should be the role of the clinician in the decision-making process?

Clinicians regularly find themselves in a double bind between a protective role on the one hand and an autonomy-promoting role on the other. Determining to what extent the clinician should take responsibility for treatment decisions was often ambiguous:

> *[T]o what extent is it our responsibility to decide? Is that your role as a caretaker, doctor, or treating psychologist? Or do you advise someone the best you can about the risks and ask whether the client is willing to take on the responsibility? (Transcript MCD)*

Additionally, the notion that clinicians have to weigh the risks of treatment against their potential benefits may morally impact the client–physician relationship. A clinician shared the following after an MCD:

> *She suddenly started crying and said: 'My depression is connected to my gender dysphoria and whether or not I'll be able to get treatment for it, but I'm afraid to show it [i.e., her depression], as I fear that it'll be interpreted as a comorbidity.' (MCD report)*

This quote illustrates the moral predicament both transgender individuals and clinicians may face: as the client does not feel safe to share her story, the clinician is hampered in making the right treatment decision.

Findings from the member check with participating clinicians

We presented and discussed a summary of our findings as a member check. We asked CEGD's team members whether they recognized our identified moral and ethical challenges. A psychologist mentioned the following: "Yes, I recognize these moral dilemmas, and if you present them like this, I suddenly realize how many decisions we're making for people." Another psychologist added: "I was also struck by the sheer number of problems we face. There are so many moments in which you can turn either left or right, where apparently, I choose to turn left." One surgeon shared: "I do [recognize these moral and ethical challenges], but this is a markedly different list than I would come up with. I would frame it more in medical situations or cases about children, adults, and surgery." These responses show caretakers' recognition of the moral challenges and illustrate how focusing on moral and ethical over medical content can provide distinctive insights.

Regarding specific themes, another surgeon responded: "We recognize [the problems of] BMI and smoking." Another surgeon responded to the permissibility of non-traditional treatment requests: "Not only socially, but also within our team, it is difficult to determine what is acceptable." An endocrinologist added, "Yes, probably because only later [in your career] do you start to look beyond the bounds of your discipline. I remember how at first, I was only prescribing hormones without taking too much notice of the full trajectory." The following psychologist shared how the presentation confronted him with his normative assumptions:

> *It's interesting to see to what extent we control whether someone can make the next step in the trajectory and that we decide on that relatively quickly. Looking at it like this makes me realize that we carry an enormous responsibility for how someone can express themselves. … I thought I knew what a full coming out entailed, but apparently, I have all kinds of presumptions.*

Discussion

This qualitative ethnographic study investigated the moral and ethical challenges experienced by clinicians of a multidisciplinary GAMC team in daily practice. We found that professionals face moral and ethical challenges in (1) determining the circumstances under which transgender individuals should be rendered ineligible for treatment; (2) shaping the content of treatment in the absence of a firm evidence base and the context of partial treatment requests; (3) dealing with the multidisciplinary nature and sequential order of treatment; (4) establishing the strictness of and possible variations from the clinical guidelines; (5) assessing the presence and authenticity of GD; and finally (6) the balancing act between protecting transgender clients and promoting their autonomy.

Are guidelines guiding or prescribing? The normative status of the local guidelines

Many moral and ethical challenges revolved around the guidelines' content and flexibility. Indeed, there appeared to be continuous tension for caretakers to determine the extent to which the guidelines guide or prescribe. In these challenges, fear of precedent and values such as "justice" and "equality" often gave rise to the following norm: We should keep to our guidelines.

We can better understand this phenomenon in the specific historical, cultural and legal context in which the local guidelines developed. For example, until July 2014 in the Netherlands, sterilization was a prerequisite for clients to have their legal gender recognized by law (art. 1:28 subsection 1 DCC Jo art. 1:20 subsection 1 DCC). The local guidelines adopted this legal requirement (Cohen-Kettenis & Gooren, 1999; de Vries et al., 2006). Hence, until recently, requests for variations from a "complete sexual reassignment surgery" were a priori rejected. Although this legal requirement has subsided, it arguably still manifests in clinicians' normative assumptions and interpretation of the guidelines. Next, although guidelines can improve the quality and consistency of clinical decision-making, this may come at the cost of elbow room for individual wishes, circumstances, and needs. For example, our findings illustrate that using numbers (e.g., BMI or age as eligibility criteria) can enable but also restrict clinicians in handling the complexity of clinical practice.

The fluidity of (gender) norms in GAMC

Furthermore, we identified how clinicians hold various implicit and explicit (gender) norms. For example, we found that clinicians consider GD more authentic when it starts before puberty (i.e., "early-onset"), clients have an unambiguous gender presentation, and role models of both birth-assigned and experienced gender are present during childhood and adolescence. These are exemplary gender norms that impact clinicians decision-making processes.

The "early-onset narrative" is a colloquial set of behavioral indicators locating the etiology of gender dysphoria in (early) childhood, implicating a stable transgender identity and focusing on the child's early response to their natal genitals and typical gender play behavior. Kreukels & Cohen-Kettenis, 2011) corroborate the use of the early-onset narrative as a clinical tool to filter those who benefit from or potentially regret GAMC as those suffering from late-onset GD experience more significant psychological sequelae and higher rates of regret after gender-affirming surgeries (Zucker et al., 2016). Indeed, we found that clinicians' fear of regret was pervasive, with values such as "well-being" and "security" underlying the norm that regret should be prevented. However, the use of the "early-onset story" was not without its moral and ethical challenges: In the literature and clinical practice, the demarcation between early and late-onset GD appeared ambiguous: "What [should] count as early onset?" (Zucker et al., 2016, p. 219). Moreover, the influence of potential recall bias, parents/caretakers, or anxiety of being rendered ineligible proved to problematize its clinical use further.

Finally, our findings show that many contextual factors impact clients' gender identity, presentation, resilience, and commitment to treatment. Team members appear to hold various normative presuppositions regarding resilience, commitment, and (gender) presentation. However, as noted by Tishelman et al. (2015), some may not have access or appear committed "because of geography, lack of financial means, and/or because of social structures that do not support them" (p. 42). Hence, deriving normatively laden indicators of (in)eligibility from these (gender) norms can be precarious.

Moral challenges of multidisciplinary and interdependent cooperation

The previous versions of the SoC describe GAMC as triadic therapy consisting of a "real-life experience," hormone treatment, and surgery. Indeed, until recently, GAMC was inherently sequential and binary (Beek et al., 2015). We described how the sequential treatment order raised moral challenges considering various eligibility criteria and the permissibility of individual, non-traditional treatment requests.

Kuyper and Wijsen (2014) quantitatively explored various aspects of GD in a self-report study among the general (adult) population in the Netherlands. They found that "there is not a one-to-one relationship between gender incongruent feelings, a dislike of one's natal sex characteristics, and the wish to obtain [full surgical treatment]" (p. 384). Their conclusions empirically support what Cohen-Kettenis and Pfäfflin (2010) dub a "dimensional" over a dichotomous conceptualization of (trans)gender identity and approach to GAMC.

According to many, the triadic or sequential model no longer represents the standard of care (Wylie et al., 2016). However, our findings attenuate claims that from the 6th iteration of WPATH's SoC onwards, "hormone therapy and surgery are seen as separate treatment options in their own right" (Cohen-Kettenis & Pfäfflin, 2010, p. 503). We illustrate that while some flexible and individualized treatment trajectories are permissible, others are not. In making these assessments, clinicians considered potential future treatment steps, referring to values such as "protection," "well-being," and "collegiality."

Decision-making and the balance between client autonomy and non-maleficence

We identified a tension between these latter values (i.e., protection and non-maleficence) and the value of client autonomy. Indeed, our findings indicate that clinicians are often trapped in a double bind between a protective role on the one hand and an autonomy-promoting role on the other. In practice, this tension leads to many moral and ethical questions, e.g., Should we start treatment when my client does not oversee or cope with the consequences of treatment? To what extent should it be my responsibility to decide about these risks? What should be the boundary of my professional responsibility? Hence, an overarching moral question is: In our decision-making process, how do we elucidate the various and often diverging moral values we encounter in the complex reality of clinical practice, and how should we go about doing justice to those values most at stake?

In their seminal paper, Emanuel and Emanuel (1992) distinguish four models of the client–clinician interaction: (1) the paternalistic model, (2) the informative model, (3) the interpretive model, and (4) the deliberative model. What we observed is that at the CEGD, clinicians opt for the informative and interpretive model in care for competent adult clients to more deliberative and paternalistic models in care for children, adolescents, and clients with limited capacity to engage in shared decision-making, e.g., due to severe co-occurring mental health concerns). Indeed, many of the challenges we described relate to the latter client groups where decisional models, clinicians' obligations, and client values are ambiguous.

Clinical implications

First, we advocate for further development and reflection on the content and normative status of the local guidelines. Specifically, in line with other specialized centers, we encourage a critical review of the use of more informed and flexible cutoff scores (regarding, e.g., BMI, calendar age) and a substantiation of numerical ones to allow for more individualized care (Tishelman et al., 2015). Additionally, we argue that creative means to gauge competence should be developed, especially in younger individuals and those suffering from co-occurring mental health concerns.

Second, our findings indicate a need for enhanced awareness of moral (gender) norms in GAMC and a more systematic way of handling them. Interestingly, multidisciplinary GAMC is usually only provided by a range of clinical disciplines. A potentially fruitful way of structurally enhancing awareness of implicit and explicit (gender) norms in GAMC is to include members with a background in social science and ethics. For example, from 2016 onward, the CEGD multidisciplinary team received structural support from the medical humanities department: two members joined the team meetings to foster reflection and offer CES. Their endeavors have been described elsewhere (Hartman, Widdershoven, et al., 2019).

Another way to sensitize clinicians to the moral dimensions of their work is by engaging in ongoing and reciprocal dialogues with clients. What moral and ethical challenges do they encounter when *receiving* GAMC? These dialogues may inform clinicians about the subjective dimensions of clients' gender identity, corresponding treatment requests, and the contextual factors that shape clients' ability to commit to treatment. Likewise, we argue for a more explicit moral deliberation on the potential benefits and pitfalls of partial, non-standard treatment requests.

Finally, our findings underscore the call for sound qualitative and quantitative research to inform guidelines and best practices, along with follow-up research on experiences with GAMC ((Deutsch et al., 2016; Safer et al., 2016).

The potential contribution of CES to transgender care

Our findings stress that clinicians in GAMC engage in several balancing acts and face diverse moral challenges. This renders their profession not only clinically but also morally and philosophically challenging and is an argument for integrated CES in GAMC (Hartman, Widdershoven et al., 2019)

Systematic CES offers a constructive and methodical approach to moral and ethical challenges and can make normative assumptions more explicit and transparent. Moreover, CES can foster clinicians' openness to the contextuality and contingency of their moral challenges (Molewijk et al., 2011) and aid in reaching and substantiating (treatment) decisions. We should emphasize that this process requires CES staff to employ a delicate balance between caring for the relationship and winning clinicians' trust on the one hand and being critical and explicitly normative on the other. We discuss this tension in another paper (Hartman, Widdershoven, et al., 2019).

Finally, the member check of this research illustrates that research can be a tool for CES by fostering awareness and discussion on moral issues that professionals are unaware of. As such, the main implication of this research is that GAMC requires ongoing moral deliberation and sensitivity toward (normative) intuitions, presuppositions, claims, and changing contextual factors. Ongoing moral deliberation on what constitutes good care is an element of (re)constructing good care.

Strengths and limitations

Our research's qualitative–observational nature allowed us to add to the current literature as follows: by providing a detailed insight into the contextuality of moral challenges in clinical practice, identifying both explicit and more implicit moral challenges, and elucidating the way professionals *experience* these moral challenges. There are also limitations to this study.

First, we methodologically focused on how *clinicians* experience moral challenges. Hence, our methodology did not allow for an analysis of what challenges might be born from team members' implicit and explicit normative presuppositions, or how such challenges ought to be "solved." We stress that our vision of ethics is dialogical: As researchers and ethicists, we engage in an ongoing dialogue on what constitutes good care rather than offer an outsider's absolute moral judgment. Through dialogue, a mutual learning process may emerge in which all stakeholders reflect on what morally good care entails.

Furthermore, we assume that moral and ethical challenges are ever-present. People and clinicians are never neutral and always have a (dynamic) normative frame of interpretation and reference (Widdershoven et al., 2009). These may come into conflict. We maintain that such challenges are catalysts of moral learning rather than weaknesses or problems.

Next, although sufficiently demarcated, the themes we described are highly entangled. Next, this research relied on CES, particularly MCD, as a data collection method. On the one hand, this specific and methodical focus on the moral dimensions of GAMC has proven to be beneficial in laying bare moral and ethical challenges. On the other hand, this enhanced sensitivity is likely to have influenced the multidisciplinary team's attention toward moral and ethical challenges. Their openness to this, however, is laudable and should be considered a strength of this research.

As mentioned, we modified or omitted some quotes at the request of team members without editing or excluding the moral or ethical issue. This illustrates how paying attention to the moral dimension of GAMC sensitized team members' responsiveness toward their profession's moral and ethical intricacies and stresses how integrative CES is an ongoing transformative learning process.

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Conflicts of interest

Karl Gerritse and Marte Fleur Antonides report no potential conflict of interest. Laura Hartman and Bert Hartman have received indirect honorarium for their supportive work at the CEGD and are engaged in a structural work engagement with the CEGD. Laura Hartman is currently working on a Ph.D. Some of the papers (forthcoming) that are a part of this Ph.D. thesis are co-authored by clinicians employed by the CEGD. Annelijn Wensing-Kruger and Annelou de Vries both receive honorarium from and are professionally invested in their clinical and academic work at the CEGD.

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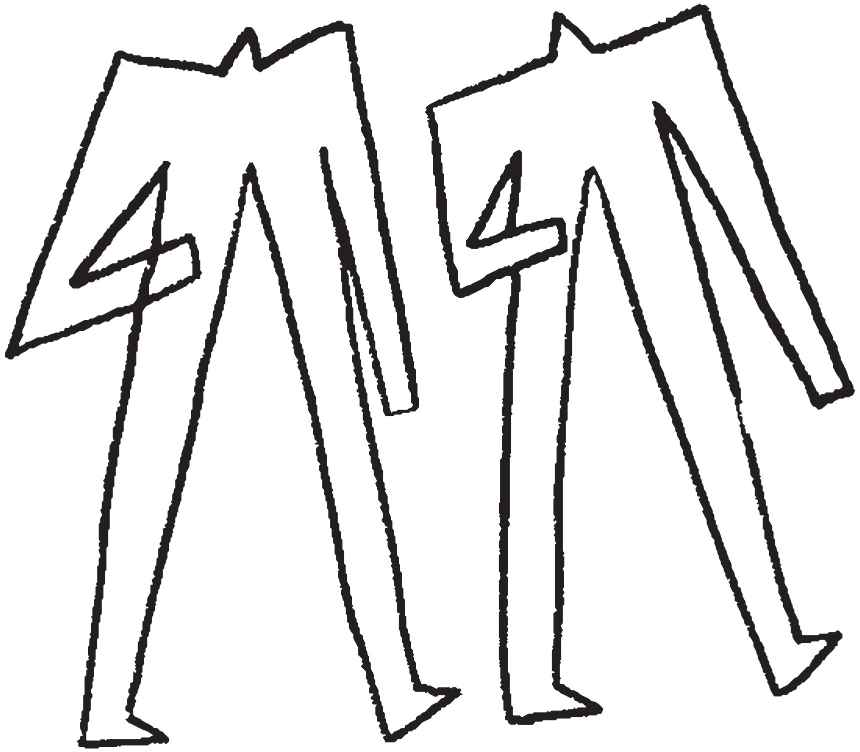

Chapter 3

"I should've been able to decide for myself, but I didn't want to be left alone." A qualitative interview study of clients' ethical challenges and norms regarding decision-making in gender-affirming medical care

Gerritse, K., Martens, C., Bremmer, M. A., Kreukels, B. P. C., de Boer, F., Molewijk, A. C. (2023). *Journal of Homosexuality.* Advance online publication.

Abstract

this qualitative study aimed to map and provide insight into the ethical challenges and norms of adult transgender and gender diverse (TGD) clients in gender-affirming medical care (GAMC). By doing so, we seek to make an empirical and constructive contribution to the dialogue on and moral inquiry into what *good* decision-making in GAMC should entail. We conducted 10 semi-structured interviews with adult Dutch TGD people who received GAMC. In our thematic analysis, we (1) included both ethical *challenges* and *norms*, (2) differentiated between *explicit* and *implicit* ethical challenges and norms, and (3) ascertained the specific *context* in which the latter emerged. We identified the following themes: (1) clients should be in the lead, (2) harm should be prevented, and (3) the decision-making process should be attuned to the individual client. These themes arose in the context of (1) a precarious client-clinician relationship and (2) distinct characteristics of GAMC. Our findings highlight divergent and dynamic decisional challenges and normative views—both within individual clients and among them. We conclude that there is no single ideal model of *good* decision-making in GAMC and argue that elucidating and jointly deliberating on decisional norms and challenges should be an inherent part of co-constructing *good* decision-making.

Introduction

Since the late 1970s, clinicians, researchers, and—increasingly—transgender and gender-diverse (TGD) individuals have worked concertedly and with diligence towards developing best practices to foster the health and well-being of TGD clients. These efforts have resulted in the formulation of standards of care and consensus regarding the guiding ethical principles of the provision of gender-affirming medical care (GAMC). GAMC comprises feminizing and masculinizing medical interventions (e.g., hormones and/or surgeries) to aid the affirmation and expression of clients' experienced gender and improve their quality of life (Coleman et al., 2012, 2022; Hembree et al., 2017; Javier et al., 2022; Wilson et al., 2021).

Notwithstanding these efforts, decision-making in GAMC is fraught with ethical challenges: situations in which stakeholders do not know, are uncertain, or are in disagreement with each other about what is good or right (Molewijk et al., 2015). Healthcare professionals (HCPs) may be confronted with questions such as: In our multidisciplinary practice, who should decide whether the risks of complication-prone interventions such as phalloplasty are acceptable (Gerritse et al., 2018)? TGD clients, on their part, may wonder to what extent they ought to be open about their doubts regarding GAMC or co-occurring social or psychological problems, as they fear it might impact their eligibility for treatment (Gerritse et al., 2018). Ethical challenges may also be shared in the client-clinician dyad. How, for example, should decisional dissensus be handled?

Characteristics of GAMC contributing to ethical challenges in decision-making include the growing but still limited biomedical evidence base (Coleman et al., 2012, 2022; Hembree et al., 2017; Wilson et al., 2021); the exponential increase of those seeking GAMC and corresponding waiting lists (Goodman et al., 2019); the diversity of the TGD community and their varying needs and wishes concerning GAMC (Koehler et al., 2018; Huisman et al., 2022); the elevated prevalence of co-occurring mental health concerns among TGD individuals (Dhejne et al., 2016); the sequential and multidisciplinary organization of GAMC (Coleman et al., 2012, 2022); the pivotal role of HCPs, especially mental health professionals (MHPs), in decision-making for GAMC (Gerritse et al., 2018); the convoluted history of (psychopathologization in) GAMC (shuster, 2021) and current ambiguities as to the clinical conceptualization of gender diversity (American Psychiatric Association, 2022; World Health Organization, 2018).

Beyond these empirical complexities and uncertainties, divergent normative views on decision-making in GAMC abound. Indeed, academic and societal discourse concerning how to serve the best interests of TGD people in decision-making in GAMC is polarizing. On the one hand, a group of clients, clinicians, and advocates argue that the role of HCPs, especially MHPs, in decision-making forms an unjust barrier to TGD clients' self-determination (e.g., Ashley, 2019; Cavanaugh et al., 2016; Schulz, 2018). Others (e.g., Evans, 2021; Littman, 2021) maintain that the principle of non-maleficence is insufficiently safeguarded in current (Western) decision-making practices. Often mentioning the risk of “regret” (the prevalence of which is considered to be low (see, e.g., Bustos et al., 2021) and “detransition” (i.e., discontinuing and/or reversing GAMC), they worry that TGD people are ushered into GAMC too quickly.

These different normative positions are also evident in decision-making and the provision of GAMC. For example, the last decade has seen an increase in local guidelines for hormone therapy that fall under the rubric of the so-called “Informed Consent Model” (ICM) for GAMC (Gerritse et al., 2021). The ICM emphasizes clients’ right to self-determination and minimizes the role of MHPs in assessing eligibility for GAMC (Deutsch, 2012; Schulz, 2018). Concurrently, (a push for) legislation aimed at curbing the provision of GAMC to, especially, TGD youth is on the rise, calling for more rigorous assessments and paternalistic approaches to GAMC (Turban et al., 2021).

Against this background, it is unsurprising that stakeholders encounter myriad decisional ethical challenges. Literature on these challenges strongly centers on those opined or expressed by clinicians and researchers (Budge & Dickey, 2017; Drescher & Pula, 2014; Wren, 2019). The same holds for empirical research. Some have focused on the ethical complexities of providing puberty suppression (Vrouenraets et al., 2015) or fertility preservation (Chen & Simons, 2018) to TGD youth. Those investigating the ethical challenges arising in decision-making with TGD adults frequently highlight the fundamental ethical challenge of weighing respect for clients’ self-determination against a duty to non-maleficence (Dewey, 2013; Gerritse et al., 2018; shuster, 2021).

Remarkably, empirical research into the ethical challenges experienced by TGD clients themselves is absent. The literature offers good reasons to assume, however, that TGD clients, too, experience decisional ethical challenges in GAMC. The ethnographic findings of Canadian GAMC by MacKinnon et al. (2020) illustrate how some TGD clients concealed co-occurring mental health conditions and faced a balancing act in presenting enough distress to receive GAMC without being deemed too “mentally unstable” by their HCPs. In the European context, an online survey conducted in Germany found that 96,5% of TGD individuals desired more involvement in decision-making (Eyssel et al., 2017). Furthermore, most respondents wished to share decisional responsibility with their HCP and strengthen their role in the decision-making process. Recent reports issued by the Dutch Ministry of Health, Welfare, and Sport echo these German findings (Zorgvuldig Advies, 2019, 2020). They note how the current organization of Dutch GAMC impedes a personalized and shared approach to care and decision-making.

This qualitative interview study aimed to map and provide insight into the ethical challenges related to decision-making experienced by adult TGD clients in GAMC. In doing so, this study seeks to make an empirical and constructive contribution to both the dialogue on and moral inquiry into what *good* decision-making in GAMC should entail, with the ultimate aim of improving current decision-making practices. This paper aimed to address the question: *What ethical challenges related to decision-making did TGD clients face in their GAMC trajectories?*

Methods

We conducted a qualitative interview study (Green & Thorogood, 2018) to explore the ethical challenges Dutch adult TGD clients experienced regarding decision-making in GAMC.

Setting

We conducted the interviews in the context of a larger project on ethical challenges and clinical ethics support (CES)[8] concerning shared decision-making in Dutch GAMC (2019 – 2022). At the time of writing, Dutch GAMC is offered at three multidisciplinary University Medical Centers (UMCs) and, increasingly, nonacademic mental healthcare centers collaborating with UMCs and other somatic healthcare providers. At the time of research and writing, Dutch GAMC guidelines were based on WPATH’s Standards of Care 7 (SoC7) (Coleman et al., 2012) and attuned to the local legal, policy, and insurance context.

Participant recruitment and selection

We included adult TGD clients who formerly engaged in decision-making regarding GAMC in the Netherlands to foreground their experiential knowledge and minimize conflicts of interest. To maximize variation, we purposively sampled for age, gender identity, and experience with academic and/or nonacademic GAMC (Green & Thorogood, 2018). Exclusion criteria were (1) current involvement in decision-making for GAMC interventions and (2) the inability to provide informed consent to the research.

Participants were recruited in three ways. First, a call was put online on the website of the participating academic institution as well as on the website of the Dutch TGD client organization. The call was also shared on the latter’s Facebook page. Second, we invited clients to respond to our call at the participating academic institution’s online public science event. Third, a stakeholder of the nonacademic partner institution approached two TGD clients based on our in- and exclusion criteria. Those interested in the study contacted us via e-mail, after which we sent them more information about the study and scheduled an introductory interview to answer questions and assess in- and exclusion criteria. Subsequently, the research team drafted a list of eligible respondents based on the abovementioned qualifiers.

Data collection

KG conducted seven, and CM, BM, and BK each conducted one semi-structured interview. Interviews were held between June 2020 and February 2021 via Microsoft Teams due to the COVID-19 pandemic. No prior contact had been established between interviewers and respondents. We based the initial interview questions on previous empirical, ethical, and conceptual research (Gerritse et al., 2018, 2021), the literature referenced above, and our experiences as clinicians, clients, and CES staff in GAMC. We did not provide definitions of “decision-making” and “ethical challenges” to evoke respondents’ lived experiences. Therefore, our interview questions were open-ended, e.g., *How were decisions concerning GAMC interventions made? How did you experience this at the time?*

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8. CES aims to support stakeholders in dealing with ethical issues in clinical practice and thereby seeks to improve moral competencies, cooperation, and quality of care. Increasingly, CES is offered in GAMC in the form of ethics consultations (Mabel et al., 2019), Moral Case Deliberation (e.g., Vrouenraets et al., 2020), and/or integrated into daily practice (Hartman et al., 2019).

What worked well for you? Did you encounter challenges? How do you feel about the decisional process in hindsight? If you were to engage in decision-making in GAMC again, how would you envision your ideal decisional process and division of roles? Interviews were audiotaped, transcribed verbatim, and anonymized. The duration ranged from 50 to 74 minutes, with a mean of 66 minutes

Data analysis

We analyzed the transcripts thematically (Braun & Clarke, 2006). We coded all fragments relevant to the research question (i.e., inductively) using words close to the original quote (i.e., in vivo coding) in MaxQDA 12.0. First, KG and CM independently coded the first two transcripts. They compared and discussed their codes and reached a consensus, resulting in an initial code list. Next, three transcripts were coded independently by KG and either MB, BK, or BM. They used the initial code list and added codes after deliberation. This iterative comparison resulted in a code system. KG used the latter to code the rest of the dataset while adding new codes. KG then re-coded the previous transcripts to ensure no fragments had been missed (to a total of 199 codes and 1051 coded fragments). Subsequently, KG and CM divided the codes into potential (sub) themes which they discussed with the research team. KG and CM then re-coded the last three transcripts for (sub)themes to allow for a deductive check. During this process, KG and CM refined the (sub)themes. Afterward, they reached a consensus about the (sub) themes with the research team through dialogue. We reached data saturation: we did not identify new codes during the deductive check (Green & Thorogood, 2018). TGD clients recognized the overall findings of this study during a member check.

In the absence of specific methodological guidelines, there are different conceptions of an ethical challenge. Consequently, it may be difficult to identify “ethical challenges” in empirical research (Schofield et al., 2021). We defined ethical challenges broadly as situations in which stakeholders do not know, are uncertain about, or disagree with each other about what is good or right (Molewijk et al., 2015). While we initially set out to identify *ethical challenges*, we found that respondents often spoke about experiencing *good* and/or *bad* (aspects) of decision-making or made statements concerning what they considered *good* decision-making. These latter expressions greatly outnumbered explicitly stated ethical challenges, e.g., ethical doubts and dilemmas. Therefore, we included *ethical norms* in our analysis as well. We also distinguished respondents’ *explicit* and *implicit* ethical challenges and norms to allow for a more thorough analysis. The former are challenges and norms explicitly verbalized by our respondents, while the latter remain largely under-discussed and are made more explicit through our interpretations. Furthermore, we differentiated between ethical challenges and norms on the one hand and the descriptive statements of the specific “context” in which they emerged on the other hand. For example, a respondent related the normative statement “people ought to be honest [about their doubts]” to the descriptive statement: “hormones aren’t sweets.” These distinctions proved useful heuristic devices.

Ethical considerations

We submitted the study protocol for review to an officially accredited IRB/REC, the Medical Ethics Committee of the Amsterdam UMC, location VUmc. They declared that a full ethical review was unnecessary under Dutch law (IRB00002991, April 21, 2020). Interested TGD clients contacted us via e-mail. We emphasized that participation in the study was voluntary and that participants could withdraw from the study at any moment. We provided the opportunity to ask questions and obtained written informed consent before the interview. At the start of the interview, we also obtained oral informed consent. We informed respondents that we would use pseudonyms and age brackets to safeguard their privacy and anonymity. Respondents received a gift card for their participation in the study.

Research team

The research team consisted of a qualitative health researcher, ethicist, and Ph.D. candidate who also worked as a junior M.D. in GAMC at the time of research (KG), a healthcare consultant and community advocate (CM), a senior researcher and psychiatrist working in GAMC for adults (MB), a senior researcher in medical psychology focusing on gender identity development and (outcomes of) GAMC (BK), an expert in qualitative health research (FdB) and an ethicist and senior researcher with experience in CES in GAMC (BM). During the study, we deliberated on how our professional and personal positionalities impact our presumptions, relationships with our respondents, and research considerations (Korstjens & Moser, 2018). An advisory and steering group comprised of academic and clinical experts, and client advocates, offered practical and methodological guidance for this study.

Results

Twenty TGD clients expressed an interest in participating in the research, of which 15 met the inclusion criteria. Of those 15, we selected 11 participants, who all agreed to participate. We conducted 10 semi-structured interviews as one selected participant was unresponsive. See table 1 for the characteristics of the respondents

Table 1. Characteristics of the research respondents

Name*	Gender	Age range	Start GAMC	Interventions	(Non)academic GAMC
Julia	TW	20-30	5-10yr	GAH, GAS (2x)	Academic
Monique	TW	40-50	<5yr	GAH, GAS	Both
Frouk	TW	50-60	<5yr	GAH, GAS	Both
Sandra	TW	60-70	5-10yr	GAH, GAS (2x)	Academic
Emma	NB/TW	60-70	<5yr	GAH, GAS	Academic
Dennis	NB/TM	50-60	>10yr	GAH, GAS	Academic
Daan	TM	20-30	<5yr	GAH	Nonacademic
Finn	TM	20-30	5-10yr	GAH, GAS (2x)	Nonacademic
Tim	TM	40-50	<5yr	GAH, GAS	Academic
Noah	TM	40-50	<5yr	GAH, GAS	Nonacademic

Abbreviations: GAMC: gender-affirming medical care; TW: trans woman; TM: trans man; NB: non-binary; GAH: gender-affirming hormones; GAS: gender-affirming surgery

**Names are pseudonyms*

We identified three main themes. Respondents expressed that (1) clients should be in the lead, (2) harm ought to be prevented, and (3) decision-making should be attuned to the individual client. We found that respondents' interpretations and practical consequences of these ethical norms frequently varied and thus required clarification. These themes arose in the context of (1) a precarious client-clinician relationship and were related by respondents to (2) distinct characteristics of GAMC.

Clients ought to be in the lead, but what should this entail?[9]

All respondents somehow expressed that they ought to be in the lead in decision-making. The latter generally entailed that (1) the client's needs and wishes should be foregrounded and (2) the pace and order of decision-making should be up to the client. Although this might suggest a call for radical self-determination, this was not necessarily so. For example, respondents frequently shared that (3) being in the lead should not preclude MHPs from having a "coaching" or "expert" role in decision-making.

The client's needs and wishes should take center stage

Julia felt she had to jump through hoops to receive GAMC, while she believed the decision-making process should have pro-actively catered to her needs:

> *You have to get the green light [for GAMC]. That could be a lot more relaxed. That you'd just start with, 'what are your wishes, and what would you like? What is it like to dress more in line with your experienced gender, for example? How does that feel?' And then: 'suppose we give you hormones; how's that for you?'... It's just better to proactively cater to people's needs.*

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[9] The questions following the normative statements in the theme headers are ours. In so doing, we stress how these overarching ethical norms ought to be interpreted and made more explicit.

She related the ethical norm that clients' needs and wishes should take center stage to the (psychological) importance of self-determination: "[I] think the feeling of being in the lead... is really important, especially when you're just starting your transition. That you really have the feeling, like, I have that influence and those options." To her, the latter has implications for the clinician's decisional role: "Ideally, the clinician has a facilitating role, so to say. I'd want the clinician to really try to understand, like, 'what is the [client's] question, and what can we do to meet that request?'"

To us as researchers, these fragments also raise questions. What does Julia mean when she speaks of "being in the lead" or "a facilitating role?" Indeed, the specific interpretations and implications of these normatively laden terms remain ambiguous.

The pace and order of decision-making should be up to the client

Respondents' paths towards GAMC were diverse and singular, with many relating how their decision-making processes started years before they first engaged with a specialized HCP. Likewise, their ethical norms and considerations regarding the pace of decision-making differed considerably. Here are Finn's:

> *[I] felt like, if I can feel more secure that way [i.e., with a penis prosthesis], ... then just leave me be for a while. I'll do my own thing and not focus on surgery. So, waiting to be truly free, so to speak, was really important to me.*

Finn noted how in his decision-making process, he took various concerns into account: recovery time, subsidiary options, the need to "take a break" from his medical trajectory, and job security. Ultimately, he balanced these concerns by waiting "to be truly free."

Next to the pacing, clients stressed the importance of deciding on the order of interventions themselves. Tim, for example, shared: "I couldn't have done it: start hormone treatment and only then have a mastectomy. For my process and the image I had in my head, it was crucial to have the mastectomy first and to start hormones later."

The HCP ought to have a coaching and/or expert role

While the above might suggest that clients seek a liberalized and informative client-clinician encounter, many respondents emphasized the importance of the role of their HCP as a "coach," "guide," or "expert" in decision-making. In the words of Daan: "I should've been able to decide for myself, but I didn't want to be left alone in my process." Tim expressed a similar sentiment:

> *I wanted to decide for myself, but also with [my MHP]. ... To me, it was important that someone ... with knowledge and experience wasn't like, 'I'm not so sure.'... I really needed that back then, also for my family and others. ... I didn't need a 'yes' or 'no' [from my MHP], and he didn't have to decide for me. That I also didn't want. But I did need someone with experience to think along with me.*

This quote illustrates how Tim holds various ethical norms regarding his MHP's role. While he did not want his MHP to decide for him, he did value their help in navigating his family relations and potential pitfalls. Similarly, clients frequently mentioned the need to be informed by their HCPs to make good decisions. Finn, for example, said: "[T]hese [medical] steps are so major that I believe you really ought to be thoroughly informed about what it is you're doing."

The quotes in this theme underscore the diversity of clients' needs, norms, and values concerning decision-making. Furthermore, they indicate that the normative conviction that clients ought to be in the lead may have various ethical and practical consequences for our respondents. An implicit ethical question is: How should GAMC account for clients' diverse—and sometimes ostensibly contradictory—needs and norms regarding decisional pace, order, and roles?

Harm ought to be prevented, but who should be responsible?

Next to the conviction that clients should be in the lead in decision-making, all of our respondents expressed that harm should be prevented. Clients held diverging views, however, as to whether preventing harm, such as regret, should be (1) the role of the HCP, (2) their responsibility, or both.

Preventing harm should be the role of the HCP

Some clients opposed the notion of radical self-determination in GAMC and believed HCPs, particularly MHPs, should have a role in preventing harm. Dennis, for example, said:

> *I'm not a part of the movement that believes [TGD] people should have radical self-determination and that there should be no involvement of a psychologist. … A thorough screening, if only to see whether someone can manage the whole process and what their social support system is, is pretty useful. I'm really not against that.*

To substantiate the ethical norm that HCPs should have a responsibility to prevent harm, they, like Sandra, often referred to the irreversibility of GAMC and the (emotional) hardship of living life as a TGD person:

> *Look, that's why there's a psychiatric screening. You want someone who can handle a transition. … [Y]ou see the number of suicides? Those typically happen about two years after the [GAMC] trajectory… because that's when you're confronted with your new life.*

Some clients, like Tim, found the rigor of the diagnostic trajectory reassuring: "What I appreciated is that they [i.e., MHPs] did a fairly thorough background analysis to check if there weren't any underlying psychological complaints. … So I knew, like, OK, it's not that. I'm not crazy or something." Later in the interview, however, Tim shared how his MHP's commitment to preventing harm also proved to be burdensome in and of itself:

> *At a certain point, just before the surgery, my psychologist asked me, 'Are you sure?' Well, and then I lost it. I'll never be sure! I can only be sure afterward. The only thing I can have is the trust and the will that this is the right way for me. Well, back then, I didn't have the guts to say yes, … and ended up on a much longer waiting list because of it. … Look, I get that it [mastectomy] is something irreversible. But it also depends on who you're asking that question that way.*

These fragments raise an important ethical question: How should stakeholders weigh the intention to prevent harm against its burdens? To Daan, for example, self-determination trumps the principle of non-maleficence:

> *You'll often hear the argument, 'yes, but what if you'll regret it?' Sure, but there are very few who do. And I just don't think it's a good argument to limit people's freedom of choice. So, more freedom of choice and self-determination are very important to me. … It all just feels a little belittling. … Yes, I believe trying to prevent regret is a lot more damaging than one person having it.*

Clients should carry their responsibility to prevent harm

Most clients said they should (also) have a role in avoiding harm. Finn, for example, stressed how he had to be sure about his decision to start GAMC as the ramifications were serious:

> *When you tell your parents [about your wish to start GAMC], you have to be sure because it's quite something. I only went to my general practitioner a couple of months later to get a referral [to a gender identity clinic] because, again, that's something you only do when you're entirely sure.*

The quotes in this theme raise implicit ethical questions: How should the ethical commitment to preventing harm be navigated between clients, MHPs, somatic HCPs, and other stakeholders? Who should have what role and responsibility in defining, weighing, and avoiding potential harms such as regret?

The decision-making process should be attuned to the client, but what should this involve?

Clients stressed how the decision-making *process* should be more attuned to the individual client and their specific needs. Tim, for example, recounted various clinical encounters where he felt too little time and space to ask questions:

> *I'm someone that needs time. And I've had to adjust to the fact that you're only granted 10 to 15 minutes [in a consultation], while I really have a hard time deciding in 10 minutes. I just need to ask more questions and, well, more time. So ideally, the appointments on the agenda of my treating physician are more flexible.*

This fragment illustrates the role of time as a condition for sound decision-making. Tim's implicit ethical norm here is that there ought to be adequate time and space for his and others' decision-making processes to unfold.

Similarly, Noah was adamant in his conviction that the duration of the decision-making process should accommodate clients' developmental needs and pacing; his normative assumption being that the latter is currently insufficiently accounted for:

> *Well, people never move too fast or hard. Everyone has their tempo, and you just don't know where someone's coming from. It really depends on someone's character or personality. I've had people in my [support] group and friends who, woosh, passed me by in their transition. And then I've friends … who trail behind me because they're even more careful than I am. In any case, it's important to attune to whoever is sitting opposite you and where that person finds themselves developmentally.*

Dennis, in turn, emphasized the importance of attuning to clients' cultural backgrounds in deliberation:

> *A [Caribbean or South-American] man said, 'I deliberately decided on phalloplasty because I'd asked my friends, and to us, it's just important to have a large penis.'… That means culturally mediated ideas about masculinity can profoundly impact someone's choice for certain surgeries. … And they [i.e., HCPs] should at least talk to them [i.e., clients] about that. How important is it to [clients] themselves? Or do they just want something because They've received the cultural message that 'this is masculinity.' If we're talking about making one's own decisions [as a client], it's unfortunate that it [i.e., the decision-making process] is solely focused on accessing treatment.*

Here, Dennis highlights the potential impact of cultural values regarding masculinity on clients' treatment wishes and stresses how the latter should be recognized, accounted for, and deliberated on in the decision-making process.

The quotes in this theme raise the following empirical and implicit ethical questions: to what extent do, or should, current work processes in GAMC accommodate the attunement of decision-making? What and whose values are, or ought, to be decisive in this process? What should be the limits of decisional attunement, if any?

Many of the above-described ethical challenges and norms regarding decision-making do not stand alone: they are specifically associated with the context of (1) a precarious client-clinician relationship and/or (2) distinct characteristics of GAMC. This is an empirical finding that we sought to accommodate theoretically and methodologically. To our respondents, decisional ethical challenges and norms are inextricably linked to the "context" they pertain to or manifest in and thus cannot be appreciated separately. In what follows, we illustrate this relation. We further reflect on the relationship between challenges and norms on the one hand and context on the other in the Discussion section.

Context: A precarious client-clinician decision-making relationship

Respondents particularly stressed the importance of and challenges in (1) open and transparent communication and (2) trust, honesty, and acceptance in relation to decisional ethical challenges and norms. Indeed, open and transparent communication based on trust, honesty, and acceptance emerged as contextual conditions for good decision-making.

Open and transparent communication

Many respondents stressed the importance of open and transparent communication in the client-clinician decision-making relationship. Dennis, for example, told how in the late 1990s, he found himself ill-informed and insufficiently involved in the decisional process:

> *The surgeon operating [on me] wasn't very communicative and immediately decided that he was going to do a nipple reduction because 'men have smaller nipples than women.' That nipple reduction went wrong: … after the surgery, I got pretty severe scarring. Afterward, he said, 'Yes, well, I'd expected that because you're dark-skinned.' [But], if you've known that all the time, why didn't you say so? … Then, I would've made a completely different decision regarding my nipples!*

Dennis' ethical norms here are that the surgeon ought to have informed him about the potential outcomes of a nipple reduction and should have made his normative presuppositions (i.e., a man should have smaller nipples than a woman) more explicit. This fragment also illustrates how to Dennis, open and transparent communication concerning (one's norms and values related to) treatment options and risks is a contextual prerequisite for *good* decision-making.

Likewise, Finn stressed the vital role of communication in establishing client-clinician rapport and trust: "[W]hat I would've wanted is reassurance. Like, 'OK, listen, I can't make any promises, but I can promise that it'll be fine and you're in the right place here.' Some sort of trust, reassurance; something!"

Trust, honesty, and acceptance

The fragment above points to another critical ethical conviction shared by many respondents: to arrive at good decision-making, you need to know and trust your HCP. Dennis, for example, stressed the significance of an accepting and respectful stance on the part of the HCP to foster client-clinician trust and, ultimately, good decision-making:

> *[I]f you as a client have trust in your clinician and feel that you're seen for who you are, and that that's OK, and that there are no judgments; then you'll also have more*

> *faith in that person [i.e., the HCP] being someone who can decide something that actually works for you.*

Alternatively, Sandra conceived of client-clinician trust as a two-way street:

> *There are many negative stories about [a Dutch gender identity clinic], but I'm actually very satisfied, maybe because I'm always very open. They can ask me anything, even if I think it's a lousy question. Answering them gives me a sense of trust that they'll help me in their turn.*

Similarly, Monique was adamant that clients must be honest with their MHPs: "I think it's really bad [when clients withhold information]. People should be honest because hormones aren't sweets."

Most clients, however, expressed that they were unsure to what extent they could or should be honest with their MHP about their doubts concerning GAMC. Clients frequently found themselves in a double bind: to arrive at good decision-making, one needs to be able to talk honestly, but this might lead to undesirable (delays in) decisions. In Daan's case, this led to moral distress:

> *Yes, well, I wasn't able to have this conversation [about my desire to have children], while I really wanted to talk more about it. … But they [i.e., the MHPs] just said, like, 'We advise against it. It'll be very uncomfortable and not good for your mental health.' You know, I get their point, but yeah. … I found that really complicated because my therapist also decided whether or not I could start my medical transition.*

To navigate the tension between wanting to talk through doubts or other essential values concerning GAMC without jeopardizing access to it, Tim, Daan, and other respondents consulted another MHP to, in the words of Finn, "Feel free to talk about everything I was struggling with and how I was actually doing."

The fragments in this subtheme raise various questions. An empirical one is: if clients share doubts, does this increase or decrease client-clinician trust? An ethical question is: should honesty always prevail, even when it produces effects that clients deem undesirable? Furthermore, they illustrate how open and transparent communication, based on trust, honesty, and acceptance, are contextual conditions for *good* decision-making.

Context: Distinct characteristics of GAMC

Furthermore, decisional ethical challenges and norms often manifested in or were related by respondents to (1) power differentials, (2) diverse conceptualizations of gender incongruence, and (3) shifting values concerning GAMC and decision-making.

Navigating power differentials

Respondents spoke of navigating decisional dependencies in GAMC, particularly the assessment of MHPs and (multidisciplinary) team discussions.

Many respondents related the hesitancy to share doubts to their dependency on MHPs for access to GAMC. Indeed, several described the decision-making process as an "exam" in which they had to convince their MHP of the need for treatment. Frouk, for example, said:

> *It feels like you're working towards an oral exam. … Because you've got it [i.e., the need for GAMC] figured out for yourself, … but it remains stressful until you're granted the 'you've got the green light, you can continue.'*

To some, like Julia, the experienced dependence changed after starting GAMC: "When I was making that decision about vaginoplasty, I didn't feel all that pressure to jump through hoops anymore because I'd started treatment; I already had my hormones."

Some clients, like Dennis and Daan, argued that the guiding and assessing roles of MHPs in the decision-making process should be separated. Others, such as Tim, did not object to their MHP's role as "gatekeeper" but voiced ethical concerns about the required multidisciplinary team consensus:

> *I don't necessarily have objections [against my MHP having to assess me and my request for GAMC], but I do object to it being done in such a big commission. Look, there might be a process behind it, but for me, it just took too long. For starters, I don't know who's in that commission. I think that if all those people present have to decide over me, they're just wasting everyone's time. If my [GAMC] psychologist says to me, 'I'm positive,' then why does it [i.e., my treatment request] need to go elsewhere?*

Finally, some respondents felt their needs in decision-making were frustrated by clinical guidelines. Monique, for example, shared:

> *Of course, you know that there are international guidelines about how to do a trans person, … but are they still correct? … Because if you've been on hormones for twelve months and you've been OK'd for your surgery, and then you have to wait another two years, … that's hell! … You want to be complete, to be done, and to continue life as a real woman!*

Here, Monique described how clinical guidelines stipulating that clients are only eligible for vaginoplasty after 12 months of hormone therapy failed to do justice to a context in which waiting times for that procedure exceeded two years. Stressing the harrowing experience of not being able to live life as "a real woman," she questions whether decision-making guidelines are ethically permissible.

Diverse conceptualizations of gender incongruence

Finally, clients linked their decisional ethical challenges and norms to diverse conceptualizations of what gender incongruence is or should be. Daan, for example, held the ethical norm that clients ought to be in the lead in decision-making *because* he takes gender incongruence to be something inherently subjective:

> *[I] t's my decision to start a medical transition or not. … At the end of the day, I'm the only person who can understand what I feel, and no one else can decide for me whether I want to transition or not. And that's the way it should be.*

While generally subscribing to the view that gender incongruence is inherently subjective, others argued that MHPs should have a role in assessing it. Emma, for example, shared: "Well, if you're gender incongruent isn't easy to determine. You either feel it, or you don't. Still, it's good that a psychologist checks, like, is it truly the case?"

Conversely, Monique argued for a paternalistic approach to GAMC, as according to Monique, only MHPs can establish gender incongruence:

> *I can tell you that I suffer from gender dysphoria, but really, that's up to you [i.e., the MHP] to decide. You're the judge of that. You determine whether you continue [GAMC] with me. And then, of course, you want to be specific and decide whether or not it's actually the case [that I suffer from gender dysphoria].*

These fragments illustrate how clients relate numerous ethical norms regarding decision-making to divergent conceptualizations of gender incongruence. Daan made this relation particularly explicit:

> *I use testosterone gel. And I mean, that's also prescribed to cisgender men who suffer from hormonal imbalance. … But when you're trans, suddenly, that's very complicated. … And I actually think that's unfair. Like, I'm not ill or something. … You'd want some informed consent system in which you're informed about the effects of hormone therapy but not obliged to go to a psychologist before you can start. … If trans people realize they're trans—and I mean, we just are—then no one else has to assess whether that's true or not. In my opinion, that's a remnant of, well, gender dysphoria is a psychological condition.*

In this quote, Daan links what he calls an unfair decisional process to the implicit conceptualization of gender incongruence as a condition that renders his competence questionable. To him, the value of justice and the principle of non-discrimination correspond to the ethical norm that clinicians should provide hormone treatment regardless of their clients' cis- or transgender status.

Clients' shifting values relevant to GAMC and decision-making

Finally, respondents highlighted how values regarding GAMC and decision-making are contingent on myriad factors and thus may shift over time. Tim mentioned the impact of changing societal conceptualizations of gender diversity on his values concerning GAMC:

> *Some people know very clearly from the start what they want, but I want to say that a 'no' [regarding a specific intervention] may become a 'yes.'… Maybe it's also because I identify as non-binary, and, well, I've grown up thinking I ought to fit in the woman's box. And I've tried really hard, but I failed. There's a lot of that I still carry with me. But the world's changing. I think it's really different if you're transitioning around my age or when you're a lot younger.*

Julia related how growing older impacted her values regarding the decision-making process itself:

> *Look, at a certain stage, I wasn't open to that [i.e., receiving psychological help] because I felt like I didn't need it and that people shouldn't meddle with me. But now I really appreciate that there's someone meddling with my head.*

A fundamental ethical question raised by these fragments is: How should decision-making in GAMC account for the notion that personal, professional, and socio-cultural values relevant to both GAMC and the decision-making process itself may shift over time?

Discussion

This study aimed to map and provide insight into adult TGD clients' ethical challenges and norms regarding decision-making in Dutch GAMC. Our findings highlight a wide diversity of ethical challenges and especially ethical norms. Overarchingly, these may be formulated as (1) Clients ought to be in the lead, (2) Harm should be prevented, and (3) The decision-making process ought to be attuned to the client. In what follows, we first consider the predominance of ethical *norms*, while this research set out to identify ethical *challenges*. Next, we reflect on our findings' moral and contextual dimensions and provide implications for the dialogue regarding what good decision-making in GAMC entails. We end the paper by outlining limitations and directions for future research.

The predominance of ethical norms

While this qualitative interview study initially focused on ethical *challenges*, we found that our respondents were more inclined to relate ethical *norms*, i.e., of *good* and *bad* (aspects) of decision-making or views concerning what should be done to arrive at *good* decision-making. The latter is noteworthy, given that numerous empirical studies (e.g., Dewey, 2013; Gerritse et al., 2018; Vrouenraets et al., 2015) illustrate how those *providing* GAMC to TGD clients face myriad and diverse ethical challenges concerning decision-making.

It also raises the question of why TGD clients postulate ethical norms while HCPs speak more in terms of ethical challenges. We hypothesize that the relative absence of explicitly formulated ethical challenges by TGD clients may, in part, be due to the current polarized and politicized state of the discourse regarding decision-making in GAMC. The latter may have contributed to the solidification of normative positions and/or a reluctance to share ethical doubts, uncertainties, or dilemmas during the interviews.

The absence of explicitly formulated ethical challenges could also be seen as a consequence of client-clinician power differentials. In current Dutch GAMC, HCPs have to establish clients' eligibility for treatment and thus carry a large part of the decisional burden and, arguably, ethical challenges (Gerritse et al., 2018). Conversely, TGD clients' limited decisional agency may preclude them from experiencing ethical doubts or uncertainties and elicit ethical norms concerning (the role of the HCP/MHP in) decision-making instead.

The moral dimension of decision-making in GAMC

In the Findings section, we added and italicized the following ethical questions to clients' ethical norms, i.e., (1) Clients ought to be in the lead, *but what should this entail?* (2) Harm should be prevented, *but who ought to be responsible?* (3) The decision-making process ought to be attuned to the client, *but what should this attunement involve?*

We did so to emphasize how clients' decisional values frequently corresponded to divergent ethical norms and how their practical and ethical consequences regularly varied. These values and ethical norms thus require interpretation and explicitation. For example, all respondents shared a commitment to "self-determination" and "non-maleficence" but differed with respect to how these values ought to be weighed and how potential conflict between them should be dealt with.

Furthermore, our findings suggest that individual clients' decisional values and ethical norms are dynamic rather than static and may be impacted by both time and GAMC. Indeed, clients' decisional norms and values regarding, say, masculinizing hormone treatment and mastectomy may differ considerably. Furthermore, having a mastectomy may affect one's needs and values regarding hormone treatment. We also illustrate how clients' ethical considerations concerning *decision-making regarding* these interventions may shift. While our findings indicate that clients arrive in the consultation room with various needs, fears, and dynamic normative views regarding good decision-making, we also found that these are not regularly shared or deliberated on in the consultation room.

The contextual dimension of decision-making in GAMC

The notion that decisional needs, fears, and dynamic normative views often remain implicit can be better understood in the context of precarious communication, trust, and honesty in the client-clinician relationship. Indeed, TGD clients may face a double bind in decision-making where they fear being open and honest with their HCP potentially jeopardizes (the duration or outcome of) the decision-making process. Clients frequently described their HCPs as gatekeepers that had to be convinced, leading to mistrust, fear, and strategizing. In correspondence with Dewey (2013) and MacKinnon et al. (2020), our findings illustrate how this dynamic may have serious ethical consequences for the client-clinician partnership and the possibility of *good* decision-making as not all relevant information, values, and ethical challenges are taken into consideration and deliberation. This aligns with Clark et al. (2021), who qualitatively identified "agreement regarding what decision is at stake," "deliberation of decisional roles," "open communication," and "supportive relationships' as conditions for successful shared decision-making in GAMC with transgender youth.

Furthermore, we described how clients relate their ethical norms concerning decision-making to diverse conceptualizations of gender incongruence. For example, some considered mandatory consultations with an MHP in the context of decision-making in GAMC unfair as they do not consider gender incongruence a mental health condition. In line with Ashley (2022) and McQueen (2017), other respondents invoked the subjective and epistemically inaccessible nature of gender incongruence to substantiate claims for more decisional self-determination. Contrarily, some referred to gender incongruence as a (mental health) phenomenon which ought to be differentiated to argue that the role of MHPs in diagnosis and decision-making is necessary and ethically warranted. These divergent conceptualizations echo a broader socio-cultural context in which gender incongruence is currently classified as both a mental disorder (i.e., Gender Dysphoria) by the American Psychiatric Association (2022) and a condition related to sexual health by the World Health Organization (2018).

Staying with the inherent moral and contextual struggle

Taken together, our empirical findings stress the inherent moral and contextual dimensions of good decision-making in GAMC (Gerritse et al., 2018, 2021; Hartman et al., 2019; Vrouenraets et al., 2020). The diversity, complexity, and temporally contingent character of clients' ethical norms regarding decision-making imply that there is no single "ideal" decision-making model for GAMC. This underscores the need to diversify and explicitly attune decision-making to the specific client and context, time and again. Moreover, the notion that these dimensions are inherent implies that stakeholders' norms and values will continue to differ and will likely give rise to ethical challenges. Rather than seeking to "solve" these ethical challenges or conflicting norms, we argue that stakeholders ought to take them seriously as they are indicative of what values are at stake for whom (Gerritse et al., 2021). In fact, "staying with the moral struggle" through recognizing such inherent challenges and making them more explicit may aid in better understanding and handling them and foster good decision-making.

The above resonates with hermeneutic ethics and philosophical pragmatism (Hartman et al., 2020). According to these schools of thought, norms and values are not doctrines but instruments that attain meaning within the practices they are put to use. They thus require interpretation and application to a specific situation (Hartman et al., 2020). Seen through this lens, the diverse and dynamic nature of clients' decisional values and norms is not surprising or problematic but the consequence of clients reconsidering their moral presuppositions and convictions in light of the particular decision and situation at stake (Hartman et al., 2020). Furthermore, pragmatism and hermeneutics emphasize that morality is contextual; it is "intimately concerned with the timely, the local, the particular and the contingent" (Abma et al., 2010, p. 245). The latter implies that good or right decision-making cannot be established without considering its specific content and contextual characteristics in this study, practice, and beyond.

Establishing good decision-making in GAMC thus necessitates an openness toward what *good* decision-making may entail for *these* stakeholders in *this* context at *that* moment. Indeed, all stakeholders in GAMC may benefit from acknowledging that there is no single "ideal" model of good decision-making in GAMC. The impetus to establish such an "ideal" model may paradoxically impede the open and constructive dialogue necessary to arrive at good decision-making. Therefore, we argue that the first steps toward good decision-making are to elucidate and jointly deliberate on clients', clinicians', and other stakeholders' values and normative assumptions regarding the decision-making process and acknowledge that these may differ.

Limitations and directions for future research

This study is not without limitations. First, although this study's qualitative and retrospective nature allowed for an in-depth exploration of TGD clients' ethical challenges and norms regarding decision-making over time, it is also susceptible to recall and hindsight bias (Green & Thorogood, 2018). Therefore, we encourage prospective qualitative investigations into TGD clients who actively engage in decision-making or seek GAMC.

Second, we should note that we included a limited sample and that all respondents received GAMC in Dutch institutional contexts where guidelines are based on WPATH's SoC7 at the time of research and writing (Coleman et al., 2012). Our findings should therefore be contrasted with those of clients receiving care under different contexts and service delivery models, including SoC8 (Coleman et al., 2022) and those emphasizing informed consent (Schulz, 2018). Likewise, it would be worthwhile to elucidate the ethical norms and challenges of people who engaged in decision-making but decided not to seek or discontinue GAMC.

Finally, it is worth noting that this study descriptively mapped and explored TGD clients' ethical challenges and norms regarding decision-making in GAMC without the ambition to settle or judge them normatively. The latter is in line with our pragmatic and dialogical perspective on ethics and CES, which stresses moral learning through dialogue and joint critical engagement (Hartman et al., 2019; Widdershoven et al., 2009). In this light, it is worth noting that TGD clients indicated the need for a product in the consultation room to make (norms and values regarding) the decision-making process and decisional roles more explicit. The findings presented in this paper provide empirical input for dialogue sessions with HCPs and TGD clients in which we will co-create an ethics support tool to foster good shared decision-making in GAMC. We hope this paper and (the development of) this tool will contribute to a constructive dialogue in which the relevant context, ethical norms, *and* challenges may be shared among the stakeholders involved.

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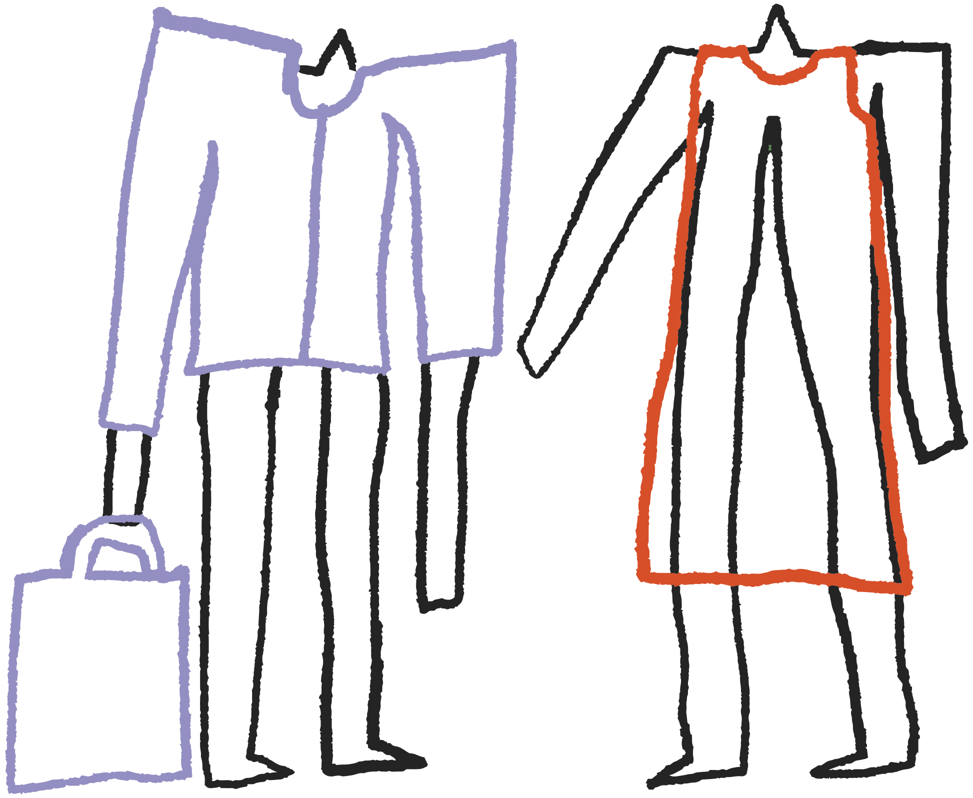

Chapter 4

Sharing decisions amid uncertainties: A qualitative interview study of healthcare professionals' ethical challenges and norms regarding decision-making in gender-affirming medical care

Gerritse, K., Martens, C., Bremmer, M. A., Kreukels, B. P. C., de Boer, F., Molewijk, A. C. (2022). *BMC Medical Ethics* 23, 139.

Abstract

Background

In gender-affirming medical care (GAMC), ethical challenges in decision-making are ubiquitous. These challenges are becoming more pressing due to exponentially increasing referrals, politico-legal contestation, and divergent normative views regarding decisional roles and models. Little is known, however, about what ethical challenges related to decision-making healthcare professionals (HCPs) themselves face in their daily work in GAMC and how these relate to, for example, the subjective nature of Gender Incongruence (GI), the multidisciplinary character of GAMC and the role HCPs play in assessing GI and eligibility for interventions. Given the relevance and urgency of these questions, we conducted a qualitative study among HCPs providing GAMC to transgender adults in the Netherlands.

Methods

Between May 2020 and February 2021, we conducted 11 semi-structured interviews with HCPs (six mental health professionals and five somatic HCPs) working in two distinct GAMC settings. We analyzed our interview data using thematic analysis.

Findings

Respondents' ethical challenges and norms centered on (1) dividing and defining decisional roles and bounds, (2) negotiating decision-making in a (multidisciplinary) team, and (3) navigating various decision-making temporalities. These themes arose in the context of uncertainties regarding (1) GAMC's guidelines, evidence, and outcomes, as well as (2) the boundaries and assessment of GI.

Conclusions

This interview study provides detailed empirical insight into both the explicit and implicit ethical challenges that HCPs experience and their ethical norms regarding decision-making. It also describes how uncertainties and (implicit) normativities concerning GAMC and GI pre-structure the moral environment in which these challenges and norms manifest. We provide reflections and recommendations on handling these ethical challenges in a way that is sensitive to the context in which they arise.

Background

An increasing number of transgender[10] and gender diverse individuals seek gender-affirming medical care (GAMC), i.e., interventions such as feminizing and masculinizing hormones and/or surgery to aid the affirmation and expression of their experienced gender (Arcelus et al., 2015). Since the late 1970s, an international group of clinicians, professionals, and other stakeholders have worked diligently to develop best practices to promote the health and well-being of transgender clients. These efforts have resulted in consensus regarding the standards of care and the guiding ethical principles of care provision (Coleman et al., 2012; Hembree et al., 2017). However, like in other care contexts, healthcare professionals (HCPs) providing GAMC are inevitably confronted with various ethical challenges (Gerritse et al., 2018, 2021; Hartman et al., 2019; Mabel et al., 2019; Vrouenraets et al., 2020). We define ethical challenges as situations in which a stakeholder asks oneself, does not know, is in doubt, is uncertain, or disagrees with another stakeholder about what is right or good (Hem et al., 2014; Molewijk et al., 2015). In previous qualitative research (Gerritse et al., 2018), we identified six themes around which HCPs experience such challenges that we will here relate to key characteristics of GAMC.

First, although the biopsychosocial evidence base is growing, current clinical guidelines for GAMC are primarily based on expert opinion leaving many clinical questions (e.g., regarding long-term follow-up and risks) unanswered (Coleman et al., 2012; Hembree et al., 2017). The latter gives rise to or complicates ethical challenges in determining who should be rendered eligible for GAMC (Theme 1) and establishing what constitutes good GAMC (Theme 2). Second, GAMC often comprises various interventions requiring different multidisciplinary professionals' involvement (Coleman et al., 2012) leading to ethical challenges in multidisciplinary cooperation and regarding the sequential order of treatment (Theme 3). Third, the growing diversity of transgender individuals, identities, and treatment requests (Richards et al., 2016) generates ethical challenges concerning the role of clinical guidelines and whether these ought to be guiding or prescribing (Theme 4). Fourth, the object of care is currently classified as "Gender dysphoria" (GD), a mental disorder in the fifth Diagnostic and Statistical Manual for Mental Disorders (American Psychiatric Association, 2013), but also as "Gender Incongruence" (GI), a condition related to sexual health in the 11th revision of the International Classification of Diseases (World Health Organization, 2018). This points to ongoing shifts in and divergent understandings of the clinical conceptualization of gender diversity and the object of care (Beek et al., 2016). Consequently, assessing GI/GD can be clinically and ethically challenging (shuster, 2021) (Theme 5).

The abovementioned culminates in the final theme: decision-making (Theme 6). Indeed, HCPs may face ethical challenges regarding shared decision-making with clients and how to organize (multidisciplinary) decision-making in GAMC. Examples of such challenges include: How should I share the responsibility for decision-making when a client suffers from co-occurring mental

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[10] We use "trans" and "transgender" interchangeably as umbrella terms referring to various forms of gender identities, roles and expressions that differ from those normatively expected of one's sex assigned at birth. Not all trans people need or seek GAMC.

health concerns, which makes me doubt their ability to consent to treatment? Or: In a triad consisting of a surgeon, mental health professional (MHP), and client, who ought to have what kind of responsibility regarding the acceptability of risks involved with surgical treatment? This paper centers on challenges in GAMC for adult transgender clients (i.e., those aged 18 years and above).

Ethical challenges regarding decision-making are further complicated by MHPs often playing a pivotal role in GAMC generally and decision-making specifically. According to the 7th version of the Standards of Care (SOC7) of the World Professional Association for Transgender Health (WPATH), MHPs are best prepared to diagnose GI and establish eligibility for GAMC as well as to guide clients throughout their gender-affirming process given their specific training and as medical treatment is intensive, often life-long and (partially) irreversible (Coleman et al., 2012).

This role, however, is not without its challenges. MHPs themselves, for example, struggle with the question of to what extent they (should) have a guiding or assessing role in decision-making (Dewey, 2013; Gerritse et al., 2018). Concurrently, debates concerning their decisional role and decision-making approaches in GAMC are polarizing. On the one hand, many HCPs and transgender activists argue that the role of MHPs in decision-making effectively renders them "gatekeepers," curbing trans clients' right to self-determination (Cavanaugh et al., 2016; Schulz, 2018). This critique has led to the development and implementation of alternative care models that seek to minimize the involvement of the MHP in decision-making and foster a more liberal individual account of "client autonomy" through so-called "Informed Consent Models" for GAMC . On the other hand, legislation aimed at criminalizing or otherwise curbing the provision of care to especially trans youth is on the rise, undergirded, amongst others, by claims that current decision-making practices insufficiently safeguard the principle of non-maleficence (Turban et al., 2021).

Against this backdrop, the paucity of empirical work investigating HCPs' ethical challenges in decision-making regarding GAMC for adults is surprising. Much empirical literature on ethical challenges encountered by HCPs in GAMC focuses on care for youth (Giordano, 2013; Swann & Herbert, 2008; Tishelman et al., 2015; Vrouenraets et al., 2015) and specific interventions such as fertility preservation (Chen & Simons, 2018). Some studies do not focus solely on decision-making (Gerritse et al., 2018) or *ethical* challenges in decision-making per se (Dewey, 2013; shuster, 2021). Both Dewey and shuster, however, identified challenges pertaining to (the implementation of) collaborative decision-making in GAMC. The literature suggests that ethical challenges related to decision-making in GAMC are ubiquitous, relevant, and urgent but remain understudied. Notably, studies seeking to understand these ethical challenges through the experience of HCPs are absent. So are those appreciating these ethical challenges in relation to the particular context of GI and GAMC.

Therefore, we initiated a qualitative interview study into the ethical challenges experienced by HCPs regarding

decision-making in GAMC for adult clients. We included a majority of MHPs (HCPs with a background in psychology or psychiatry) as their involvement in decision-making is central and contested. To account for the multidisciplinary nature of GAMC, we also included HCPs with other professional backgrounds (i.e., endocrinology, plastic surgery, nursing). The research question was: *What ethical challenges related to decision-making do HCPs face in their daily work in GAMC?*

This study aims to contribute to various goals, including (1) better understanding HCPs' ethical challenges related to decision-making in the specific context of GI and GAMC; (2) informing various stakeholders about these challenges; (3) identifying barriers and facilitators for recent calls from a variety of stakeholder groups to implement *shared* decision-making in GAMC (Clark et al., 2021); (4) reflecting on the question as to what good decision-making in GAMC should entail. Ultimately, this study seeks to improve decision-making practices and the handling of ethical challenges related to decision-making in GAMC

Methods

We conducted a qualitative interview study to explore the ethical challenges of HCPs regarding decision-making in GAMC.

Setting

Dutch GAMC is offered by three multidisciplinary University Medical Centers (UMCs) and, increasingly, nonacademic mental healthcare centers that often work in partnership with UMCs and other somatic healthcare providers. Dutch GAMC guidelines largely follow WPATH's SOC7 (Coleman et al., 2012) and are adapted to the local infrastructural, legal and professional context. For this study, we recruited HCPs at an academic and nonacademic center participating in a larger project on ethical challenges concerning (shared) decision-making in Dutch GAMC (2019 – 2022).

Participant selection and recruitment

We included HCPs with a minimum of one year of working experience in GAMC. To meet the criterion of maximum variation, we purposively sampled for professional background and years of experience (Green & Thorogood, 2014). Recruitment took place by asking a gatekeeper, in this case, a member of the steering group of the larger project, to bring us in contact with possible respondents. This person informed and provided a list of potential respondents from the participating academic center, of which we approached ten via e-mail. Another steering group member contacted a nonacademic GAMC center's stakeholder, who proposed two participants based on our in- and exclusion criteria.
The names used in this writing are pseudonyms.

Data collection

KG conducted nine, and CM and BM each conducted one semi-structured interview. In six interviews interviewer and respondent were not acquainted with each other, while in the other five, the interviewer and respondents knew each other as (in)direct colleagues. We based our interview guide on previous empirical and conceptual research (Gerritse et al., 2018, 2021), the abovementioned literature, and our experiences and observations as clinicians and CES staff in GAMC. We purposefully abstained from providing theoretical definitions of "decision-making" and "ethical challenges" as we wanted to elicit respondents' concrete experiences. Our final interview guide included open-ended questions, e.g., *What ethical challenges related to decision-making do you experience in your daily work? Can you give an example of a case or situation in which it was hard to come to a decision or where the decision-making process felt wrong or uncomfortable to you? Conversely, can you sketch a case or situation in which the decision-making process felt particularly right or good?* The interviews were audiotaped, transcribed verbatim, and anonymized.

Data analysis

We analyzed the anonymized transcripts thematically (Braun & Clarke, 2006). First, KG read the transcribed data and listened to the recordings to ensure the accuracy of the transcription and foster data immersion. Second, fragments relevant to the research question were coded inductively in MaxQDA 12.0 employing open codes, which entails that we coded all potentially relevant textual fragments. We emphasized respondents' original wording (in-vivo coding). KG and CM independently coded two transcripts resulting in an initial code list. They compared their code lists, reached a consensus, and resolved discrepancies through dialogue. Using and adding to this initial code list, KG and BM independently coded the third transcript and reached a consensus, resulting in a code system that KG, MB, and BK used to code independently and discuss the fourth transcript. KG drew from this last code system to code the rest of the dataset while adding new codes. Third, KG and CM convened to cluster codes to identify initial (sub) themes they discussed with the other authors. Fourth, further coding by KG took place to ensure no codes had been missed in the earlier stages (to a total of 239 codes and 1147 fragments). Furthermore, KG and CM re-coded the last three transcripts to allow for a "deductive check" of the (sub)themes. During this process, KG and CM refined the (sub)themes which they subsequently discussed with the other authors. We reached data saturation: we did not find underexplored (sub)themes during data analysis or identify new codes during our deductive check (Green & Thorogood, 2014). The last stage involved selecting relevant quotes to illustrate the identified (sub)themes.

In the absence of an agreed definition, clear methodological guidelines, and consensus in social scientific and empirical ethics literature, it is challenging to identify "ethical challenges" in empirical qualitative data (Davies et al., 2015; Molewijk et al., 2015). We developed the following approach. First, following Molewijk et al. (Molewijk et al., 2015) we defined "ethical challenges" as situations in which a stakeholder (a) asks oneself whether one does the right or good thing; (b) does not know what the right thing to do is; (c) is uncertain or in doubt about what is the right or good thing to do; (d) disagrees (with another stakeholder) about what is morally right or good to do; € knows what is right or good to do but is not able to or allowed to do that; or (f) feels obligated or forced to do something which one believes to be morally wrong or bad. As we found that some HCPs were more inclined to speak in terms of *what should or ought (not) to happen* to arrive at good or right decision-making, we also included "ethical norms" in our analysis. Subsequently, we differentiated between explicit and implicit ethical challenges and norms. Explicit challenges and norms are those verbalized by our respondents. We identified Implicit ethical challenges as those that HCPs (seemingly) use without intention and/or are unaware of (Molewijk et al., 2003). Furthermore, we distinguished ethical challenges and norms from the "context" they pertained to. For example, the context of "having co-occurring psychiatric problems" often corresponded with the explicit ethical norm "we shouldn't rush decision-making." This approach proved a useful heuristic device which we will elaborate on in the Findings and Discussion sections.

Research team

The research team consisted of a trained ethicist, qualitative health researcher, and Ph.D. candidate who was also a junior M.D. working in GAMC at the time data collection took place (KG), a healthcare consultant, and community advocate (CM), a senior researcher, and psychiatrist working in GAMC for adults (MB), a senior researcher in medical psychology focusing on gender identity development and (outcomes of) GAMC (BK), an expert in qualitative health research (FdB) and an ethicist and senior researcher with experience in clinical ethics support (CES) in GAMC (BM). To foster reflexivity, we engaged in dialogues among the research team members about how our professional and personal positionalities impact our assumptions, relationships with respondents, and research decisions (Korstjens & Moser, 2018). Furthermore, an advisory group and steering group consisting of academic and clinical experts, experience experts, and client advocates offered practical and methodological input for this study.

Results

Out of the 12 HCPs we approached, 11 agreed to participate in the study, and one did not reply. We conducted 11 interviews between May 2020 and February 2021, nine of which took place via Microsoft Teams due to the COVID-19 pandemic. Information about respondent characteristics can be found in table 1.

Table 1. Characteristics of the research respondents

Respondent*	Institution	Professional background	GAMC Experience	Interview duration
Jasper	Academic	Mental health	<5 years	69 minutes
Maria	Academic	Mental health	5-10 years	58 minutes
Ellen	Nonacademic	Mental health	<5 years	55 minutes
Marieke	Nonacademic	Mental health	<5 years	54 minutes
Stefan	Academic	Mental health	10+ years	60 minutes
Wil	Academic	Mental health	10+ years	80 minutes
Ellis	Academic	Endocrinology	<5 years	58 minutes
Wietske	Academic	Plastic surgery	<5 years	57 minutes
Tim	Academic	Endocrinology	5-10 years	72 minutes
Mike	Academic	Plastic surgery	5-10 years	69 minutes
Sara	Academic	Nursing	5-10 years	74 minutes

*Names are pseudonymized

We identified three main themes. Respondents' ethical challenges and norms centered on (1) how and when not to share decision-making with clients, (2) negotiating decision-making in a (multidisciplinary) team, and (3) navigating through various decision-making temporalities. These themes arose in the context of uncertainties regarding (1) GAMC's guidelines, evidence, and outcomes, as well as (2) the boundaries and assessment of GI/GD.

How should we divide and define decisional roles and bounds?

HCPs expressed ethical challenges and norms regarding the following aspects of the client-clinician decision-making process: (a) determining client-clinician decisional roles, (b) MHPs' gatekeeper role, and (c) delaying or withholding treatment. The overarching ethical challenge in this theme was: How should we weigh respect for clients' self-determination against our duty to non-maleficence?

What ought to be my role in the decision-making partnership?

Generally, HCPs strive to form a team with their clients and seek to work towards a shared goal. Some HCPs engage in a meta-conversation to discuss this explicitly. For example:

> *At the start of someone's trajectory, I always tell my patients, 'We're a team, and as a team, we're going to figure out how your dysphoria works for you, but especially whether medical steps will contribute to your happiness.' I feel that whenever possible, I just want to stand by a patient's side, form a team that works towards whatever that patient wants, but also see whether that's sensible. (Jasper, MHP)*

Here, we see that the ideal of "forming a team," "standing next to someone," and "working towards the clients' goal" has its boundaries. Indeed, Jasper also expressed an ethical obligation to assess whether the client's goal is sensible and likely to contribute to their happiness. An implicit ethical question we identified here is: Who should define "happiness," and what it entails for decision-making in GAMC?

As Maria shared, the commitment to respecting self-determination and informed consent in decision-making may come into conflict with one's professional responsibilities:

> *In our multidisciplinary team meeting this morning, we discussed a case in which, well, there were some concerns. At the same time, one of our colleagues rightly said, 'Yes, but there's obviously informed consent.' And, you know, someone has to have the ability to decide for themselves and have a say in, well, what they want in terms of [medical] steps. And if someone can do that [i.e., give informed consent], who are we to say that we're not going to treat? On the other side, there's your responsibility, of course: your responsibility as a psychologist or your medical responsibility as a doctor. That can be pretty complicated when I think a patient may want something very much, but it just doesn't sit right with me. (Maria, MHP)*

Many MHPs described how they adapt decision-making roles and responsibilities to their clients, for example, by distinguishing between "relatively good functioning" and "complex" clients or those who are and are not able or willing to communicate.
Maria shared how her role in decision-making becomes more paternalistic when confronted with clients with "questionable capacity" or those unwilling to seek treatment for interfering mental health concerns. Defining one's role and responsibilities in decision-making may also create ethical uncertainty. Consider, for example:

> *Interviewer: What isn't black or white?*
>
> *Jasper (MHP): Well, the road to happiness. In this case, how sure should we be of our assessment that hormones will do this patient [with suspected co-occurring mental health concerns] good? Which obstacles and hoops should this patient jump through before we can do that? And sometimes, that's very clear. So, you'll say that someone has to be in mental health care, and well, they might live with their mother, so in that case, the mother has to be somewhat on board with it, too. Well, then, you know what you're working towards. But a lot of the time, it's more ambiguous. … How far should you go?*

How should MHPs relate to their gatekeeper role?

We can better understand Stefan's ethical uncertainty in the context of MHPs having dual ethical obligations in decision-making. Many MHPs, like Maria, explicitly spoke of how their responsibilities regarding guidance may come into conflict with those regarding assessment, or gatekeeping:

> *As a clinician, you have a strange role. On the one hand, you try to stand by your patient's side to find out, like, 'What do you need? And what is necessary for you to take that step towards medical treatments here?' On the other hand, you're indicating clients for treatment and deciding when that's happening. (Maria, MHP)*

MHPs were often cognizant of the effects their gatekeeping role can have on (the possibility of) forming a client-clinician partnership in decision-making. Here is Stefan:

> *I don't think it's good when patients feel like I'm an obstacle they must overcome. … I want to have a position in which I'm taking them along or guiding them in their trajectory in an expert role, but with the client as a second expert or something. But at the same time, these two [roles] are at odds … because in the end, you as a clinician, well—in the context of our team-based approach, of course—have to say something about whether there is or isn't Gender Dysphoria and whether or not we should treat. (Stefan, MHP)*

The above can give rise to a situation in which clients—due to pragmatic motivations or mistrust—may approach their MHP instrumentally, e.g., by refraining from divulging information MHPs consider important in decision-making. Stefan, for example, recounted a client who did not tell him about a dissociative identity disorder diagnosis out of fear of being rejected for mastectomy. As Marieke emphasized, such a breach of trust in the client-clinician relationship can have serious ethical consequences for (the quality of) decision-making: "When a client doesn't trust me because he's afraid that I've something to decide … I also can't determine what's going on or what he needs" (Marieke, MHP).

When should we delay or withhold treatment?

Finally, HCPs expressed ethical challenges and norms related to going against clients' wishes by withholding or delaying treatment. Although HCPs generally considered this undesirable, many shared the normative view that one should always be able to withhold or delay treatment. To ethically justify this, clinicians often refer to the principle of non-maleficence:

> *You know, you've made an oath that you want to do good and that you shouldn't harm. Sometimes that's… When somebody requests a treatment that I believe will do more harm than good, I'll explain that and won't go along. (Ellis, Endocrinology)*

HCPs expressed myriad reasons for delaying or withholding treatment, including doubt regarding the assessment of GI/GD, the conviction that co-occurring mental health concerns ought to be treated or monitored before and/or during GAMC, insufficient social and/or psychological resilience, and serious concerns about a client's ability to consent to treatment. Besides the normative view that one may only go against the wishes of the client when this is sufficiently substantiated and in their best interests, HCPs hold that they should communicate their rationale for doing so. The following quote illustrates how the latter may make shared decision-making possible even when the client's treatment request is not (yet) granted:

> *Yesterday, for example, I was able to explain and motivate very clearly why I didn't refer someone to an endocrinologist. And that person understood it, was able to follow it, and got it, too. She was disappointed, but we could talk about it with each other. And she agreed with the advice [to seek mental health care] and was going to organize it. And then I think: it's great that we could accomplish that together. (Marieke, MHP)*

How should we negotiate decision-making as a (multidisciplinary) team?

As in many healthcare contexts, decision-making in GAMC involves many stakeholders beyond the classic client-clinician dyad. HCPs with different disciplinary backgrounds have to relate to their clients, colleagues, teams, institutions, professional organizations (and their guidelines), and the broader socio-cultural-legal context. HCPs experienced ethical challenges, particularly in (a) determining their specific responsibility in multidisciplinary decision-making and (b) handling (multidisciplinary) decision-making dissensus.

What should be my specific responsibility in multidisciplinary decision-making?

As Mike explained, decision-making in GAMC consists of different tasks or elements that are shared among various professionals and disciplines:

> *It is very different if you [as an MHP] are exploring with a patient whether a particular diagnosis fits their situation or whether you [as a somatic HCP] are discussing with someone whether we'll perform a specific surgery. … That's shared decision-making of a completely different caliber. (Mike, Plastic Surgery)*

The latter entails that decision-making in GAMC encompasses a variety of multidisciplinary processes and responsibilities. Indeed, HCPs distinguish between "psychological" and "medical/somatic" duties in decision-making that tie into but are also distinct from each other:

> *As a [somatic] medical doctor, I feel I should only prescribe something if I can support it and believe it will benefit someone. And, the way I see things is that it's just really great that a psychologist has already determined whether treatment is the right step for a client. And that I, based on [the MHP's] advice combined with my endocrinological point of view, get to decide whether to start treatment. (Tim, Endocrinology)*

Tim holds that he should only initiate treatment when he agrees with it. In reaching this judgment, however, he appears to rely heavily on the MHP's assessment, highlighting the interrelated nature of various (multidisciplinary) decision-making processes. An implicit ethical question we identified here is: How should these different (multidisciplinary) decision-making processes be integrated, and what professional/discipline should carry what responsibility?

How should we handle (multidisciplinary) decision-making dissensus?

MHPs considered it crucial for the multidisciplinary team to agree with a treatment decision they reached with their clients:

> *I'll explain [to my client] that the team has to be on board. So, there can be a situation where I'll tell a patient, 'Yes, to me, it's clear, but I wonder how I'm going to sell it to a team of medical doctors and psychologists who don't know you.' (Jasper, MHP)*

This fragment illustrates Jasper's anticipation of potentially differing views regarding decision-making between him and the multidisciplinary team, the implicit normative assumption being that there ought to be general support from the team for a treatment decision. This may play into a state where MHPs are reluctant to share certain case specifics with their team. As Will shared:

> *[T]o some extent, what I'll share in a [multidisciplinary] team meeting, I'll filter to what I think people want to hear. And that's what I call the peculiar paradox of a gatekeeping model I take to my meetings. … That I guess I shouldn't say too much. … I'm convinced that my omitting, or telling some details differently, will lead to another decision. Well, it's not always clear-cut, but my strategizing is increasing, and I find that pretty annoying. (Will, MHP)*

Conversely, diverging normative convictions regarding decision-making may be acknowledged, understood, and discussed:

> *We weren't really on the same page about how to continue [in the case of a client with co-occurring psychiatric problems who suffered from complications following phalloplasty]. The surgeons said, 'Well, should we even perform surgery again?' And I understood why they found that difficult when looking at his resilience and how he dealt with his complications, especially considering that a second surgery carries the same—or perhaps an even higher—risk of complications. On the other hand, I felt that because we've said 'A,' we ought to say 'B,' too, because otherwise, we would've just left him hanging. … So, it felt tough that we didn't try it one more time, while I really understood my colleagues' arguments. (Maria, MHP)*

In grappling with whether performing surgery (again) is ethically permissible, Maria has to weigh her commitment to values such as trustworthiness against the surgeons' reference to non-maleficence. In this specific case, this balancing act is made more difficult by four contextual factors, i.e., a high complication risk, the severity of suffering, the client's co-occurring mental health concerns, and, as this MHP mentioned, his failure to understand the surgeons' hesitance to perform surgery again. This quote also illustrates how HCPs and MHPs may engage in different decisional relationships with their clients that correspond with differing responsibilities, values, and norms. An implicit ethical challenge we identified here is: How should these diverse relationships and corresponding obligations, values, and norms be integrated into (the various steps of) the decision-making process?

How should we navigate between various decision-making temporalities?

In the quotes above, various temporalities carry implicit or explicit normative valence in decision-making. Ethical challenges arose, particularly around (a) potential future concerns in current decision-making and (b) potential future consequences of treatment on values relevant to decision-making.

How should we grapple with (potential) future concerns in current decision-making?

GAMC encompasses a variety of potential treatment steps (e.g., masculinizing hormones, mastectomy, genital surgery) that are conceptualized as separate modalities with different psychosocial and physical eligibility criteria but also function as parts of a whole. In practice, this can lead to ethical challenges, for example, regarding the "stepwise" approach to decision-making:

Well, I always try to keep the big picture [of the client] in the back of my mind. But the way we decide about treatment, so when you're talking about decision-making, is really step-by-step. … We approve *this* step, and the client can't derive any rights for future treatment from that approval. But OK, when I know that there's a clear wish for further treatment, I'll consider that. I find that very complicated now and then because I've patients who say from the get-go, "Just give me those hormones, then at least I have something," while I worry: How are we to move forward from there? I've three or four [clients who have started hormone treatment] in my caseload who are still not eligible [for surgical treatments] five years down the line. (Maria, MHP)

Consequently, Maria feels she has an ethical duty in decision-making to prevent clients from getting "stuck in the middle." Hence, like Ellis, many HCPs found it "very important… that the timing of the start of treatment is right" (Ellis, Endocrinology). Yet, determining the right timing may pose challenges. Marieke, for example, shared how she experienced difficulty deciding whether a client with co-occurring mental health concerns should seek psychological care before starting GAMC and who should determine this. In handling this ethical challenge, she explicitly took into account potential future consequences of (her role in) decision-making: "What's worse? Referring someone for hormones when you're worried that person will become even more unstable, or postponing [hormone treatment] and having that make them unstable. That's a really tough call sometimes" (Marieke, MHP).

How should we do justice to (potential) future consequences of treatment?

Wietske explains how she anticipates the way time, treatment, and lived experience may change clients' values and preferences regarding said treatment:

> *When you take the example of a relatively young person who has always felt a great aversion towards their genitals, and they say: 'Well, I don't want to have sex; I want a shallow vagina [i.e., vulvaplasty],' then that's possible, but I find it complicated when it concerns someone in their twenties. … Look, you can't just deepen a vagina during a second surgery … And if you've had an operation that causes your*

> *aversion to subside, you may start to think differently about sex. And then you've decided on a situation you might not have been able to imagine. In those cases, I don't say 'no,' but I give extensive information about the pros and cons, and I want someone to think it through before we decide. Look, I'm not talking about someone convinced and says, 'I don't want to take risks, and I'm overweight and in my sixties, and I just can't be bothered.' To me, that's a different story than someone who's 25. So, what I tend to do in these situations when someone is 25, is I'll give them very detailed information, and I'll say, 'You'll have another consultation with a surgeon, and then you've thought about it, and you can decide together.' And then I don't decide but postpone. (Wietske, Plastic Surgery)*

Wietske appears to face the following ethical question: What should be the impact of potential future consequences of treatment on (my role in) decision-making in the here and now? In grappling with this question, she refers to various temporalities carrying normative valence: possible treatment outcomes, effects, calendar age, and the prospective preclusion of other surgeries. Ultimately, she handles this ethical question by thoroughly informing clients, involving more stakeholders in decision-making, and employing yet another temporality, i.e., delay.

We identified how many ethical challenges and norms described arise in a context characterized by uncertainties regarding (a) GAMC and (b) GI/GD. Indeed, HCPs in GAMC have to navigate various uncertainties and corresponding contestations concerning the object of care and its treatment.

Uncertainties regarding GAMC

We found that diverse HCPs related their ethical challenges and norms regarding decision-making to uncertainties and contestations related to GAMC, particularly its guidelines, evidence, and outcomes.

Uncertain guidelines

Many HCPs, like Mike, believe it is important to establish limits to decision-making through the use of guidelines, for example, through stringent criteria concerning BMI and smoking:

> *Setting boundaries as a clinician is essential. You know, a BMI of 30 is a BMI of 30 and not a BMI of 30.5. When someone smokes, they have to stop, and you shouldn't be like, 'It's OK; two cigarettes won't make much of a difference.' No, you should treat everyone the same. Don't set a precedent, … [but] within these boundaries, there are many options. (Mike, Plastic surgery)*

This quote exemplifies how HCPs may invoke eligibility criteria to substantiate and solidify ethical norms regarding decision-making (i.e., we should treat likes alike/not set a precedent), marking both real and perceived boundaries of decision-making.

However, other HCPs question the certainty of such guidelines, highlighting how firm boundaries may give rise to ethical uncertainties. Sara, for instance, challenges the criterion that clients are only eligible for genital surgery after a year of hormone therapy:

> *You start to work here, and this is the guideline we use, which is, of course, European and worldwide. … [B]ut it makes me think, like, why do we take this route, and why is it a year and not nine months? Or a year and three months? Why don't we tailor it to the client's needs? (Sara, Nursing)*

Sara's ethical question could be formulated as: Are current guidelines curtailing client involvement in and personalization of decision-making ethically justifiable?

Uncertain evidence

Often, HCPs seek to refer to (biomedical) evidence to support and justify criteria, guidelines, and treatment decisions. Although the field of trans medicine is working towards increasing its biopsychosocial knowledge base, many clinical questions remain unanswered. The latter may lead to contestation in the client-clinician decision-making relationship and ethical challenges regarding decision-making:

> *We don't have any literature on these specific lab results and corresponding risks. So, I tell my client, 'We just don't have the evidence!' And she asks, 'But then, what are you basing your recommendations on?' So, I say, 'On our guidelines; we have to stick to our guidelines. Studies have found that long-term exposure to high [hormone] levels can lead to problems.' And she just couldn't do anything with that because she found it too general. She stuck to her position and said, 'No, I'm not going to lower my dose.' And I wondered, where does my responsibility end, and where does the patient's begin? … What I'm leaning towards is that if I've clearly explained the risks, and she still decides to use more, then that's her responsibility. (Tim, Endocrinology)*

Tim grapples with ethical questions such as: Who should carry the ethical responsibility for the potential risks of elevated hormone levels? An implicit question we identified here is: What, if any, should count as sufficient (biomedical) evidence to warrant or necessitate a different approach to this decision-making disagreement?

Uncertain outcomes

These questions point to another challenging characteristic of GAMC: the notion that the *effects and outcomes* of a treatment decision are—to some extent and especially on an individual level—uncertain and unpredictable. The latter can give rise to especially pressing practical and ethical challenges in the context of decision-making with non-binary clients:

> *[T]he most complicated are, of course, clients that say, 'I want to look more [gender] neutral,' because you just can't with these hormones. You know, you can't choose a bit of*

> *this and a bit of that. … So, you find yourself in a difficult situation [when a client says], 'Yes, I do want a lower voice, and then I'll just take the increase in hair growth for granted.' Yes, I find that really tough, like, are we doing the right thing or not? (Jasper, MHP)*

Uncertain treatment outcomes may not only complicate decision-making but also lead to ethical contestation and distress in the context of the client-clinician decision-making relationship:

> *What makes it difficult is that it's not a black-and-white thing. You can't say, 'If you're depressed and your mother is not on board, it's a no.' You can only say, 'I reckon it's important that you do this or that first.' Well, of course, a patient will think, like, 'What the fuck? You think? I think differently, and it's my decision, so leave me alone.' (Jasper, MHP)*

We identified the following implicit ethical questions: In the absence of unequivocal evidence and individual predictors, should clinicians withhold or delay treatment to prevent potential adverse outcomes? How should the potential benefits of GAMC be weighed against its potential harms? How should these benefits and harms be defined? And who ought to weigh them?

Uncertainties concerning GI/GD

Furthermore, we found uncertainties regarding GI/GD to impact ethical challenges in decision-making. Many HCPs referred to GI/GD as a complex problem or phenomenon. For example: "Interviewer: If one of your clients asks you, 'What is Gender Dysphoria?' what would you tell them? Jasper (MHP): Gosh. I'd say, 'What a shitty question.'" Part of what makes this such a shitty question has to do with GI/GD being ambiguous and challenging to prove. Marieke (MHP) said: "When we're talking about decision-making, the hard thing is that it's all based on something we can't measure." Indeed, HCPs are critically aware of the absence of a validated marker: "Can we scan someone and say, 'You've got Gender Dysphoria?' Well, I don't think so, I'm inclined to say" (Will, MHP). The notion that GI/GD is ontologically ambiguous and epistemically inaccessible has severe ramifications for the establishment of its boundaries and its assessment.

Uncertain boundaries

Questions related to the boundaries of GI/GD mainly surfaced when clinicians spoke of non-binary clients. Indeed, the diversification of gender identity/expression and the influx of non-binary clients in GAMC gives rise to ethical challenges in decision-making. Consider the following fragments:

> *When people just want a mastectomy, now they can. I've some clients who are non-binary and who suffer terribly from having breasts. But can you really make Gender Dysphoria out of that? For example, I have a client who says, '75 Percent of the time I feel like a man and suffer from my breasts, but the other 25 I feel like a woman and then I don't,' who still wants a mastectomy. Well, I find that really complicated. (Marieke, MHP)*

And:

> *The tricky thing is that some requests are hard to imagine … [like] patients who don't want [their] nipples [placed back after mastectomy]. … Yes, well, maybe that's due to my limited views and the fact that I tend to think in terms of 'men' and 'women.' At the same time, there are no animals in nature without nipples. So, men and women have nipples. Why do you [i.e., the client] feel the need to be different? And so, we said, we think that's just too odd. Some people just want to be different for the sake of being different. We shouldn't abuse a medical transition for that. … Or people who want both a phallus and a vagina. … Are these my limitations, or is that just a really strange request? (Mike, Plastic surgery)*

These fragments illustrate how uncertainty and contestation as to whether HCPs can understand a particular treatment request in the context of GI/GD may give rise to feelings of ethical uncertainty regarding decision-making. Indeed, clients requesting nippleless chests or both male and female genitals confront Mike and make him reflect on his implicit binary norms and values regarding gender identity and expression.

Uncertain assessment

The inability to measure, visualize, or otherwise "prove" GI/GD poses obvious practical and ethical challenges. One of these is that many HCPs consider GI/GD to be something that could be something else. In other words, clients may be mistaken about their condition:

Sometimes there are people who really shouldn't [have GAMC] but are convinced they are [gender dysphoric]; where it turns out that—in the end—it was a good decision *not* to start [GAMC]. People who really believe they're gender dysphoric aren't always. (Marieke, MHP)

MHPs mentioned "trauma," "autism," or "psychosis" as potential explanations for (something that at first glance may appear as) GI/GD. Many MHPs feel an ethical obligation to establish how these phenomena (inter)relate and differentiate between "authentic" or "real" GI/GD and other potential "causes." Indeed, most MHPs held the ethical norm that as long as there is uncertainty as to whether some other phenomenon could explain GI/GD, a careful approach to decision-making is warranted. Such an approach is often anchored in the principle of non-maleficence and the corresponding norm that adverse outcomes such as regret should be prevented:

> *I find it important that people whose gender dysphoria is caused by psychiatric problems are identified quickly. It doesn't happen often, but I've experienced it over the past years when it became clear that Gender Dysphoria, or alleged Gender Dysphoria, was caused by a psychotic disorder, for example. … And that's bad because if the psychosis were to be left untreated … [GAMC] could lead to feelings of regret. (Stefan, MHP)*

Yet, many HCPs, like Stefan, also question the possibility of genuinely diagnosing GD:

> *Well, you know what's difficult is that we're talking about identity, which is challenging to classify in terms of whether it's there or not. And, well, how someone experiences their identity is highly subjective and, by definition, true because someone feels it that way. Yet, in the diagnostic phase, we try to assess whether that's right. That's what I find difficult. (Stefan, MHP)*

As Will shared, the uncertainties concerning diagnosis may have consequences for the establishment of rapport and trust in the client-clinician decision-making relationship:

> *Well, I've spoken to many people over the years who ask me, 'Look, what do you want to hear?' To which I respond, 'Well, your story,' so to speak. And then people say, 'No, you're not! You say you are, but what you want to hear is that I've suffered from Gender Dysphoria for a long time; that I meet two out of seven DSM criteria because then I have the diagnosis; that I suffer tremendously; and that I haven't felt like a man but a woman since years long past and I would've preferred to have been born a woman; and that I don't have any problems, or at least not too many. That's what you want to hear!' (Will, MHP)*

Indeed, this fragment illustrates how uncertainties regarding GI/GD may propel (largely implicit) normative assumptions about what GI/GD is or should be and, consequently, ethical challenges related to decision-making.

Discussion

This qualitative interview study investigated the ethical challenges and norms regarding the decision-making of HCPs working in Dutch GAMC. These pertain to the following overarching ethical questions: (1) How should we weigh respect for clients' self-determination against a duty to non-maleficence in decision-making? (2) How should we negotiate decision-making as a (multidisciplinary) team and (3) navigate various decision-making temporalities? We elucidated that these ethical challenges and norms arise in a context characterized by epistemic and normative uncertainties (and consequently, contestations among stakeholders) regarding (1) GAMC's guidelines, evidence, and outcomes and (2) the boundaries and assessment of GI/GD. Given these distinct characteristics, making and sharing decisions regarding GAMC is arguably characterized by context-specific and inherent moral and normative dimensions (Gerritse et al., 2018; Hartman et al., 2019; Vrouenraets et al., 2020).

Clients, policymakers, and professional bodies increasingly advocate the principles of shared decision-making as an ideal when more than one medically reasonable option is available, and the role of stakeholders' values and preferences in decision-making is amplified (Elwyn et al., 2016; Stiggelbout et al., 2015). In light of the above, the appeal for shared decision-making in GAMC (Clark et al., 2021; Eyssel et al., 2017) is not surprising. Conceptually, shared decision-making has its place between informative and paternalistic decision-making and stresses the importance of personalized care, client-clinician partnership, and shared responsibility for outcomes (Elwyn et al., 2016). Shared decision-making is often operationalized as a sequential and deliberative process consisting of (1) introducing choices and eliciting goals ("team talk"), (2) comparing and weighing alternatives ("option talk"), and (3) discussing decisional role preference and decision-making ("decision-talk") (Elwyn et al., 2016). In what follows, we reflect on our findings and provide normative reflections and recommendations for (shared) decision-making in GAMC. Finally, we outline the limitations of our study and suggest corresponding avenues for future research.

Maneuvering roles, duties, and moral distress in shared decision-making

The first theme illustrates how decisional roles and boundaries in the client-clinician dyad may be ethically ambiguous, with HCPs having to straddle respect for clients' self-determination with their duty to non-maleficence. In line with Dewey (Dewey, 2013) our respondents identified shared decision-making as a general best practice in GAMC but also expressed how they found it unattainable with, or not in the best interests of, specific clients. Indeed, our findings show how HCPs implicitly adopt various decision-making models. They may engage in informative and deliberative decision-making with so-called "(relatively) good functioning" clients while opting for a more paternalistic approach vis-à-vis clients whom they characterize as "complex," e.g., those with co-occurring mental health concerns or low social/psychological resilience (Emanuel & Emanuel, 1992). Like others have shown in neonatology and end-of-life care (Prentice & Gillam, 2018), our findings illustrate how the call or desire for shared decision-making may lead to moral distress when HCPs feel it is not in line with (their assessment of) the client's best interests. However, HCPs' conception of clients' best interests and their doubts and reasoning behind the decision to (not) share decision-making with clients often remain implicit and under-discussed with clients.

The above has consequences for shared decision-making in GAMC. Clark et al. (Clark et al., 2021) identified open communication as necessary for shared decision-making with trans youth. Its absence may constitute a breach of the client-clinician partnership and have serious ethical consequences for the quality of decision-making, the possibility of shared decision-making, and, thus, the realization of *good* care (Dewey, 2013; Gerritse et al., 2018). The latter entails that the (motivations for/doubts about a particular) decision-making approach should be made more explicit, shared, and discussed with clients. The first step towards *good* (shared) decision-making in GAMC is to foster the clarification of the local decisional context and deliberation of stakeholders' normative assumptions, perspectives, and preferences concerning (shared) decision-making. This is in keeping with those stressing dialogue and dialogical consensus as the moral basis for shared decision-making (Walker, 2019) and its guiding ethical principles, i.e., self-determination and relational autonomy (Elwyn et al., 2016).

Sharing decision-making in a (multidisciplinary) team

The second theme highlights how decision-making in GAMC involves stakeholders beyond the archetypal client-clinician dyad and deals with more than a single treatment decision. Today's GAMC combines psychosocial care, hormone therapy, and gender-affirming surgeries, often provided by multidisciplinary teams (Coleman et al., 2012). The latter poses complex ethical challenges concerning decision-making: How should multidisciplinary decision-making be shared among MHPs, somatic HCPs, and clients? Who should have what role and responsibility? These various multidisciplinary decision-making roles and responsibilities may conflict, while HCPs often seek (multidisciplinary) team consensus. Our findings show how the latter may also impact (the possibility of) sharing decisions in the client-clinician relationship. Indeed, the multidisciplinary team having final decisional authority may limit the dyad in attuning decisional roles and frustrate the requirement for open communication (Clark et al., 2021; Walker, 2019)

The above has implications for shared decision-making in GAMC. First, HCPs should discuss multidisciplinary decisional roles, responsibilities, and processes. As GAMC is a dynamic field, it may benefit from iterative deliberation on questions such as who should introduce choices, elicit goals, and compare and weigh alternatives; in other words, who is involved in (shared) decision-making, when, and with what purpose (Elwyn et al., 2016) Another critical question is to what extent shared decision-making in GAMC should allow for dissensus between HCPs. Given the inherent moral dimension of GAMC, stakeholders will inevitably dissent. Our findings (pp. 87–89) illustrate how acknowledging (multidisciplinary) dissensus and discussion of its underpinning value conflicts may aid in pinpointing what good care and decision-making entail. Therefore, sharing and developing best practices concerning identifying and handling (multidisciplinary) dissensus may prove more worthwhile than concealing it.

The impact of time on (shared) decision-making

The third theme foregrounds the role of time in these various decision-making processes. We may best understand decision-making in GAMC as a stepwise process comprised of multiple interconnected decisional moments (Gerritse et al., 2018). Our findings demonstrate how different temporalities (e.g., calendar age, waiting time, potential projected futures) normatively impact decision-making. Most notably, HCPs regularly took into account possible future consequences of treatment in current decision-making to minimize harm, such as regret. However, our findings indicate that the question of what harm entails, how it is weighed against benefits, and by whom often remains unclear. Others have questioned to what extent such a consequentialist decision-making approach fits GAMC. McQueen (McQueen, 2017) for example, argues that as decisions in GAMC concern "personally transformative treatments" and have inherently unforeseeable effects, the possibility of post-treatment regret should have no bearing on the decision-making process. He proposes a more deontological approach, i.e., assessing whether the client has good reasons to want treatment during decision-making. While the HCPs we spoke to uniformly acknowledged the impossibility of foreseeing the consequences of decision-making, they utilized divergent tactics to manage or cope with it.

The above has implications for shared decision-making. First, shared decision-making presupposes that after the introduction of choices, comparison of alternatives, and the discussion of decisional roles, the client and HCP come to a shared decision. How should shared decision-making be adapted to a series of decisions that are also a part of an overarching decision-making process? We argue that these parts and processes should be elucidated to facilitate the iterative calibration of shared decision-making and decisional roles between the client, HCPs, and other stakeholders. A guiding question for practice could be: What should be our decisional roles *in relation to this* particular decision, and how do these relate to the overall decision-making process? Next, a fundamental challenge to be grappled with is the impact of potential future consequences, such as harm—particularly regret—on current decision-making. Exploring this question further in conceptual and empirical-ethics research involving diverse stakeholders could prove fruitful. How do various stakeholders define harm and/or regret? What should be the normative consequences of the possibility of harm/regret in the (shared) decision-making process?

Uncertainties regarding GAMC and GI/GD

Hypotheses abound as to what underpins these various ethical challenges regarding decision-making in GAMC. These range from an inconsistent interpretation of clinical guidelines, insufficient formal education, and little institutional support for GAMC (Dewey, 2013) to a lack of evidence regarding (long-term) risks of GAMC, uncertain expertise, and the fear of relinquishing medical power (shuster, 2021). Our findings suggest that these ethical challenges arise in the context of uncertainties (and corresponding contestations) regarding GAMC and GI/GD.

Uncertainties regarding GAMC

The growing but relatively small evidence base of GAMC and the inherently unpredictable effects and outcomes pose an obvious challenge to a core feature of shared decision-making, i.e., weighing benefits and harms. The latter, in turn, exacerbates ethical challenges concerning decision-making. We found that HCPs responded to this differently. While some acknowledged it, others appeared to mobilize implicit or explicit normativity to contain it. As Cribb notes: ethical challenges, such as ethical uncertainty, are potentially very destabilizing in medicine as they are "pervasive and because [they may be] hard to resolve" (Cribb, 2020). He illustrates how they are often contained through (implicit) normativity, i.e., (unstated) assumptions regarding what is good and bad in routine practice. This is in line with our findings. Take, for example, the contestation regarding the importance of BMI criteria for specific surgical interventions (pp. 91–92). The two quotes are arguably an acknowledgment of, and a means to contain ethical challenges regarding decision-making, respectively. Indeed, the ethical question the guidelines arguably help to control *and* prompt is how various considerations in decision-making about GAMC in those with a certain BMI (e.g., regarding the impact of GI/GD, the risk of complications) ought to be weighed and by whom.

Uncertainties regarding GI/GD

We observed a similar dynamic concerning uncertainties regarding the object of care: GI/GD. The inherently subjective nature of GI/GD and corresponding uncertainty regarding its assessment, as well as uncertainty as to whether a particular set of phenomena can be understood as GI/GD, may compound ethical challenges regarding decision-making. Here, too, (implicit) normativity may be mobilized to manage ethical challenges. An example we identified in previous observational research (Gerritse et al., 2018) is the use of the so-called "early-onset narrative," a colloquial set of client characteristics that lodges the etiology of GI/GD in (early) childhood, implicates a stable trans identity and consequently offers reassurance to HCPs in decision-making. The surgeon who struggled to determine whether he could understand a particular non-traditional treatment in the context of GI/GD (p. 94) illustrates how normativity may function to manage ethical challenges regarding decision-making. In both examples, critical questions from colleagues, clients, or interviewers resulted in HCPs' normativities becoming the subject of deliberation. The latter shows how (implicit) normativity may help to contain, but also prompt, ethical challenges regarding (shared) decision-making.

We concur with Cribb that (implicit) normativity "should not be lazily valorized, that is, seen automatically as either a bad thing (obscuring important ethical questions) or as a good thing (preventing an explosion of contention)" (Cribb, 2020). We described how (implicit) normativities regarding GAMC and GI/GD pre-structure the moral environment in which ethical challenges and norms regarding decision-making manifest. We are also amenable, however, to others such as Berger (Berger, 2015). He argues that HCPs should acknowledge and discuss uncertainties to ensure shared decision-making applies to real-life clinical encounters. Given the diversity of the transgender population, and as individual tolerance for uncertainty in shared decision-making differs (Medendorp et al., 2021), its omnipresence in GAMC arguably necessitates a balancing act between mindful obfuscation and reflective illumination.

The contribution of CES for (shared) decision-making in GAMC

Our respondents indicated a clear need for support in recognizing and handling (shared) decision-making-related ethical challenges. CES aims to support HCPs and clients in dealing with ethical issues in clinical practice, thereby improving stakeholders' quality of care, cooperation, and moral competencies. CES may be provided through different services (e.g., ethics consultation, ethics committee, moral case deliberation) with varying aims, methods, and theoretical backgrounds (Hartman et al., 2018). Increasingly, CES is offered in GAMC in the form of ethics consultations (Mabel et al., 2019) and Moral Case Deliberation (Vrouenraets et al., 2020). Furthermore, CES may be integrated and interwoven into daily practice (Hartman et al., 2019), for example, through the co-creation of theme- and practice-specific ethics support tools (Hartman et al., 2018; van Schaik et al., 2022).

The findings presented above will provide the starting point for dialogue sessions with MHPs and clients aimed at co-creating a CES tool for (shared) decision-making in GAMC.[11]

It is interesting to note how several of our respondents started reflecting on, questioning, and reevaluating the moral dimension of their decision-making practice during the interviews. The latter illustrates how research can be a tool for CES in and of itself.

Limitations and related recommendations for future research

This study is not without limitations. First, the semi-structured character of the interviews contributed to the depth of our findings as it allowed for the verbalization and identification of ethical challenges and norms that often remain implicit. However, although our conclusions corroborate a previously conducted focused ethnography (Gerritse et al., 2018), they cannot be considered direct reflections of the practice we sought to understand (Green & Thorogood, 2014). Indeed, our interview findings should be interpreted cautiously, being inevitably (re)constructed—in memory, dialogue, and at a specific time.

Second, the findings of this paper provide an in-depth exploration of decision-making-related ethical challenges and norms experienced by HCPs working in Dutch institutional contexts where clinical guidelines are currently based on WPATH's SoC7 (Coleman et al., 2012). Qualitative research in other socio-economic, cultural, social, and geographical contexts on similar and different service delivery models (Wylie et al., 2016) should be conducted to complement and contrast our findings. The scope of future research should do justice to the breadth of actors implicated in decision-making in GAMC. Given the paucity of literature, studies on clients' ethical challenges and norms should be prioritized.[12]

Third, the double role of two authors as both researchers and MHPs in GAMC may have helped sensitize responsiveness to practice and build rapport with respondents, but it could also have increased the likelihood of interviewer/researcher bias. To attenuate the latter and enhance the credibility of our findings, we engaged in recurring reflexive dialogues among the research team and conducted a member check, i.e., a presentation and discussion of our findings during a policy day of HCPs in Dutch GAMC.

Fourth, we acknowledge that the *implicit* ethical challenges and norms we describe are our interpretations of the data. The latter entails that they might not always be experienced or shared by our respondents or readers. By offering (methodological) transparency regarding our approach, we hope to provide space for constructive disagreement and dialogue.

Fifth, we stress that this paper offers a descriptive lens on these ethical challenges and norms without the ambition to settle them normatively. The latter is in keeping with our dialogical approach to ethics which strives for moral learning through joint critical engagement and reflection rather than an outsider's moral judgment (Widdershoven et al., 2009).

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[11] We report on the co-creation process of this theme and practice-specific CES tool in a separate manuscript.

[12] We report on client's ethical challenges and norms regarding decision-making in a different manuscript.

Conclusion

The discussion of what constitutes *good* (shared) decision-making in GAMC is in full swing. To contribute to this discussion, we elucidated the ethical challenges and norms of HCPs, particularly MHPs, regarding decision-making in GAMC. Our findings illustrate how decision-making in GAMC is ethically complex and dynamic. It is best understood as an ongoing dynamic process constantly, yet often implicitly, negotiated among and distributed across various stakeholders, places and times. The latter defies the archetypal client-clinician decision-making dyad and the notion of a single decision-making moment.

The multidisciplinary and temporal structure of GAMC entails that decisional role(s), responsibilities, and values may be opaque and come into conflict. Furthermore, we expounded how the context of (shared) decision-making in GAMC is rife with uncertainties and corresponding contestations. On the one hand, clients' and HCPs' values and norms regarding treatment are ever-changing due to the diversification of treatment options and shifts in socio-cultural discourse concerning gender(diversity). On the other hand, the subjective and ambiguous nature of GI/GD complicates assessment and establishing its boundaries. Given these distinct characteristics, (shared) decision-making in GAMC is arguably characterized by context-specific and inherent moral and normative dimensions.

Consequently, ethical challenges and normative divergence are arguably inevitable. The implications of the latter should not be underestimated: our findings indicate that—particularly underacknowledged—ethical challenges may put a significant burden on the client-clinician and clinician-team relationship, (shared) decision-making, the organization of care processes and, in the end, the quality of care. This underscores the need for more awareness of and sensitivity toward the inherent ethical challenges, normativity, and contextual uncertainties regarding decision-making. We argue that working towards *good* (shared) decision-making necessitates the joint identification and handling of ethical challenges and an open, reflective, and ongoing dialogue between clients and clinicians and among (multidisciplinary) teams. CES seems to offer promising means towards these ends and may consequently allow for more explicitly deliberated and justified (shared) decision-making.

Declarations

Ethics approval and consent to participate

The methods used to carry out the study followed the Declaration of Helsinki and all other relevant guidelines. We submitted the study protocol for review to an officially accredited IRB/REC, the Medical Ethics Committee of the Amsterdam UMC, location VUmc, which issued a declaration that under Dutch law, a full ethical review was not necessary (IRB00002991, April 21, 2020). We informed eligible respondents via e-mail about the study and their rights at least a week before the interview. We emphasized that participation in the study was voluntary and that participants could withdraw from the study at any moment. We provided the opportunity to ask questions and obtained written informed consent before the interview. We also obtained oral informed consent at the start of the interview after reiterating the study objectives and data management. Given the relatively small number of clinicians working in Dutch GAMC, privacy and anonymity were subject to concern. We preserved participant anonymity (and, by extension, that of their clients) in this writing by using pseudonyms. Furthermore, we omitted the locations of the participating institutions, some demographic characteristics such as age and gender, and specifics regarding cases or HCPs' current positions.

Competing interests

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Authors' contributions

K.G. drafted and revised the study protocol and design, recruited the participants, and took the lead in drafting and revising the manuscript. K.G., B.K., C.M., and B.M conducted interviews. K.G., M.B., B.K., C.M. and B.M. revised the study protocol and design, coded, analyzed, and interpreted the data, and revised the manuscript. F.B. provided methodological assistance and contributed to the analysis. All authors revised the work critically for intellectual content, approved the version to be published, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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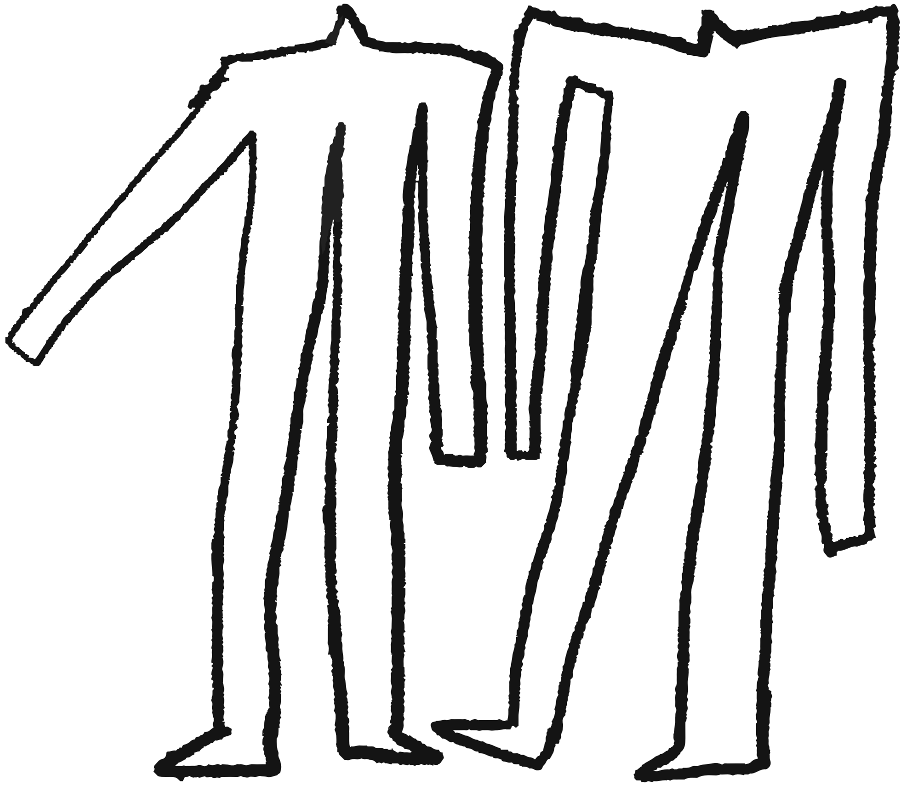

Chapter 5

Decision-making approaches in transgender healthcare: Conceptual analysis and ethical implications

Gerritse, K., Hartman, L. A., Bremmer, M. A., Kreukels, B. P. C., Molewijk, A. C. (2021). *Medicine, Health Care & Philosophy* 24(4), 687-699.

Abstract

Over the past decades, great strides have been made to professionalize and increase access to transgender medicine. As the (biomedical) evidence base grows and conceptualizations regarding gender dysphoria/gender incongruence evolve, so do ideas regarding what constitutes good treatment and decision-making in transgender healthcare. Against this background, differing care models arose, including the "standards of Care" and the so-called "Informed Consent Model." In these care models, ethical notions and principles such as "decision-making" and "autonomy" are often referred to but left unsubstantiated. The latter not only transpires into the consultation room where stakeholders face many different decisional ethical challenges but also hampers a more explicit discussion of what good decision-making in transgender medicine should be. This paper aims to clarify the conceptual and normative assumptions regarding decision-making and client autonomy underpinning the "standards of Care" and "Informed Consent Model" currently used in transgender care. Furthermore, we illustrate how this elucidation aids in better understanding stakeholders' ethical challenges related to decision-making. Our ethical analysis shows how distinct normative ambiguities in both care models influence decision-making in practice and how foregrounding one normative model for decision-making is no moral panacea. We suggest that the first steps toward good decision-making in gender-affirming medical care are acknowledging its inherent normative and moral dimensions and a shared, dialogical approach to the decision-making process.

Introduction

Transgender (trans)[13] persons often experience an incongruence between their gender identity and sex assigned at birth. In recent history, healthcare professionals took this incongruence to justify the need for psychiatric hospitalization and reparative psychotherapy (De Cuypere & Gijs, 2014; Suess Schwend, 2020). Over the last decades, however, significant shifts in conceptualization and classification dovetailed with the emergence of more affirming care approaches (Beek et al., 2016; Suess Schwend, 2020). Currently, many trans people use hormones and/or seek surgery to express their experienced gender (Coleman et al., 2012).

The field of gender-affirming medicine is characterized by a growing yet relatively slim (biomedical) evidence base, a great diversity of clients and treatment requests, and complex history and multidisciplinary organization of care (Coleman et al., 2012). The field is unique compared to other parts of the Western healthcare system in that a mental health professional often determines eligibility for medical treatment. Establishing eligibility includes the assessment of an inherently subjective phenomenon that is currently classified as both a mental disorder (American Psychiatric Association (APA), 2013)[14] and as a condition related to sexual health (World Health Organization, 2018).[15,16] These factors play into a state in which experts, clinicians, and clients often dissent when it is appropriate to initiate medical treatment, organize decision-making, and serve the client's best interests. In this convoluted context, various professional organizations provide guidelines for care, treatment criteria, and decision-making approaches (Coleman et al., 2012; Deutsch, 2016; Hembree et al., 2017; Reisner et al., 2015).

Currently, the most widely adopted care model is the Standards of Care 7 (SoC7) offered by the World Professional Association for Transgender Health (WPATH) (Coleman et al., 2012).[17] Criteria for medical treatment consist of a minimum age; persistent, well-documented gender dysphoria; capacity to make a fully informed decision; and the absence of uncontrolled co-occurring medical or mental concerns. According to WPATH, mental health professionals are best prepared to diagnose and assess eligibility given their specific training, and as medical treatment is intensive, often life-long, and (partially) irreversible. This arguably makes their role that of a "gatekeeper," a role that is not without ethical challenges (Fraser & Knudson, 2017; Schulz, 2018). Clients argue that "gatekeeping" interferes with "autonomous" decision-making (Bockting et al., 2010; Eyssel et al., 2017), while mental health professionals note the strain it puts on the therapeutic relationship, decision-making process, and consequently their ability to offer *good* care (Dewey, 2013; Lev, 2009).

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13. In this paper, we use "transgender" and "trans" interchangeably as umbrella terms referring to various forms of gender identities, roles and expressions that differ from those normatively expected of one's sex assigned at birth.

14. The APA, in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), has outlined criteria pertaining to the psychiatric diagnosis of Gender Dysphoria (capitalized) (APA, 2013).

15 The WHO, in the eleventh edition of the International Classification of Diseases (ICD-11), moved the classification of Gender Incongruence out of the "Mental and behavioral disorders" chapter and into the new "Conditions related to sexual health" chapter (WHO, 2018)

16. Regarding this inconsistency, experts in the field write: "The diagnostic classifications of disorders related to (trans)gender identity is an area long characterized by a lack of knowledge, misconceptions and controversy. The placement of these categories has shifted over time within both the DSM and ICD, reflecting developing views about what to call these diagnoses, what they mean, and where to place them" (Drescher et al., 2012, p. 568)

17. In various (multidisciplinary) clinics, the SoC are implemented in local care models

Seeking to foster "client autonomy," several community health centers developed an approach to decision-making that has become known as the "Informed Consent Model" (ICM) for transgender healthcare (Deutsch, 2016; Reisner et al., 2015; Schulz, 2018; Wylie et al., 2016).[18] In the ICM, clients may access medical interventions—particularly hormone treatment—without mental health evaluation and, in some cases, without a formal diagnosis (Schulz, 2018). The precedence attributed to self-determination curtails the health professional's role in decision-making to providing information about the risks and (side) effects of treatment and obtaining informed consent (Schulz, 2018). Here too, however, ethical challenges arise. For example: in the absence of a formal diagnosis and assessment of eligibility, how should the initiation of medical treatment be decided (Giordano, 2012)? Should this decision be based on self-determination or, for example, alleviation of gendered distress?

The SoC7 and ICM appear to differ significantly concerning how decision-making and client autonomy are conceptualized and normatively laden. In both care models, however, this remains largely implicit. For example, the SoC7 speak of "[assisting] clients with making fully informed decisions" (Coleman et al., 2012, p. 181), and the ICM stresses the value of "client autonomy" (Cavanaugh et al, 2015). These notions' specific interpretation and normative implications remain ambiguous: When is a decision *fully* informed? What understanding of "client autonomy" is intended, and how should clinicians do justice to it? These ambiguities feed into clinical ethical challenges related to decision-making (Dewey, 2013; Gerritse et al., 2018) and impede a more explicit dialogue regarding what *good* decision-making in transgender healthcare is or should be.

This paper aims to analyze decision-making and client autonomy in two care models for adult transgender healthcare through a conceptual framework of decision-making models and corresponding notions of client autonomy. Explicating the conceptual and normative assumptions regarding decision-making and client autonomy in the SoC7 and ICM will aid in better understanding clinical ethical challenges related to these care models. This conceptual analysis has ethical implications for the discussion of what *good* decision-making in transgender healthcare should entail. Taken together, the ultimate aim of this paper is to elucidate and ameliorate current decision-making practices.

This paper is structured as follows: First, drawing from conceptual and ethical literature, we provide a theoretical background of decision-making models and corresponding notions of client autonomy. Then, for both SoC7 and ICM, we describe the decision-making processes regarding gender-affirming medical treatments. Next, we elucidate what decision-making model and notion of client autonomy these models assume. Finally, we illustrate how this elucidation aids in better appreciating ethical challenges experienced by stakeholders in practice. We wrap up this paper by offering ethical implications for decision-making in transgender healthcare.

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[18] While acknowledging the myriad meanings and interpretations of informed consent (Beauchamp, 2011) we focus here on how "informed consent" is intended/operationalized in the specific context of the ICM for transgender healthcare.

Theoretical background: decision-making and autonomy

In this section, we discuss *informative, paternalistic,* and *deliberative* decision-making models and corresponding interpretations of the principle of autonomy (Emanuel & Emanuel, 1992). Decision-making models such as these build on previous work about the client-clinician relationship (Szasz & Hollender, 1956) and inspire current debates surrounding shared decision-making (e.g., Elwyn et al., 2012; Stiggelbout et al., 2015) and person-centered (Epstein & Street, 2011). For our theoretical background, we draw from Emanuel and Emanuel (1992), as these authors explicitly link decision-making models to notions of client autonomy. Next to the conceptual clarity their work offers, their decision-making models remain central to the fields of clinical and bioethics and medical decision-making.

In discussing decision-making models and corresponding notions of client autonomy, the distinction between positive and negative freedom is helpful (Berlin, 1969). Negative freedom is the absence of barriers, obstacles, or constraints from others (i.e., freedom *from).* Notions of "autonomy as negative freedom" aim to protect the agent from interference by others. Conversely, positive freedom seeks to enhance the agent's freedom to act and choose (i.e., freedom *to*). Interpretations of "autonomy as positive freedom" thus emphasize and seek to support the capacity of a person to be the authentic source of their decisions and to live life according to one's values, goals, and plans (Berlin, 1969).

The informative model and a liberal legal ideal of autonomy

In the *informative* model, the clinician should provide information (e.g., on disease state, benefits, and harms of treatment), so the client can select the treatment most aligned with her values. The clinician, in turn, executes the treatment chosen by the client (Emanuel & Emanuel, 1992). This model holds that clients know their values and need relevant (medical) facts to make the right decision. As such, the informative model leaves little space for clinicians' values or their interpretation of their clients'. In the informative model, the clinician is thus conceived of as a technical expert, while the client becomes a consumer whose autonomy is understood as the choice of, and control over, decision-making (Emanuel & Emanuel, 1992).

The informative model assumes a "liberal legal" notion of autonomy in line with Berlin's negative concept of freedom (Berlin, 1969). This interpretation of autonomy is also at the root of the (judiciary) doctrine of informed consent (Beauchamp & Childress, 2013). A liberal legal notion of autonomy protects clients from undue interference by others in decision-making by demanding respect for the client's integrity. Respecting autonomy in the context of an informative decision-making model implies a "negative obligation" on the part of the clinician to not constrain the client's decision-making process (Beauchamp & Childress, 2013). It thus addresses those treating the client rather than the client herself.

The paternalistic model and autonomy as critical reflection

In the *paternalistic* decision-making model, the clinician tests and determines the client's condition and subsequently decides what treatment is most likely to promote health and well-being. This model presumes shared, objective criteria for what is best and that a clinician, based on experience or professional status, may discern what is in the client's best interest (Emanuel & Emanuel, 1992). Emanuel and Emanuel write about paternalism in the context of the client-clinician *relationship*. The ethics literature often distinguishes between weak and strong, or hard and soft, paternalistic *decision-making*. Beauchamp and Childress, for example, define paternalism as: "the intentional overriding of one person's known preferences or actions by another, where the person who overrides justifies the action to benefit or avoid harm to the person whose preferences or actions are overridden" (2013, p. 178). According to these authors, weak paternalism refers to a situation where a clinician overrides—based on beneficence or non-maleficence—substantially non-autonomous actions. For example, when a decision is insufficiently informed, deliberated, or voluntary (Beauchamp & Childress, 2013). On the other hand, strong paternalism involves superseding a substantially autonomous client.

Strong paternalism usurps client autonomy and is justified by values such as protection (Beauchamp & Childress, 2013). Weak paternalism is arguably grounded on a positive interpretation of autonomy closely related to the notion of "autonomy as critical reflection" in Dworkin's 1988 theory of procedural independence. This notion of autonomy centers on the agent's ability to critically reflect upon one's (pre-reflexive) "first-order" needs, wishes, and desires and to align them to the values and preferences of a higher order. Acts and decisions are autonomous when agents can critically reflect on and identify with the influences that motivate them. Conversely, impulsive or pre-reflexive actions and decisions are not (Dworkin, 1988). In medical decision-making, this notion of autonomy asks the clinician to assess whether a client's decision is based on critical reflection and to what extent superseding is warranted.

The deliberative model and relational autonomy

In the *deliberative* model, the clinician seeks to aid the client in determining their health-related values (Emanuel & Emanuel, 1992). This requires the clinician to share information relevant to the client's clinical situation and help elucidate what values correspond to which treatment option. The client may then come to choose a particular treatment more reflectively. The clinician's objectives may be more normative and include proposing why specific health-related values are more worthy of aspiring to. Through moral deliberation and dialogue, the clinician and client determine the best treatment option. In this process, the clinician not only lays out the different possibilities but, while avoiding coercion, also suggests what is in the client's best interest based on deliberation.

Deliberative decision-making thus assumes a positive, "relational" notion of client autonomy which questions the idea of self-sufficiency and independence as principal moral values (Elwyn et al., 2012). Care ethics deems these latter values perilous as they obscure values such as trust, caring, and responsibility (Mackenzie, 2008; Verkerk, 2001). Care ethicists emphasize the need for relationships to see oneself as autonomous, rendering autonomy a notion that cannot be appreciated nor developed in isolation from interpersonal relationships and social communication (Verkerk, 2001). In a clinical context, "relational autonomy" stresses the clinician's positive obligation to take individual differences seriously to arrive at "genuine respect" (Mackenzie, 2008, p. 530). Respecting autonomy in relational terms requires the clinician to attune to the client and their needs actively. In decision-making, this process involves a consideration of thoughts, values, and corresponding treatment options through deliberation. It is reciprocal in that through an intention of mutual understanding, both client and clinician may arrive at new insights and revised values (Verkerk, 2001).

With this theoretical background on decision-making and autonomy, we now turn to two care models for transgender healthcare.

Care models: description and analysis

In this section, we describe the decision-making processes regarding gender-affirming medical interventions in the SoC7 and ICM and elucidate what decision-making and notion of client autonomy these care models assume.

Decision-making in the SoC7

WPATH has put forward its SoC since the end of the 1970s,[19] when its goal was to protect those seeking gender-affirming care and the providers' reputation (Fraser & Knudson, 2017; Wylie et al., 2016). The SoC has since become the leading care model for gender-affirming care. Currently, in its seventh iteration, the SoC7's overall goal is "to provide clinical guidance for health professionals to assist transsexual, transgender and gender-nonconforming people with safe and effective pathways to achieving lasting personal comfort with their gendered selves, to maximize their overall health, psychological well-being and self-fulfilment" (Coleman et al., 2012, p. 165).

The SoC7 outline options for (medical) care to alleviate gender-related distress, offered by a wide range of mental and somatic health professionals. The SoC7 are purposefully flexible[20] to meet a range of transgender healthcare needs. While providing more leniency than preceding versions (cf. de Cuypere & Gijs, 2014; Meyer et al., 2002), the current SoC7 strongly emphasizes the need for a comprehensive (mental health) assessment before clients may access gender-affirming medical treatments. Hence, the SoC7 foregrounds the importance of the role of a mental health professional in the decision-making process. The eligibility criteria for hormonal therapy and surgical treatment options are as follows (adapted from Coleman et al., 2012):

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[19] From 1979 until 2007 WPATH was known as the Harry Benjamin International Gender Dysphoria Association.

[20] The criteria for hormonal and surgical treatment options allow for motivated departures for a variety of individual, institutional, legal, or policy-related reasons (Coleman et al., 2012, p. 166).

Criteria for Hormone Therapy, Breast/Chest Surgeries (1 Referral)[21]

1. *Persistent, well-documented gender dysphoria*
2. *Capacity to make a fully informed decision and to give consent for treatment*
3. *Age of majority in a given country*
4. *If significant medical/mental concerns are present, they must be reasonably well controlled*

Criteria for Genital Surgery: Hysterectomy and Orchiectomy (2 Referrals)[22]

5. *12 continuous months of hormone therapy as appropriate to the patient's gender goals (unless hormones are not clinically indicated for the individual)*

Criteria for Genital Surgery: Phalloplasty and Vaginoplasty (2 Referrals)[23]

6. *12 continuous months of living in a gender role that is congruent with their gender identity*

SoC7 describes medical decision-making in tandem with clinicians' tasks related to assessment and referrals, which include: (1) assess gender dysphoria, (2) provide information regarding gender identity and expression and possible medical interventions, (3) assess, diagnose, and discuss treatment options for coexistent mental health concerns, [24] (4) if applicable, assess eligibility, prepare, and refer for hormone therapy,[25] and/or (5) surgery. Hence, the SoC7 suggest that the decision-making process not only involves informing clients about the range of gender identities, expressions, and corresponding treatment options but also the need to evaluate eligibility through the assessment of gender dysphoria, psychosocial adjustment, and potentially coexisting mental health concerns.

WPATH's SoC7 holds that mental health professionals are best suited to conduct these tasks given medical treatment is intensive, often life-long, and (partly) irreversible. The role of mental health professionals in assessing gender dysphoria in the context of a client's psychosocial adjustment "includes making sure that the gender dysphoria is not secondary to, or better accounted for, by other diagnoses" (p. 180). Another rationale for emphasizing the role of the mental health professional in decision-making is that clients presenting with gender dysphoria may struggle with a range of coexisting mental health concerns such as "anxiety, depression, self-harm, a history of abuse and neglect, compulsivity, substance abuse, sexual concerns, personality disorders, eating disorders, psychotic disorders and autistic spectrum disorders" which may be related or unrelated to gender dysphoria and/or a long history of minority stress (p.180-181). Although the presence of mental health concerns does not necessarily preclude access to treatment, "these concerns need to be optimally managed prior to, or concurrent with, treatment of gender dysphoria [and] [i]n addition, clients should be assessed for their ability to provide educated and informed consent for medical treatments" (p. 181). According to the SoC7, "[a]dressing these [mental health] concerns can greatly facilitate the resolution of gender dysphoria, possible changes in gender role, the making of informed decisions about medical interventions, and improvements in quality of life" (p. 181).

In conjunction with the assessment of eligibility criteria, SoC7 calls on professionals to explore clients' needs based on their goals for gender expression: "mental health professionals may facilitate a process in which clients explore these various options, with the goals of finding a comfortable gender role and expression and becoming prepared to make a fully informed decision about available medical interventions, if needed" (p. 180). To best facilitate the decision-making process, "mental health professionals need to have functioning working relationships with their clients and sufficient information about them" (p. 180). The SoC7 emphasize that treatment decisions are first and foremost a client's decision. At the same time, mental health professionals "have the responsibility to encourage, guide and assist clients in making fully informed decisions and becoming adequately prepared", sharing "the ethical and legal responsibility for that decision with the physician who provides the service" (pp. 181–182).

SoC7: Conceptual analysis of decision-making and client autonomy

Decision-making in the SoC7 appears to be characterized by both (weak) paternalistic and deliberative components and corresponding notions of client autonomy.[26]

First, the SoC7 emphasize mental health professionals' role in evaluating gender dysphoria, checking for co-occurring concerns, and assessing the client's capacity to consent to medical procedures (Coleman et al., 2012). The latter highlights the clinician's assessorial role in decision-making. In paternalistic decision-making, the clinician establishes the client's condition and decides what treatment is in the client's best interests (Emanuel & Emanuel, 1992). Seeing how a client's ability to engage in the decision-making process is contingent on the (mental) health professional's assessment of eligibility criteria, decision-making in the SoC7 can be rendered weak paternalistic.

These weak paternalistic elements indicate a carefulness and vigilance that appear to be justified by the need to exclude those unable to cope with or might regret (irreversible) medical treatment; put briefly: to avoid harm. For example, the SoC7 speak of "cases … of people who received hormone therapy and genital surgery [who] later regretted their inability to parent genetically related children" (p. 196). Similarly, the SoC7 stress the need to screen for coexisting mental concerns as these might better account for the client's gender dysphoria or hamper her ability to give informed consent (Coleman et al., 2012). These fragments imply that clients' (gendered) values might be inchoate or erroneous and presume a notion of "autonomy as critical reflection" (Dworkin, 1988). Indeed, in assessing eligibility, mental health professionals appear to ascertain whether a client's wish for medical treatment is based on critical reflection with the ultimate aim of fostering beneficence and non-maleficence. This corresponds with empirical-ethical findings in clinical practice: in "complex" cases where doubt arises regarding the

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[21] In line with the sixth version of the SoC, surgical interventions currently require one (for breast/chest surgeries) or two (for genital surgeries) referral letters from mental health professionals (Coleman et al., 2012).

[22] Including criteria 1 to 4 above

[23] Including criteria 1 to 5 above

[24] The purpose of a mental health assessment is to determine "gender identity and gender dysphoria, the impact of stigma attached to gender nonconformity on mental health, and the availability of support" (p. 180).

[25] The SoC7 note that although mental health professionals are best prepared to conduct these tasks, medical professionals with appropriate training, i.e., primary care physicians, nurses, and nurse practitioners, may also carry them out.

[26] Throughout the SoC7, "autonomy" is not explicitly mentioned.

"authenticity" of gender dysphoria or the client's ability to give *full* informed consent, (mental) health professionals may abstain from granting access to medical treatment based on values such as protection (Gerritse et al., 2018).

Meanwhile, however, the SoC7 stress a more deliberative side to decision-making in the more general task bestowed on mental health professionals to work out, together with their clients, what treatment options fit best with their values. The SoC7 press mental health professionals to recognize that treatment decisions are "first and foremost a client's decision" (p. 181). In reaching those decisions, mental health professionals should "encourage, guide and assist clients with making fully informed decisions," necessitating "functioning working relationships with their clients and sufficient information about them" (p. 181). Indeed,

> *An important task of mental health professionals is to educate clients regarding the diversity of gender identities and expressions and the various options available to alleviate gender dysphoria. Mental health professionals then may facilitate a process in which clients explore these various options, with the goals of finding a comfortable gender role and expression and becoming prepared to make a fully informed decision about available medical interventions, if needed. (p. 180)*

These latter quotes contrast with paternalistic conceptions of decision-making and imply a process more in line with the deliberative model where clinician and client, collaboratively and through moral deliberation, work out what treatment option is best (Emanuel & Emanuel, 1992).

These deliberative elements of decision-making in the SoC7 hint at the presupposition of a more relational conception of client autonomy (Mackenzie, 2008). Indeed, the SoC7 stress the importance of assisting clients in making informed choices, as well as individualizing and working out together with clients a treatment plan that aligns with their experienced gender identity. This emphasis can be read as a positive obligation on the part of the clinician to take differences between clients seriously and attune to the needs of the care-receiver, necessitating a mutual engagement to the deliberative process of care (Verkerk, 2001).

Thus, decision-making in the SoC7 appears normatively underpinned by weak paternalistic and deliberative assumptions. Correspondingly, client autonomy is implicitly conceptualized as "critical reflection" and relationally. It seems that the weak paternalistic duties of the mental healthcare professional are informed by values such as "non-maleficence" and "protection" with corresponding norms such as "we should prevent harm such as regret." The deliberative duties, on the other hand, could be underpinned by values such as "self-actualization" or "happiness" related to norms such as: "people should be able to realize their gendered selves."[27] However, these values, convictions, and norms remain largely implicit and unspoken in the SoC7. In the next section, we illustrate how this elucidation aids in better understanding ethical challenges encountered by stakeholders.

SoC7: Clarifying clinical ethical challenges in decision-making

The discussion regarding decision-making in the SoC7 centers particularly on what has become known as "gatekeeping": the state of affairs in which a mental health professional assesses eligibility and, in effect, holds final decision-making power over medical treatments (Dewey, 2013; Fraser & Knudson, 2017; Lev, 2009). As mentioned above, the SoC7 expect mental health professionals to perform both assessorial and more supportive tasks in decision-making. These assessorial and supportive tasks are rooted in diverging normative assumptions regarding decision-making and conceptualizations of client autonomy. Hence, they are morally conflicting. Especially when bestowed on one mental health professional, it is unsurprising that these tasks may give rise to moral challenges on both sides of the dyad.

A recent German survey shows how many trans clients consider mental health counseling helpful during their medical transition, both for trans-related and unrelated issues (e.g., depression) (Eyssel et al., 2017). Mandatory consultation with a mental health professional in medical decision-making, on the other hand, can be experienced as pathologizing (Murphy, 2016) or an undue burden (Cavanaugh et al., 2016). Indeed, some trans clients report that they run up against barriers in accessing medical care (Safer et al., 2016) or feel medical decisions are unnecessarily prolonged (Eyssel et al., 2017). In effect, some clients are reluctant to engage with their mental health professional, feel that they have to "jump through hoops" or cannot tell the "full story" (Cavanaugh et al., 2016; Eyssel et al., 2017; Fraser & Knudson, 2017; Schulz, 2018). The latter makes for a clinical encounter where clients may feel hampered to freely share information regarding their gender dysphoria or potentially coexisting concerns (Benson, 2013; Budge & Dickey, 2017). Clients' hypothesized key ethical questions are: In the decision-making process, should I perceive my clinician as a guardian, friend, or someone with shifting professional roles and values? What are my clinician's assumptions regarding my autonomy, capacity, and moral status? Fundamentally, should I trust my clinician? Consequently, clients may arrive as educated social actors who know how they should frame their narrative of gender identity, development, and dysphoria to convince their mental health professional during the decision-making process (Budge & Dickey, 2017; Cavanaugh et al., 2016; Schulz, 2018). Consequently, another ethical question for the client could be: Should I frame my narrative authentically or in such a way that increases the likelihood of my clinician respecting my treatment request?

Mental health professionals, on their part, have questioned how their professional role and responsibility should materialize in decision-making. Indeed, some note that they find their professional responsibility ambiguous and their various roles conflicting (Gerritse et al., 2018), quoting a mental health professional regarding the decision to start hormone therapy: "[T]o what extent should it be our responsibility to decide regarding these risks? Is that one's role as a caretaker, doctor, or psychologist" (Gerritse et al., 2018, p. 2327)?

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[27] Previous empirical research identified some of these underlying values and norms guiding decision-making of clinicians working in a multidisciplinary clinic where a local interpretation of the SoC7 is used (Gerritse et al., 2018).

The latter indicates that this clinician faces ethical questions such as: What should be my (professional) role and responsibility in this decision-making process? How should I consolidate my paternalistic duties with those that are more deliberative? How should I navigate these different tasks to build the trust and rapport necessary for *good* care and decision-making?

Furthermore, mental health professionals are often aware of how their role conflict impacts the client's presentation. For example, regarding a persistent, life-long, and "early-onset" history of gender dysphoria, a Dutch psychologist noted in a case discussion how "maybe this story is being told, because [the client] thinks it increases their chance of getting treatment" (Gerritse et al., 2018, p. 2327). Similarly, a U.S. mental health professional experienced an ethical dilemma in relying on client narratives in decision-making while knowing that clients may feel compelled to alter their histories (Dewey, 2013). Again, when made more explicit, these clinicians could face ethical questions such as: Knowing that my assessorial tasks might preclude my client from talking freely, how should my client and I arrive at a sensible treatment decision? Besides hampering client-clinician rapport building, another perilous implication of selective information exchange in the decision-making process is that potentially important information, preferences, and values are omitted from deliberation and final decision-making (Dewey, 2013; Schulz, 2018). When unable to hear the authentic client narrative, both mental health professional and client may be hampered in arriving at a *good* treatment decision. Having expounded on the SoC7 through our theoretical background, we now turn to the ICM.

Decision-making in the ICM

In an alternative care model based on the principle of informed consent, transgender clients may access gender-affirming treatment by directly engaging with a primary care provider. This "informed consent model" for (particularly hormonal) gender-affirming medical care is implemented in several community health centers in the United States and Canada (Callen Lorde Community Health Center, 2018; Cavanaugh et al., 2015; Deutsch, 2012, 2016; Reisner et al., 2015). The "ICM" is, in fact, an umbrella term for a variety of closely-related care approaches in gender-affirming medical care that focus on informed consent as a means to structure decision-making: while the SoC also have informed consent procedures put in place, "the focus [in the ICM] is on obtaining informed consent as the threshold for the initiation of hormone therapy in a multidisciplinary, harm-reduction environment" (Coleman et al., 2012, p. 188).[28] The main difference between the SoC7 and ICM is that "the SoC puts greater emphasis on the important role that the mental health professional may play in alleviating gender dysphoria and facilitating changes in gender role and psychosocial adjustment" (ibid).

For example, in 2007, Fenway Health in Boston implemented their interpretation of an ICM for gender-affirming hormone therapy. They aimed to remove barriers such as a mental health evaluation and the necessity of psychotherapy or "real life experience"[29] that was called for in the sixth version of the SoC that was in force at the time (Reisner et al., 2015).[30] Their interpretation of the ICM stipulates that clients may access hormone therapy after engaging in a "hormone readiness assessment." Their eligibility criteria for gender-affirming hormone therapy are:

> *Candidates for hormone therapy must be 18 years old and able to make and give informed consent for therapy.*
>
> *Candidates have a consistent and persistent gender variant identity meeting the DSM-5 criteria for gender dysphoria. If significant mental or medical health conditions are present, they must be reasonably well controlled.*

The initial assessment is usually made by a primary care provider who is competent in (1) establishing the client's readiness and appropriateness through a bio-psycho-social screening; (2) engaging in and assessing the informed consent procedure, as well as (3) prescribing hormone therapy and (4) providing follow-up care (Cavanaugh et al., 2015). The initial assessment generally requires two to three appointments, and hormone therapy is often initiated in that timespan due to a collaborative decision between client and clinician. Along with a medical evaluation, the assessment includes the clinician taking the history of a client's realization and understanding of gender identity and evaluating the presence of gender dysphoria (Cavanaugh et al., 2015). The latter includes a discussion of treatment goals and options, as well as exploring and assessing a client's social and mental health history. As hormone treatment is expected to be life-changing and partially irreversible, informed consent procedures are implemented. They include providing information regarding the benefits, risks, usage, and expected time-course, and discussion of "realistic expectation of changes" and, amongst others, effects on fertility (Cavanaugh et al., 2015, p. 7).

Although Fenway Health's interpretation of the ICM draws from the DSM-5 diagnostic criteria for Gender Dysphoria, psychotherapy and evaluation by a mental health professional are not requirements to access hormone therapy.[31] However, their interpretation of the ICM does not categorically exclude the involvement of mental health professionals. More specifically, the ICM distinguishes supportive mental health from gender-evaluating assessments and the process of evaluating informed consent (Cavanaugh et al., 2016). When the primary care provider doubts the client's ability to give valid informed consent or suspects the presence of a mental health condition that is not "reasonably well controlled," a client may be referred to a mental health professional (Cavanaugh et al., 2015, p. 8). In turn, the latter works with the primary care provider and client to establish readiness for hormone and surgical treatment. In a supportive role, conversely, mental health professionals are encouraged to support a balanced and optimally healthy gender affirmation process (Cavanaugh et al., 2015). Fenway Health's ICM stresses the potential importance of starting or continuing psychotherapy or mental health treatment during (medical) transitioning (Cavanaugh et al., 2015).

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[28] In this paper, we predominantly draw from the ICM model offered by Fenway Health in Boston (Cavanaugh et al., 2015).

[29] A period in which transgender clients were expected to life full-time in their experienced gender role.

[30] In the current SoC7, WPATH notes that since the guidelines are flexible, "[ICM] protocols are consistent with ... the Standards of Care, Version 7" (Coleman et al., 2012, p. 187).

[31] Of the twelve sites working with the ICM included in a study by Deutsch in 2012, four required contact with a mental health provider prior to the initiation hormone treatment.

ICM: Conceptual analysis of decision-making and client autonomy

Decision-making in the ICM, compared to the SoC7, takes an alternate starting point in that the mental health professional often does not play an explicit role. In the ICM, clients provide informed consent after clinicians have provided them with treatment information and conducted an initial bio-psycho-social screening. Indeed, "the focus is on obtaining informed consent as the threshold for initiating hormone therapy" (Coleman et al., 2012, p. 188). As the name suggests, decision-making in the ICM parallels the *informative* decision-making model (Emanuel & Emanuel, 1992). In this relationship, the client receives all relevant medical information from the clinician to make a decision that aligns with her values. Correspondingly, the role of the client is that of a well-informed consumer, while the clinician is a technical expert whose values should not interfere in the decision-making process. In the words of the Callen Lorde Community Health Center (2018, p.3), one of the pioneering clinics advocating the ICM:

We strive to establish relationships with patients in which they are the primary decision-makers about their care, and we serve as their partners in promoting health. This partnership supports the patient's ongoing understanding of the risks and benefits of hormone therapy. By providing thorough education around hormones and general health, we also aim to enhance a patient's ability to make informed decisions about all aspects of their health.

At the root of the principle of informed consent is a liberal legal ideal of autonomy (Stiggelbout et al., 2004). Indeed, in the ICM, this notion of autonomy as negative freedom is upheld and respected by minimizing undue external interference in the client's decision-making process. It stipulates that when a client can give valid informed consent, they ought to be able to choose "freely," i.e., with as little intrusion as possible: "We believe patients who are well informed have a right to make their own decisions." (Callen Lorde Community Health Center, 2018, p 3).

However, Fenway Health's interpretation of the ICM appears to concurrently prescribe weak paternalistic duties in decision-making through the assessment of Gender Dysphoria, the client's mental health status, and capacity to give informed consent. When in doubt, a clinician may refer the client to a mental health professional for further evaluation. What thus remains ambiguous is to what extent decision-making in the ICM is concurrently underpinned by a positive notion of "autonomy as critical reflection" (Dworkin, 1988).

ICM: Clarifying clinical ethical challenges in decision-making

We can schematically subdivide clinical ethical challenges in decision-making in the ICM into those pertaining to the limits or ambiguity of "informed consent."

First, emphasizing (especially a limited or legalistic take on) "informed consent" in decision-making could corrode the therapeutic alliance (Fraser & Knudson, 2017). For example, when informed consent becomes the threshold for decision-making, how should we do justice to the expert status of the clinician? Here, a clinician could ask: Should an informative decision-making model preclude me from making my (professional) knowledge, experiences, and values explicit? In the decision-making process, should I keep my values, apprehensions, and clinical judgment regarding potential outcomes at bay or instead deliberate on them with my client? Likewise, an informative decision-making model might not meet some clients' needs and concerns surrounding gender-affirming medical care. For example, those with uncertain (gendered) values could be underserved by a decision-making process resting on informed consent and a negative, liberal legal notion of their autonomy.

Relatedly, the notion that clients may bypass a mental health screening in decision-making for medical treatment prompts ethical questions. Given the (partial) irreversibility [32] of medical treatments, the phenomenology of gender incongruence/gender dysphoria, which is often characterized by a history of distress, and the high prevalence of coexisting mental health concerns, some argue that doing away with a (mandatory) mental health assessment is unwarranted. Selvaggi and Giordano (2014), writing on gender-affirming surgeries offered in other care contexts without compulsory mental health screening, argue that "offering or requesting psychological assistance is in no way … an attack on the patient's autonomy" (p. 1177). Echoing a positive, care-ethical interpretation of autonomy, they add: "To treat people as equal does not mean that they should be treated in the same way but with the same concern and respect, so that their unique needs and goals can be achieved" (p. 1177). A clinician's ethical question could be: Does the informed consent procedure sufficiently support my client's autonomy in decision-making?

Second, in the absence of clear criteria, the ambiguity of informed consent could give rise to a state in which assessing a client's ability to provide *valid* or *full* informed consent becomes a gatekeeping surrogate (Dewey, 2013). A clinician evaluating informed consent in the ICM must ensure that their client understands the nature of the interventions, consequences, risks, benefits, and alternatives to medical interventions (Cavanaugh et al., 2015; Murphy, 2016; Schulz, 2018). It remains opaque, however, when this understanding is sufficient and when clinicians are adequately and appropriately trained. Indeed, a clinician could ask: What should count as *valid* or *full* informed consent to treatment? How should we assess the impact of a co-occurring mental problem on the capacity to give informed consent? When is a referral to a mental health professional justified or obligatory?

Relatedly, an ethical concern is that the purported positive impact on the client-clinician relationship envisioned by advocates of the ICM may prove fruitless. For example, the emphasis on assessing client capacity to make a *fully* informed decision might give rise to the reproduction of a gatekeeping dynamic hinging on the assessment of decisional capacity. A qualitative interview study illustrates how clinicians in transgender healthcare often use the rhetoric of informed consent while failing to put it into practice: "In performing informed consent, providers revert to a paternalistic model of care, which amplifies their medical authority while veiling power differentials in their clinical

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32. Some authors (e.g., Cavanaugh et al., 2016) have challenged the notion that hormone and even most surgical options should be considered irreversible.

encounters and decision-making in trans medicine" (shuster, 2019, p. 190). This quote demonstrates how the ambiguity of informed consent may obscure an underlying notion of client autonomy as critical reflection (Dworkin, 1988).

Discussion

In this paper, we elucidated conceptual and normative assumptions regarding decision-making and client autonomy in two care models for transgender healthcare: the SoC7 and ICM. Subsequently, we illustrated how these assumptions feed into distinct role and value conflicts influencing decision-making in practice.

In the SoC7, the tension between mental health professionals' assessorial and supportive tasks indicates a tension between weak paternalistic and deliberative assumptions in decision-making and conflicting conceptions of client autonomy. This tension gives rise to a role conflict on the part of the clinician, which may be met with apprehension, mistrust, and selective information exchange on the client's part. In effect, both mental health professionals and clients may be hindered in arriving at a properly deliberated and attuned medical decision and ultimately in realizing *good* care. At first glance, the ICM appears to bypass this ethical predicament. However, upon closer inspection, our analysis suggests that the ICM is no ethical cure-all. Indeed, attuning to the individual needs of transgender clients and collaborative decision-making in the ICM could be hampered by an informative model rooted in a legalistic and narrow interpretation of informed consent and client autonomy. Moreover, the normative ambiguity of informed consent and client autonomy potentially veils professionals' paternalistic duties undermining the ICM's project.

Our analysis thus reveals how decision-making in transgender healthcare is characterized by inherent moral and normative dimensions that often remain implicit. The notion that these moral and normative dimensions are *inherent* implies that stakeholders' norms and values regarding decision-making will continue to differ and sometimes come into conflict. As a consequence, clinical ethical challenges are arguably inevitable. Our analysis thus suggests that seeking to resolve clinical ethical challenges by emphasizing one ideal care model for decision-making is futile. Moreover, potentially dangerous as such reflexes tend to obscure the underlying moral and normative dimensions at the root of these challenges. Instead, we believe our analysis illustrates how explicating these moral and normative dimensions can aid in recognizing, better understanding, and handling (but not resolving) clinical ethical challenges regarding decision-making.

Ethical implications

Based on the above, we plea for more explicit attention to the (fluid and evolving) moral and normative dimensions of (shared) decision-making in transgender healthcare. It is increasingly recognized that clients do not always have strong, clear, or stable values they can issue after being sufficiently informed about a specific treatment modality which can then be relied on to secure *good* decision-making (Entwistle & Watt, 2016). Indeed, clients' opportunities to share decision-making can be contingent on their conditions, co-occurring mental and medical concerns, and socio-economic and cultural circumstances (Entwistle & Watt, 2016; Gerritse et al., 2018). Clinicians in transgender healthcare, too, arrive in the consultation room with a diverse set of implicit normative presumptions and values regarding decision-making (Gerritse et al., 2018). Moreover, given the multidisciplinary and sequential character of transgender healthcare (Coleman et al., 2012), we can best understand decision-making as an ongoing process distributed across people, places, and times, defying the archetypal client-clinician decision-making dyad. For example, values regarding (shared) decision-making may depend not only on the type of intervention (e.g., hormonal or surgical), the clinician's multidisciplinary background but also on the particular gender identity, future treatment wishes, and family background of the client (Gerritse et al., 2018).

These differing values, needs, and complexities underscore the need to diversify and individualize decision-making models in transgender healthcare. To reason with Emanuel & Emanuel: "clearly, under different clinical circumstances, different [decision-making] models may be appropriate" (1992, p. 2225). We suggest that the first step towards this ongoing process of shaping *good* (shared) decision-making in transgender healthcare is making explicit stakeholders' various normative assumptions, perspectives, and preferences regarding (shared) decision-making. Indeed, the notion that there is no panacea regarding decision-making models in transgender medicine emphasizes the need for dialogue and transparency regarding what it means to co-construct a *good* decision-making process before and during the actual decision-making process. The latter is in keeping with recent accounts stressing the role of dialogue and dialogical consensus as the moral basis for (shared) decision-making (Walker, 2019). Future dialogical empirical-ethics research with and for all involved stakeholders could aid in explicating their normative assumptions and help to develop a normative framework about what a *good* (shared) decision-making process in transgender medicine could entail (Widdershoven et al., 2009). Besides a normative framework, practical avenues to support stakeholders in dealing with moral challenges in the actual decision-making process are also necessary. Dialogical empirical-ethics research can inform the co-creation of ethics support tools, such as a moral compass (Hartman et al., 2019). Such ethics support tools may aid in methodically elucidating and reflecting on clients' and clinicians' values relevant to good (shared) decision-making. In this way, empirical-ethics research and ethics support tools may contribute to reflecting on and fostering *good* decision-making in gender-affirming medical care.

Limitations and further work

There are several limits to this paper. First, conceptually we treated the SoC7 and ICM as distinct care models, whereas in practice, a variety of local interpretations of both the SoC7 and ICM are developed and used. Furthermore, these guidelines inform practice but do not directly reflect what goes on *in* that practice since there will always be a level of discretion and interpretation, both individually and institutionally. Research into the similarities and differences between these local interpretations of the SoC7 and ICM and the ethical challenges encountered by stakeholders working with these various guidelines is necessary to help further the discussion. This research could benefit from ethnographical and observational methods. Given the lack of empirical literature on clinical ethical challenges in the decision-making context of the ICM, further research into this area is especially warranted.

Second, our analysis relied on the literature on decision-making models (Emanuel & Emanuel, 1992) and client autonomy (Stiggelbout et al., 2004). Although this particular literature is widely used and appropriate for the themes at hand, it by no means offers an exhaustive analysis of decision-making in gender-affirming medical care. Analyses drawing from other ethical theories or frameworks, such as the four principles approach (Beauchamp & Childress, 2013) or care ethics (e.g., Tronto, 1993), could offer insights that should be compared and contrasted to those presented here. Likewise, approaching the topic through the prisms of shared decision-making (e.g., Elwyn et al., 2012; Stiggelbout et al., 2012) and person-centered care (e.g., Epstein & Street, 2011) could further the conversation.

Third, we did not explicitly consider the broader normative context in which decision-making occurs. However, the broader normative context of transgender healthcare (including cultural, financial, legal, and social dimensions as well as professional expert opinion) has a pervasive influence on how decision-making regarding gender-affirming medical care is organized and offered (see, e.g., Cavanaugh et al., 2016; Dewey, 2013; Gerritse et al., 2018). Future research should acknowledge and further investigate the impact of this broader normative context on ethical challenges in (shared) decision-making.

Fourth, foregrounding the ethical dimensions of (shared) decision-making could obscure the presence and more explicit handling of more fundamental epistemological and ontological views and questions regarding gender dysphoria/gender incongruence, its treatment, and its impact on (shared) decision-making. It remains ambiguous, for example, how gender dysphoria/gender incongruence is conceptualized in the SoC7 and ICM by stakeholders in practice and how this influences decision-making. How do these ambiguities impact, for example, the idea and possibility of medical indication in gender-affirming medical care? Elucidating these questions through the philosophy of psychiatry (e.g., Kendler et al., 2011), medical anthropology (e.g., Mol, 2003), or literature on medical indication (e.g., Jonsen et al., 2015), could foster a deeper understanding of how epistemological and ontological ambiguities shape the normative framework in which (shared) decision-making in transgender medicine takes place.

Conclusion

The discussion of *good* decision-making in transgender healthcare is thorny and ongoing. To contribute to this discussion, we elucidated the various normative assumptions regarding decision-making and client autonomy in two current care models: the SoC7 and ICM. For both models, we formulated "key" ethical questions illustrating how our analysis aids in better appreciating the ethical challenges of stakeholders in practice. More specifically, our key questions lay bare how the inherent normative ambiguities regarding decision-making and client autonomy in both SoC7 and ICM could frustrate decision-making in practice. Our analysis suggests that the inherent moral and normative dimensions of decision-making in transgender healthcare entail that ethical challenges regarding what *good* decision-making entails are inevitable. Rather than devising or debating care models to resolve these ethical questions and dilemmas, we argue that the first steps towards a *good* decision-making process in transgender healthcare are acknowledging and discussing its inherent normative presumptions and values.

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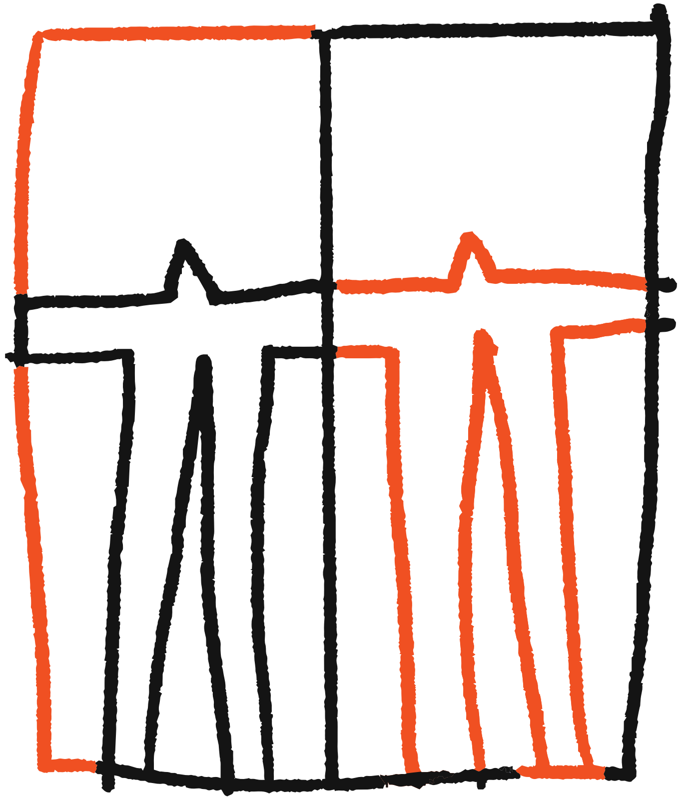

Chapter 6

Doing and Undoing Transgender Healthcare: The Ordering of “Gender Dysphoria” in Clinical Practice

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Abstract

A formal Gender Dysphoria classification is a prerequisite for the reimbursement of transgender healthcare in the Netherlands. Gender Dysphoria and its conceptual precursors have always been moving targets: moving due to research, policy, care practices, and activism. This raises the question of what Gender Dysphoria *is*. To elucidate this question, we turn to the people who use the concept in clinical practice: clinicians in gender-affirming medical care and transgender mental healthcare. Using a material semiotics approach, we explicate how Gender Dysphoria is done in clinical practice. Based on an analysis of seventeen practice-based interviews with clinicians and an examination of clinical guidelines and texts, we describe four modes of ordering Gender Dysphoria. These modes illustrate that Gender Dysphoria is not one, but multiple. We demonstrate how in the mode of "doing diversity," Gender Dysphoria is embraced as individual diversity. This enactment potentially conflicts with the mode of *isolating,* where Gender Dysphoria is carefully isolated from mental disorders. Finally, we describe the modes of *doing the future* and *narrating,* in which Gender Dysphoria is done as a continuous and predictable object of care. This study's empirical findings may provide a foundation for normative debates about what *good* transgender healthcare is.

Introduction

Transgender Healthcare in the Netherlands

Contemporary Dutch transgender healthcare has its roots in the 1980s. The Netherlands then started to offer specialized medical services to people whose gendered bodies did not align with how their minds were gendered in the context of a large, academic healthcare institution. Until the 1950s, the medical professions in the Netherlands and other parts of Europe and Northern America understood the experience that one's gendered sense of self did not match the sexual characteristics of one's body as a delusion. A condition that warranted psychiatric treatment aimed at re-aligning the mind to the body, a procedure now referred to as "the corrective approach" (Bakker, 2020; shuster, 2021).

As it gradually became evident that these corrective approaches were harmful and ineffective, clinicians began to offer what is now called gender-*affirming* medical care: medical interventions such as hormone therapy and surgeries that seek to affirm and support one's gendered sense of self. Currently, in the Netherlands, three multidisciplinary University Medical Centres and, increasingly, non-academic mental healthcare settings that work in partnership with somatic healthcare providers, offer gender-affirming medical care. All these centres work according to Dutch clinical guidelines, which are, in turn, mainly based on the Standards of Care as outlined by the World Professional Association of Transgender Health. During the research we describe in this paper, the seventh version of these standards was in effect (Coleman et al., 2012). In September 2022, the eighth version of these standards was published (Coleman et al., 2022).

Object: Gender Dysphoria

While shifting from a "corrective" to an "affirmative" approach, the role of psychiatry and psychology in gender-affirming medical care remained significant. The pivotal role of these disciplines in gender-affirming medical care continues to this day, with the 7th version of the Standards of Care recommending an assessment and a diagnosis of "Gender Dysphoria" by a trained mental health professional as a prerequisite for gender-affirming medical care.

Transgender identities have, over the years, been variously classified by the medical profession. During the revision process leading up to the publication of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) in 1994, transgender and gender non-conforming people, clinicians and academics alike expressed criticism of the framing of diverse gender identities as disordered (Suess Schwend, 2020). To meet these criticisms, the working group of the fifth version of the DSM (2013) decided on the term "Gender Dysphoria" to emphasize that the dysphoria resulting from the experienced incongruence between one's gendered body and gendered self should be the focus of clinical attention, rather than (trans)gender identity per se (Beek et al., 2016). Somewhat later, the World Health Organization (2018) also responded to calls for depathologization, changing the classification of "Gender Identity Disorder" in the 10th edition of their *International*

Classification of Diseases (ICD-10) into "Gender Incongruence" in ICD-11 and removing it from the chapter on mental disorders.

Another criticism the authors of the DSM aimed to address was the binary understanding of gender (Suess Schwend, 2020). While DSM-IV defined "Gender Identity Disorder" as "[a] strong and persistent cross-gender identification" (American Psychiatric Association, 1994, p. 537), DSM-5 no longer requires the need for "cross-gender identification." Instead, it refers more loosely to "[a] marked incongruence between one's experienced/expressed gender and assigned gender" (American Psychiatric Association, 2013, p. 452). Here we see how, due to shifting clinical and societal understandings of gender, the understanding of transgender healthcare's object changed remarkedly over the years. Gender Dysphoria, thus, is a "moving target" (Hacking, 2006, p. 1). While the history of the classification of transgender identities shows the association made changes in an effort to meet criticisms, contemporary critics point out that current transgender healthcare is still poorly equipped to care for people with non-binary, non-linear or more fluid genders.

The Contemporary Field: New Criticisms

In the Netherlands, transgender activist groups continue to demand the further depathologization of gender-affirming medical care, a healthcare system anchored in client autonomy and self-determination, and the abolishment of a mandatory diagnostic trajectory, in which a clinician has to diagnose "Gender Dysphoria" (Trans Zorg Nu!, 2021). Their critiques echo several social science scholars who have highlighted how clinicians function as gatekeepers to gender-affirming medical care in The Netherlands (Naezer et al., 2021), the United States (Dewey & Gesbeck, 2017; shuster, 2019), and the United Kingdom (Speer & Parsons, 2006), and enforce a binary notion of gender (shuster, 2016; Whitehead, Thomas, Forkner, & LaMonica, 2012).

Simultaneously, recent years have seen an increase in conservative voices criticizing gender-affirming medical care. In the Netherlands, as elsewhere, these critiques typically concern the rise in applications and the changing demographic of the population presenting for gender-affirming medical care (more transmasculine than transfeminine adolescents presenting for care). Critics question if people can obtain a diagnosis of Gender Dysphoria too easily, if gender-affirming medical care has become a solution for underlying mental health concerns, or to the misogynist culture to which people assigned female at birth are exposed (see Ashley, 2020). In the Netherlands, thus far, no trans-antagonistic laws have been proposed. Still, internationally it is clear that public criticisms about gender-affirming medical care can have far-reaching consequences, as evidenced by legislation aimed at curbing or banning access to hormone therapy for transgender youth, especially in the UK (see Siddique, 2021) and the US (see Krishnakumar, 2021).

Overall, we can say that the context in which Dutch mental health professionals have to do their job is fraught. On the one hand, international and national guidelines strongly recommend that mental health professionals classify "Gender Dysphoria." This object, in turn, is scrutinized by various stakeholders, some of whom demand the abolishment of the diagnostic trajectory, and the diagnosis of Gender Dysphoria altogether. On the other hand, those working in gender-affirming care face criticism from those who call for stricter diagnostic criteria and assessments. In these debates, the entity Gender Dysphoria takes on different shapes and forms: it becomes something *different* within the various ways the object is talked about or treated.

Zooming out from the abovementioned genealogies and criticisms, but also to inform them, we seek to shed light on the site where Gender Dysphoria is interacted with on an interpersonal level: the practice of transgender healthcare. How, we ask in this paper, do clinicians, especially mental health professionals, enact Gender Dysphoria in clinical practice?

This study

Whereas several social science scholars have critiqued the way clinicians function as gatekeepers (shuster, 2016; Whitehead et al., 2012), or perpetuate binary notions of gender, only some have focused on transgender healthcare as a site where care is delivered (Hirschauer, 1997a; Sadjadi, 2019; van Eijk, 2014). Most notable is the work of Hirschauer. Based on ethnographic work in a German clinic in the 1990s, Hirschauer suggested that all disciplines involved in gender-affirming medical care work together to create a "substance." We shouldn't understand this substance as a tangible thing like a table or a chair but as an intangible entity with which the practices of clinicians are concerned (Hirschauer, 1997b). Hirschauer describes how through the assessment of biographical data and the interpretation of the therapeutic relationship, the psychiatrist determines the client's "true" gender identity. Next, the endocrinologist prescribes hormones to adjust hormonal blood levels to those corresponding to the "other" sex. Finally, the surgeon operates to establish corporeal features that fit gendered standards. Through these cumulative, reinforcing practices, clinicians create their object of care, the "substance," in interaction with the transgender person they are treating. According to Hirschauer, this object becomes embodied by the transgender person during the treatment (Hirschauer, 1997b). Importantly, Hirschauer holds that via this substance, not only a personal but also a social conflict is settled. This "substance" not only consists of the client's "true" gender identity but also of cultural norms embedded in the practices of clinicians, which in turn get substantiated in the transgender person's body. Crucially, Hirschauer shows that the "object" of a care practice never just "is," but rather, is *done* in clinical practice.

Some thirty years after Hirschauer's fieldwork, the field of transgender healthcare looks markedly different, and new questions have emerged. For example, Hirschauer does not mention non-binary or fluid gender identities nor the necessity to depathologize gender identities. In this paper, we want to take on these questions and ask: how is the current object of transgender healthcare, Gender Dysphoria, done in clinical practice? We aim to provide some empirical groundwork of how transgender healthcare is currently done to inform and provide a foothold for normative debates about what *good* transgender healthcare entails.

Throughout this paper, we refer to Gender Dysphoria with capitals to indicate the object with which transgender healthcare is concerned. To be clear: while individual experiences of distress might also be referred to as gender dysphoria, here we are concerned with Gender Dysphoria as a *diagnostic category.*

Methods

Design

To examine how Gender Dysphoria is done in transgender healthcare, we conducted semi-structured interviews with clinicians and analysed clinical guidelines and documents.

Settings

This research is part of a larger study on shared decision-making in gender-affirming medical care for adults in the Netherlands (2019-2022). Our research team conducted 11 interviews in a previous qualitative study with clinicians in academic and non-academic gender-affirming medical care (see Gerritse et al., in press). Additionally, we interviewed five mental health professionals who work in transgender mental healthcare, a setting where clinicians offer counselling and psychological treatment to transgender people.

Theoretical approach

We used a material semiotics approach to study our research question. Semiotics proposes that words do not have an essential significance in and of themselves but gain meaning in their relation with others. Material semiotics departs from the same theoretical commitment but includes *things* in its analysis as well. These things–materials, concepts, ideas–thus gain meaning in relationship with each other (Law, 2009). As Mol (2002, p. vii) notes, medicine "attunes to, interacts with, and shapes its objects in its various and varied practices." She states that, because of these various practices, objects of medicine become slightly different in the entanglements of the specific practice concerned with them. We can understand "Gender Dysphoria" as an object enacted in practice. Within every practice, it becomes something (slightly) different. Therefore, Gender Dysphoria is not one but multiple (Mol, 2002, p. viii).

Our choice for a material semiotics approach is twofold. First, material semiotics is not solely concerned with *language* or *parole* but with practice: with what is being *done.* Here, materiality comes in: not only words *do* things, but also non-verbal practices, guidelines, diagnostic categories and so on. Second, material semiotics is not necessarily concerned with what objects *mean* in various settings but with what they *are.* The ontology of Gender Dysphoria has very real consequences for clinical practice, and thus for clients who present for care. Studying the *ontology* of Gender Dysphoria

in practice thus helps to facilitate normative debates (Mol, 2002, p. viii). By studying Gender Dysphoria as such, we hope to create a ground on which clinicians, advocates, researchers and policymakers can ask questions about the appropriateness of the way Gender Dysphoria is done in transgender healthcare.

In this paper, we turn to the question: how is Gender Dysphoria *done?* We focus on practices: what is being *done,* and how are these *doings* entangled? We are thus concerned with what others have called "modes of ordering" (Law, 1994; Moser, 2005): how, in everyday clinical practice, is Gender Dysphoria "ordered," and within these modes of ordering, what does Gender Dysphoria become? We aim to show that, depending on the way and context in which it is done, Gender Dysphoria becomes something different time and again and therefore *real* in many different ways.

Participant selection

All interlocutors included in this study had a minimum of one year of working experience in transgender healthcare. We purposively sampled interlocutors based on professional backgrounds and years of experience (Green & Thorogood, 2018). See Gerritse et al. (in press) for the recruitment and selection of clinicians in gender-affirming medical care. The fourth author (BK) brought us in contact with a mental health professional working in transgender mental healthcare, through which we snowball sampled the other interlocutors.

Data collection

First, this research made use of 11 transcripts of qualitative interviews with clinicians (six mental health professionals, two endocrinologists, a plastic surgeon, and a registered nurse) in gender-affirming medical care that KG and BM conducted in the context of a study focusing on the ethical challenges in the decision-making of clinicians working in gender-affirming medical care. They conducted the interviews between May 2020 and February 2021, nine of which took place via Microsoft Teams due to the COVID-19 pandemic. See Gerritse et al. (in press) for the details of data collection.

Second, WdB conducted five interviews with mental health professionals working in transgender mental healthcare. WdB approached six mental health professionals, of which five agreed to participate. One refused due to concerns regarding anonymity. WdB conducted the interviews between April and July 2021, also via Microsoft Teams. During the first interview, KG was present to ensure continuity in the data collection. In these interviews, WdB probed into the everyday clinical practice of clinicians, asked how they ascertain whether someone has Gender Dysphoria, and how their clinical encounters play out. In these interviews, the focus was not on clinicians' opinions but on how their care practices play out while determining if someone "has" Gender Dysphoria (see Mol, 2008). The interviews were audiotaped, transcribed verbatim and anonymized.

Third, we collected documents consisting of clinical guidelines, introductory texts and medical and psychological literature on gender and Gender Dysphoria. We included these documents in the conviction that these "do" Gender Dysphoria, too, and strongly influence how transgender healthcare is structured. These documents include the chapter on Gender Dysphoria in DSM-5 and the Standards of Care 7 (Coleman et al., 2012).

Data analysis

We thematically analysed (Braun & Clarke, 2006) all interview transcripts and relevant sections of the collected documents. We approached the data with the question of *what* clinicians were *doing* (see Emerson et al., 2011). We coded textual fragments in Atlas.ti, either when they stated *what* gender dysphoria is or *how* clinicians establish if someone has Gender Dysphoria. In naming the codes, we remained as close as possible to the original quotes (in-vivo coding) and used steps of *open, axial* and *selective* coding (Green & Thorogood, 2018). We drew from principles of "the constant comparison method" to ensure codes and themes did not overlap and were sufficiently distinctive (Boeije, 2002). First, WdB and KG coded the first transcript and reached a consensus about the used codes through discussion. Next, WdB coded all fourteen remaining interviews. Throughout this process, WdB discussed codes recurrently with KG. Together they grouped the various codes into code groups and then merged these groups into themes, reaching a consensus through discussion. They subsequently presented the code groups and themes and discussed them with the other authors. This process resulted in the identification of four modes of ordering Gender Dysphoria. We discussed our preliminary findings twice with clinicians working in transgender healthcare to sharpen our analysis.

Research team

The research team consisted of a master's student in Medical Anthropology and Clinical Psychology (WdB), a professor of clinical ethics support and quality of care providing and researching ethics support in gender-affirming medical care (BM), a senior researcher and psychiatrist working in gender-affirming medical care for adults (MB), a professor in medical psychology focusing on gender identity development and outcomes of gender-affirming medical care (BK), a professor of medical anthropology who focuses on health, illness and gender (EM) and a PhD candidate in clinical ethics who also worked as a junior MD in gender-affirming medical care at the time of research (KG). We fostered reflexivity by engaging in recurrent dialogues about the project. An advisory group and steering group consisting of academic, clinical and experience experts and client advocates offered practical and methodological input for the larger study of which the current study was a part.

Ethical considerations

We submitted the study protocol of the larger study to an officially accredited institutional review board, the Medical Ethics Committee of [location of study group]. The Committee issued a declaration stating that under Dutch law, a full ethical review was unnecessary [date and code of decision]. We informed eligible respondents via e-mail about the study and their rights at least a week before the interview. We emphasized that participation in the study was voluntary and that participants could withdraw from the study at any moment. We provided the opportunity to ask questions and obtained written informed consent before the interview. At the beginning of each interview, we reiterated the study objectives and data management and obtained oral informed consent.

To protect the anonymity of our interlocutors, we omitted their work locations and changed personal characteristics such as gender. Additionally, we use broad categories to describe professional backgrounds (for instance, "mental health professional" instead of "psychologist" or "psychiatrist"). The names used in the Findings section are pseudonyms.

Findings

First Mode of Ordering: Doing Diversity

The first mode of ordering we identified was the ordering of Gender Dysphoria as a matter of diversity. Understanding gender identities as a matter of diversity is something which is endorsed by the Standards of Care, in its opening chapter explicitly mentioning that "[b]eing transsexual, transgender, or gender-nonconforming is a matter of diversity, not pathology" (Coleman et al., 2012, p. 168). Senna, a mental health professional in gender-affirming medical care, reflected on her last years working in the gender team:

> *Well, since we are now talking to more non-binary people as well … we do more often have conversations like, what is your position in the gender spectrum? And is it more like this, or is it more like that? And that somebody says that what they want the most is to have that 'X' in their passport, but well, that's not possible … Or more coming from a feeling like, well, I really don't feel like a woman, I really don't want people to see me as a woman because that just doesn't fit me at all.*

Here Senna stretches how gender-affirming care has changed in recent years: while before, there was a binary understanding of gender, nowadays, the conversations in the clinic have changed, and Senna talks about somebody's place on a spectrum instead of one's binary position. *Doing diversity* is, we suggest, a way of perceiving gender identities as a form of gender diversity.

However, the system of gender-affirming medical care does not seem to be ideally suited for this mode of ordering. As Sem, a mental health professional in gender-affirming medical care, questioned:

> *How do you justify that we require a diagnosis of a mental disorder [Gender Dysphoria], but we take that out of its context? Instead, we say: 'It [Gender Dysphoria] is not a psychiatric disorder, but an expression of diversity… I am not sure if this [way of working] is what I wish for. Because if we do that [work from a diversity perspective], I am inclined to say, like, let's get rid of that diagnosis and say, 'there's just diversity.' If someone walks through the door and says, 'I have a gender problem,' then that is diversity, and then doesn't that whole diagnosis become fundamentally unnecessary? … It seems like in our team, to an increasing extent, there's the following logic: let's not talk too much about that [the question*

> *if Gender Dysphoria is a form of gender diversity or a psychiatric disorder]. To the outside world, we have to sell gender diversity, but on the inside, we have strict criteria that everyone should meet [to be considered for gender-affirming medical care]. I think that is a problematic way of working.*

In the fragment above, Sem identifies a tension between psychiatric classification and fully embracing gender diversity. Indeed, when a phenomenon must be classified using a psychiatric manual but is concurrently understood as "an expression of diversity," the differing frameworks on which these understandings rely may come into conflict. This conflict raises an important question for transgender healthcare: is it possible to truly account for gender diversity when working within a "mental health" framework?

Second Mode of Ordering: Isolating

One of the tasks of professionals working in gender-affirming medical care is knowing whether a client *has* Gender Dysphoria. To the professionals we spoke to, a first step in coming towards this classification is getting to know about the client's "gender identity." But, as Gerda, a mental health professional in gender-affirming medical care, explained, she was well aware that the gendered experiences of her clients were largely inaccessible to her:

> *See, what's hard, is that it [Gender Dysphoria] is about identity, and that [one's identity] is very hard to classify like: is it there or not? And yes, how someone experiences their identity is, of course, very personal and per definition 'true.' Because if someone says they have a particular identity or gender identity… that is, yes… that is 'true' because someone just feels it that way. Still, in the diagnostic process, we try to assess whether that's right. So, I always think that's kind of complicated: when someone experiences their identity in a certain way… to still look at that critically.*

While Gerda says that someone's identity is always "true" *because* that is how someone feels, she still needs to make an evaluation regarding the start of treatment. Similarly, Paula, a mental health professional in gender-affirming medical care, tries to ascertain whether it is "wise" to start or continue treatment at a particular moment in time:

> *The only thing I know at a particular moment is that it is not wise [to start gender-affirming medical care] because there are so many extra problems. Things that are mixed up and that are intertwined… At such a point, you have to say 'stop.' And then, you first have to assess what we ought to do first. What is wise?*

We can understand Paula's statement better in the context of the Standards of Care 7, which recommend that for clients to be eligible for hormone therapy "significant medical or mental health concerns … must be reasonably well-controlled" (Coleman et al., 2012, p. 187). However, as Paula mentioned, this is a very complex task for her, as things are "mixed up" and "intertwined." Like many other mental health professionals, Paula opts for the following strategy: circumventing gender identity and focusing on mental health diagnoses she *can* be surer about. As she told us:

> *The only thing I can do is to explore, together with you [the client], whether there aren't any other things that play a part in … leading you [the client] to think: I am gender dysphoric. While if we were to solve those things, maybe nothing of [the] gender dysphoria remains. That is what we have to figure out. Because if we don't do that and continue blindly, it could be the case that later on, we think like, well damn it, now we've done things that are irreversible. That's not wise.*

As Paula explains, for her as a mental health professional, it is not always clear whether gender dysphoric feelings *are part of* Gender Dysphoria. Here Paula complicates Gerda's account: while Gerda states that someone's Gender Dysphoria is always *true,* Paula problematizes this. She distinguishes between "true" Gender Dysphoria and gender dysphoric feelings that aren't "really" Gender Dysphoria but a part of something else. Rob, a mental health professional in gender-affirming medical care, talks about the potential consequences of starting gender-affirming treatment for something that isn't "truly" Gender Dysphoria:

> *See, I think it's important that people whose gender dysphoria actually arises from psychiatric problems, well, get identified quickly. It is quite rare, [but] I have seen it several times in the last years. That during the diagnostic trajectory, it becomes obvious that the gender dysphoria, or the alleged gender dysphoria, really stemmed from a psychotic disorder, for instance. … And well, if we would've started [gender-affirming] medical treatment with these patients, that would've done a lot of harm, I think. Because then we would've started sex reassignment surgery [sic] for the wrong reasons. … That is a problem because if the psychosis were treated, a patient would realise that… That he would regret it [gender-affirming treatment] and have a body that is no longer congruent with his gender identity. While before, this was the case. … I tell this story to illustrate that I think there is still an important role for the health professional to filter out these kinds of cases.*

Within this mode of ordering, to "get to" Gender Dysphoria, mental health professionals tend to take a detour via other objects. In other words: by ruling out or establishing mental health concerns that are *not* Gender Dysphoria, mental health professionals try to "get to" Gender Dysphoria. As Gender Dysphoria is assessed alongside mental health conditions, and in a context where clinicians use the DSM, there is a tendency for Gender Dysphoria to be *done* similarly. Therefore, there might be a discrepancy between the way Gender Dysphoria is *seen* or *talked about* in a treatment team (as a form of diversity) and the way it is *done in* clinical practice (as a mental disorder, or as in this mode of ordering, in between mental disorders).

Third Mode of Ordering: Doing the Future

To the question of what is important to her in decision-making, Senna, a mental health professional in gender-affirming medical care, responded:

> *[Y]ou don't have a crystal ball. You can't look into the future. … So, you have to think really hypothetically about what a particular [treatment] step is going to*

> *provide you and what it's probably not going to provide. … That you have thought about all the scenarios at least once. … Like, suppose that [a particular scenario] would happen. What would that mean for me [the client]? And would that change the client's decision?*

While Senna considers it essential for clients to have considered various hypothetical scenarios, she knows that someone can never be entirely sure about the future.
To increase (a sense of) certainty regarding current decision-making, clinicians invoked various temporal dimensions. As Bart, a mental health professional in gender-affirming medical care, explained:

> *[I]t is important that someone knows what they're getting into. And that someone, for instance, has already socially transitioned or … knows what the support system [i.e., family and friends] thinks about things [i.e., gender-affirming medical care]. … Someone [may then] assess the risk of disappointment, regret, I don't know, whatever, much better, compared to someone who may have had a very clear gender development but is still nowhere regarding their social transition.*

The idea of a "social transition" is that a client starts expressing their experienced gender. Clients may do so in various ways: by using make-up and particular clothing, changing how they talk or move, telling people their social environment about their gendered experiences, and adopting a new name. By doing so, clients gain experiences that may provide valuable insights for themselves and their clinicians. For Bart, this is more important than having a "clear gender development" because a "social transition" allows him to assess if someone can "bear all the complicated bumps in the road that you will experience if you are openly transgender." Here we see how Bart brings in *gender*, and not so much as a concept via which he can assess Gender Dysphoria but as a tool to evaluate future outcomes. By practising a particular social gender role, clients are *doing their gender,* a doing in the here and now that may inform decision-making about gender-affirming care—decision-making which is concerned with the future. While Senna stated that it is impossible to predict the future, Bart described a practice that helps him gauge and thus feel more certain about the future. A social transition, then, is one of the temporal dimensions by which Gender Dysphoria is done.

And there are others. Another common temporality in Dutch gender-affirming medical care is waiting. Senna reflects on how waiting is a temporality that potentially complicates her assessment of eligibility:

> *Well, they [clients] just want… They want something, right? They come to get something from us. And the faster, the better for most people. Now and then, there is someone who says like, 'help me to clear things up. I really don't know it at all, I want to investigate it.' But most people, especially with the current waiting times, have a really concrete idea of what they are coming to get from us. Well, and the more you say… about the stuff a [mental health professional] wants to know more about or maybe has concerns about, well, the longer the diagnostic trajectory takes, and the longer it takes before you [i.e., the client] have a doctor in front of you [to initiate gender-affirming medical care].*

Here Senna describes how, while a client is waiting, Gender Dysphoria is rendered inaccessible to her as a clinician. "Especially with the current waiting times," Senna says, indicating that during *that* time, some clients may become more certain about their Gender Dysphoria and what to do about it. Here, she also brings in another tension that seems to be the effect of waiting: she says that clients might be hesitant to share information about "their Gender Dysphoria" as they might be afraid that this lengthens the diagnostic process. Here a double-edged temporality seems to be at work. While the process appears unnecessarily prolonged for a client because they have to wait for a longer time, for Senna, it is harder to access the Gender Dysphoria she needs to decide about. Here, two contradictory forces seem to be at play. While a client might become more certain about "their Gender Dysphoria" and their treatment wishes during the (excessively long) time they are on the waiting list, such certainty seems to contradict Senna's wish to openly investigate with a client. Paradoxically, Senna needs more time to explore a Gender Dysphoria about which a client is "more sure," thereby lengthening the process further.

In sum, although clinicians might readily acknowledge that they cannot predict the future, they employ several temporalities to approximate it. These practices, which happen *now,* transform Gender Dysphoria into something that is not only present at the moment but also in the future.

Fourth Mode of Ordering: Narrating

We asked Christian, a mental health professional in transgender mental healthcare, about the steps he takes to establish if someone *has* Gender Dysphoria. He said knowing whether someone has Gender Dysphoria was not such an interesting question. To him, what mattered is "the story that you work on in treatment, that is what you are giving shape to." He elaborated:

> *Well, what you [i.e., the client] have gone through and how it felt. How it was when you wanted to play soccer with the boys at school and weren't allowed to, or you got sent out of the girls' dressing room. How that impacted your development, and how things are now. … You give someone a chance to let the story come out a little, also concerning the future: What do you want to be? What do you think and feel about that? What do you hope? We aren't entirely malleable, right, so the outcome might not match your ideal. When you're born as a man, [and] you're one meter ninety, you weigh a hundred kilos, and you want to transition to womanhood, then that's quite a complicated thing, and you'll have to reconcile with … certain aspects of yourself and learn to embrace things that weren't on your wish list. That also has to do with letting someone's story be.*

Christian reflects on how, together with a client, he *narrates* the past. Via the practice of narrating, the mental health professional and the client may "give shape to a story" or "let a story come out." In this story, Gender Dysphoria is stabilized by anchoring it in various stages of someone's life story. This becomes apparent in what Christian says: a story is about someone's youth, but also the present. It is also about the future: how may the client's past inform this unknown temporality? Locating Gender Dysphoria at these various stages arguably serves a similar function as a "social transition." Gender Dysphoria is rendered a reasonably stable, continuously-existing entity, affording the clinician a sense of security regarding its existence in the future.

The way Christian talks about the way he helps to let "a story come out" suggests that the story is already there, waiting to be excavated. At the same time, Christian stated that, together with his client, he "gives shape to" a story. The notion that this is an interactive process implies that another story could "come out." Sem, in the following fragment, highlights the role of clients in this process:

> *Well, I've spoken to many people over the years who ask me, 'Look, what do you want to hear?' To which I respond, 'Well, your story,' so to speak. And then people say, 'No, you don't! You say you are, but what you want to hear is that I've suffered from gender dysphoria for a long time; that I meet two out of seven DSM criteria because then I have the diagnosis; that I suffer tremendously; and that I haven't felt like a man but a woman since years long past and I would've preferred to have been born a woman; and that I don't have any problems, or at least not too many. That's what you want to hear!'*

Here, Sem describes he is well aware that *his clients are well aware* of what kinds of stories mental health professionals want to hear from them to be able to receive treatment. However, stories may also be challenging to the clinician for other reasons. Sem continues:

> *[R]ecently, I saw a new patient … with a colleague, and we had huge doubts [about initiating gender-affirming medical care]. This patient met four or five DSM criteria, but there was no suffering … Or at least, no suffering that we could see.*

Because "clinically significant suffering" is a criterion needed for the classification of Gender Dysphoria in DSM-5, in Sem's account, the absence of suffering from the client's story complicates the formal classification and hence the indication for gender-affirming medical care.

Lisette, another mental health professional in gender-affirming medical care, also stated that some clients' narratives might impede her work as a clinician:

> *I have one client, and that's also rather complicated, he is on the spectrum of, well… 'In 75 percent of the cases, I feel like a man, but in 25 percent of the cases, I feel like a woman. And so, 75 percent of the time, my body troubles me, but 25 percent of the time, it doesn't.' But still, he wants a breast removal. Well, I think that's rather complicated! … because that person also doesn't know so clearly what they want. And well, I don't either. And in addition, if you refer [for gender-affirming treatment], you [i.e., the clinician] do have to be sure that someone [i.e., the client] is doing something that they won't regret. And well, if you want something for 75 percent of the time but 25 percent of the time you don't … Those are complicated bases!*

Here, Lisette reflects how a story that isn't linear or binary might complicate things in the process of decision-making, as she can't be as sure as with other stories that someone isn't going to regret gender-affirming medical care.

In the end, narrating is a way of creating continuity, and much like "doing the future," offers (a sense of) a grip on the future. But, as shown, clinicians see some stories as more useful to make decisions about the future than others, thereby rendering some more viable than others.

Discussion

This paper centred on the question of *what* Gender Dysphoria *is* in clinical practice. We showed that Gender Dysphoria is not just something "out there" but that Gender Dysphoria becomes something according to the mode it is ordered. We identified four such modes: *doing diversity, isolating, doing the future* and *narrating.* In what follows, we reflect on the various norms that appear to be embedded in these particular modes of ordering. After describing this study's limitations and corresponding suggestions for future research, wwe conclude by reflecting on the Gender Dysphoria we enacted in this paper ourselves.

Depathologizing: Saying and Doing

In the mode of ordering we called *isolating*, mental health professionals struggle with classifying and making treatment decisions while holding Gender Dysphoria inaccessible. One strategy they employed to be still certain about its presence is getting to it via a detour: via objects they regard as more readily accessible.

Transgender studies scholar Davy (2015) notes how in transgender healthcare, clinicians assess gender via its negative: clinicians and clients know someone "is" of a particular gender because someone is not "the other" (for an empirical example, see Hirschauer, 1997a). In this study, we wrote about a mode of ordering in which Gender Dysphoria, too, is encountered via its negative. In this case: through assessing "other" mental health categories, like psychosis or autism. Establishing the latter categories appears to provide clinicians with a means through which they can get closer to Gender Dysphoria and hence, classification and medical decision-making. In *isolating*, Gender Dysphoria is placed between other mental health categories.

In this mode of ordering, we can understand Gender Dysphoria and its predecessors (such as "Gender Identity Disorder") as "absent presences" (M'charek et al., 2014). While contemporary discourse on transgender healthcare centralizes depathologization, the way its object is done in clinical practice arguably shows the struggle of fully relinquishing a pathologized account of gender diversity (also see MacKinnon et al., 2021; shuster, 2016). Here, it is important to stress the institutional background of the clinicians we spoke to find themselves. In biomedical contexts, it might be hard to do anything other than "isolating", as it is a mode of ordering that meets biomedical logic. Notwithstanding the effects of pulling Gender Dysphoria out of the realm of mental disorders, its history arguably deters different modes of ordering it.

Delays: Getting a Grip on the Future

Our findings illustrate how time is a central "thing" that does Gender Dysphoria. Within the mode of ordering we called "doing the future," it becomes evident how temporal dimensions are played with to fix Gender Dysphoria in time. The implicit norm here is that Gender Dysphoria, and therefore gender and gender identities, should be (to some extent) predictable.

Pitts-Taylor (2020) emphasizes how pauses or delays have historically been used to help "measure" the stability and authenticity of (trans)gender identities. A clinician might propose these "delays," but in Western gender-affirming medical care, delays are also ubiquitous in the form of lengthy waiting lists. As current waiting times for an initial consultation in Dutch gender-affirming medical care can exceed three years in some clinics, clients often start expressing and "doing" their gender long before their first appointment. While clients' "already-doing" proved insightful for Bart, Senna stated that it might also "close off" Gender Dysphoria, thus encumbering her work. Clients often know what treatment(s) they want, so they "come to get something" from the clinician. Through the eyes of Senna and Bart, we see that the workings of time can have different outcomes with varying consequences for clinical encounters. Time can do various things to Gender Dysphoria and, depending on how the clinician looks at things, may close off Gender Dysphoria as an object, rendering it easier or harder to engage with and, thus, easier or harder to make decisions about.

Here we also see how various modes of doing might clash or contradict each other. For instance, isolating and doing the future might be in harmony: both modes of ordering might help ensure Gender Dysphoria's presence, now and in the future. Doing the future in a linear way, however, is less compatible with "doing diversity," as the latter presupposes gender as a fluid, more open-ended phenomenon. In other words, modes of ordering do not stand alone but depend on and may conflict with each other, too.

Looking for the Right Story

Finally, Gender Dysphoria may be narrated and thus rendered into a story. As within "doing the future," in this mode of ordering, Gender Dysphoria becomes an object that existed in the past and present but should also exist in the future. The norm implicit in the narration of Gender Dysphoria seems to be that gender identity ought to be continuous.

Our findings illustrate how, within this mode of ordering, clinicians experience challenges in grappling with particular narratives. This is in line with the ethnographic findings of our research group (Gerritse et al., 2018) on ethical challenges in gender-affirming medical care. We found, for instance, that clinicians deemed the narratives of clients presenting with a persistent, life-long or "early-onset" Gender Dysphoria more convincing than those with a later onset. This, again, is in line with the guidelines, which stipulate that there should be "[p]ersistent, well-documented gender dysphoria" (Coleman et al., 2012, p. 187). Here, the logic inherent to "doing the future" is dominant. This logic assumes that when gender identity has been "stable" in the past, it will be so in the future. At the same time, in this mode of ordering, some narratives may be harder for clinicians, such as narratives in which Gender Dysphoria is not always present or a Gender Dysphoria that arises in adolescence or early adulthood.

As we, as well as others (see for instance shuster, 2016) illustrate, there are uncertainties involved in diagnosing Gender Dysphoria. Consequently, the diagnosis is "negotiated" between the client and clinician (Lane, 2020). This negotiation feeds into a dynamic in which clients know they must tell a particular story to help them get the treatment they believe they need (see Davy, 2015). Here, as well as in the other modes of ordering that we described, the clinical category of Gender Dysphoria is reified into a stable entity that existed in the past and will exist in the future, too.

Limitations and Future Research

This study is not without limitations. First, due to the COVID-19 pandemic, we conducted interviews online via Microsoft Teams and could not conduct on-site participant observations. This complicated our grappling with the "materiality" of transgender healthcare, as a material semiotics approach proposes. By being attentive to "doings" and "materials" and by including guidelines, texts and literature, we sought to account for the latter. Still, we suggest that future in-person social scientific work focuses on multidisciplinary meetings and clinical practice, emphasising its material dimensions. Hormones, blood values, surgeries and psychological tests all do Gender Dysphoria in their particular ways, too, and it is important to open these doings up as well.

Second, the modes of ordering we encountered might be typical for the clinical settings we investigated. We focused on mental health professionals' practices and the enactments of guidelines in clinical encounters. It would be worthwhile to "open up" care practices in other branches of transgender healthcare to further clear up their modes of ordering as well. Undoubtedly the modes of ordering we encountered are entangled with the Dutch context in which they are done. It would be worthwhile to investigate care practices in different national contexts, especially those which organize transgender healthcare differently. Also, we focused predominantly on mental health professionals.

It would be of great value to investigate the care practices of other clinicians working in transgender healthcare, such as surgeons and endocrinologists, as well as other clinicians not working *in* but also concerned *with* transgender healthcare, such as general practitioners. Additionally, it would be worthwhile to investigate care practices outside a biomedical context. Worthwhile localities include trans-led grassroots clinics and private mental healthcare settings. There, Gender Dysphoria and/or gender identity will be “ordered” as well, but probably in different ways than we encountered.

An even more critical question is how transgender people “do” Gender Dysphoria within and outside healthcare settings. For instance, what do the self-care practices of transgender people look like? Are these also focused on an object such as “Gender Dysphoria?” Promising avenues include (auto-)ethnographic work of community care and self-care practices.

Expanding the possibilities of ordering is essential because, as we’ve seen, the question of *what* Gender Dysphoria *is,* is a question that is and will remain open-ended as the object changes within every practice that is concerned with it. The way Gender Dysphoria is ordered is not just an effect of how healthcare settings are organized but is also due to Gender Dysphoria being a “moving target” (Hacking, 2006, p. 1). Gender Dysphoria is multiple in its ontology. At the same time, this multiple ontology is never stable due to changing clinical, personal and societal understandings of gender, identity and distress. As we’ve shown, different modes of ordering imply different norms and thus have different effects on *what* Gender Dysphoria, or the object of transgender healthcare, *is.*

Particular norms are reproduced in clinical practice via the “present absence” of Gender Dysphoria as a pathological category or the tendency to enact Gender Dysphoria as a continuing category in the past, present, and future. In these ways, gender identities are continuously done and redone in clinical encounters. Understanding which modes are operative in clinical settings and which norms they imply, might help better understand which modes are wished for by clients, clinicians and researchers, and which are not. Understanding how Gender Dysphoria is ordered in various medical and non-medical contexts can thus help us to further understand the “goods” and “bads” of transgender healthcare.

Conclusion

This paper is, first and foremost, an *intervention* into Gender Dysphoria and transgender healthcare. As Law (1994; 2009) emphasizes, methods do not describe realities *out there.* Instead, they help to create realities. Our approach thus does its own ontologies: Gender Dysphorias that are ordered as a matter of diversity or as a matter of the future, that are isolated and narrated. In doing so, we enacted another ontology: a Gender Dysphoria that is opened up through social science. But what for?

Some 30 years ago, Hirschauer’s work showed how the practices of transgender healthcare carry and reproduce particular cultural norms. Although the norms have shifted, this is the case now as much as it was thirty years ago. These norms may be more hidden nowadays but still have very material consequences, such as denying or granting a treatment wish. Therefore, they must be made visible, time and again.

Not only transgender healthcare practices change. So too, do the objects these practices are concerned with. Different doings make for different ontologies that carry different normative assumptions. We have illustrated how material semiotics offers a lens through which to untangle and make these practices, ontologies and norms visible. This visibility, in turn, can help clinicians and other stakeholders to become more aware of aspects and consequences of their practices and thus contribute to understanding and discussing what *good care* should entail in transgender healthcare. In the end, the task for transgender healthcare and its research is not to strive for closure, solidification, or well-roundedness, but instead, to stay with the struggle of doing their object of care, that is to say, staying with its fluidity and open-endedness.

Credit authorship contribution statement

Wolter de Boer: Conceptualization, Methodology, Formal analysis, Investigation, Writing – Original Draft, Writing – review & editing. Bert C. Molewijk: Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing. Marijke A. Bremmer: Conceptualisation, Investigation, Supervision, Writing – review & editing. Baudewijntje P.C. Kreukels: Conceptualization, Investigation, Supervision, Writing – review & editing. Eileen Moyer: Conceptualization, Methodology, Supervision, Writing- review and editing. Karl Gerritse: Conceptualization, Formal analysis, Investigation, Methodology, Supervision, Project administration, Writing – original draft, Writing – review & editing.

Declaration of competing interest

None.

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Chapter 7

GenderJourney: participatory development of an ethics support tool to foster dialogue and reflection on shared decision-making in gender-affirming medical care

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Abstract

Objective
To describe and reflect on the development process of GenderJourney: an ethics support tool that seeks to foster (dialogue and reflection on) shared decision-making (SDM) in gender-affirming medical care (GAMC).

Methods
Part of a larger project, this study used a participatory design. We included transgender and gender diverse (TGD) clients and healthcare professionals (HCPs) throughout the study in co-creation workshops. In an iterative process, we (1) established stakeholders' needs, (2) reached a consensus on the aims, content, and design, (3) developed and tested successive renditions, and (4) presented the final version of the tool.

Results
The final tool aims to (A) elucidate the client's care request and corresponding treatment preferences, (B) foster an explicit dialogue between TGD client and HCP about expected/preferred decisional roles and collaboration, (C) stimulate a systematic joint reflection on and handling of SDM-related ethical challenges.

Conclusion
The GenderJourney provides non-directive ethics support to jointly reflect on and foster good SDM, including its inherent ethical challenges. Future studies should focus on its implementation and actual contribution to good SDM.

Practice Implications
GenderJourney may be used in GAMC to support the dialogue on what good SDM entails and the identification, discussion, and handling of SDM-related ethical challenges.

Introduction

Conceptually positioned between paternalistic and informed decision-making, shared decision-making (SDM) stresses the importance of person-centered care, client-clinician partnership, and shared responsibility for outcomes (Elwyn et al., 2016; Stiggelbout et al., 2015). Although there is no definitive or universal SDM model, SDM is often operationalized as a deliberative and sequential process consisting of the (1) introduction of choices and elucidation of goals, (2) comparison of the relevant options, and (3) discussion of decisional role preferences and decision-making (Elwyn et al., 2016; Stiggelbout et al., 2015). SDM is becoming ever more prominent in healthcare (policy) and is considered the preferred decisional model, especially for so-called preference-sensitive decisions, i.e., decisions where more than one reasonable treatment option is available (Stacey et al., 2017).

Gender-affirming medical care (GAMC) is a preference-sensitive care practice *par excellence.* GAMC comprises interventions such as feminizing and masculinizing hormones and/or surgeries to aid transgender and gender-diverse (TGD) clients[33] in affirming and expressing their experienced gender (Coleman et al., 2022). Given the expanding number of GAMC options and the diversity of clients' needs and values regarding their medical transition (Beek et al., 2015), the growing appeal for SDM in GAMC (Clark et al., 2021; Coleman et al., 2022) is not surprising.

However, our and others' previous empirical research shows that stakeholders encounter various SDM-related ethical challenges (Dewey, 2015; Gerritse et al., 2018, in press; shuster, 2021). In their multidisciplinary practice, healthcare professionals (HCPs) face questions such as: How should we deal with dissensus among team members regarding the acceptability of possible complications from GAMC interventions (Gerritse et al., in press), given that long-term evidence is sparse (Coleman et al., 2022)? Or, how should we share decision-making when clients suffer from co-occurring mental health conditions (Gerritse et al., 2018; MacKinnon et al., 2021), the prevalence of which is increased in those seeking GAMC (Dhejne et al., 2016)? Conversely, due to client-clinician power differentials (Dewey, 2015; shuster, 2021), TGD clients may wonder whether they ought to be honest about their doubts regarding GAMC or co-occurring mental health concerns, as they fear it might delay or otherwise impact their eligibility for treatment (MacKinnon et al., 2020). Given the subjective dimensions of gender identity and GI, ethical challenges also revolve around the question of who is best suited to establish its presence. Relatedly, the central role of mental health professionals (MHPs) as "gatekeepers" establishing readiness for GAMC is contested by some TGD clients (MacKinnon et al., 2020; shuster, 2021) and other stakeholders (Ashley, 2019; Cavanaugh et al., 2016; Schulz, 2018)

We elucidated how such challenges arise in the context of precarious client-clinician collaboration and (meta-)communication (Gerritse et al., in press). For example, while TGD clients had various ethical challenges, normative views, and needs concerning SDM, they did not regularly share those with their HCPs.

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[33] We use "transgender," "trans," and "TGD" interchangeably as umbrella terms for gender identities, roles and expressions that differ from those normatively expected of one's sex assigned at birth.

Likewise, while HCPs identified (an unspecified interpretation of) SDM as an ideal, they implicitly adopted various decision-making models, e.g., informative and deliberative with so-called "well-functioning" clients, and more paternalistic vis-à-vis clients whom HCPs deemed "complex" (i.e., those with co-occurring social or psychological concerns). In line with others (Dewey, 2015; MacKinnon et al., 2020) we found that HCPs' reasonings for (not) sharing decision-making often remained implicit and under-discussed with their clients. The above is worrisome as collaboration, open communication, and discussion of decisional roles have been identified as prerequisites for good SDM with TGD youth (Clark et al., 2021) and the joint handling of ethical challenges (Roodbeen et al., 2021).

Both HCPs and TGD clients recognized the importance of more explicit dialogue concerning SDM in the consultation room (Gerritse et al., in press). They particularly mentioned the need for more clarity regarding the decisional process (e.g., what decision is at stake), discussion of decisional role preferences, and means to handle SDM-related ethical challenges. As GAMC is characterized by inherent uncertainties, subjective dimensions, and dynamic and divergent normative views concerning decision-making, SDM-related ethical challenges are arguably inevitable (de Snoo-Trimp et al., 2022; Gerritse et al., in press) Thus, stakeholders should find ways to discuss and grapple with such challenges even when a "solution" is impossible. Not only as they are indicative of what values are at stake for whom, but also as—particularly underacknowledged—ethical challenges may put a significant burden on the client-clinician relationship, the decision-making process, and, in the end, the quality of care (Gerritse et al., 2018, in press).

This call is timely, relevant, and urgent as the referrals for GAMC are growing exponentially (Coleman et al., 2022; Goodman et al., 2019; Wiepjes et al., 2018). Moreover, as reflecting on and shaping *good* SDM may be hampered by an increasingly polarized and politized discourse and oppositional normative positions concerning decision-making in GAMC (Turban et al., 2021). Stakeholders may benefit from supportive structures and instruments to aid the dialogue about SDM and handle SDM-related ethical challenges (Clark et al., 2021; Gerritse et al., 2018). Promising avenues are clinical ethics support (CES) and SDM tools.

CES aims to support stakeholders in constructively dealing with ethical challenges (Bell et al., 2022; Haan et al., 2018) and is increasingly used in GAMC in the form of ethics consultations (Feldman et al., 2022; Mabel et al., 2019) and Moral Case Deliberation (Vrouenraets et al., 2020). CES may also be integrated into the daily practice of GAMC through, for example, the co-creation of theme- and practice-specific ethics support tools (Hartman, Widdershoven, et al., 2019). Compared to regular CES, such tools provide (contextual) information, norms, and values pertaining to ethical challenges. An example of such a tool in GAMC is the "Competence Consultant," which aims to assist HCPs in dealing with ethical challenges around decisional competence in GAMC for adolescents (de Snoo-Trimp et al., 2022).

There are (at least) two types of SDM support tools: client decision aids and conversation aids (Montori et al., 2017). Decision aids are aimed at clients and seek to enhance client involvement in SDM through decision explication, information provision, and value clarification (Stacey et al., 2017). Decision aids are increasingly implemented in GAMC (Mokken et al., 2020; Özer et al., 2018). However, they do not directly target SDM as they tend to focus on the client and the content of the decision rather than the client-clinician dyad, the decisional process, and normative dimensions of SDM (Montori et al., 2017). Conversely, conversation aids are used within clinical encounters to support conversations HCPs and clients have when making decisions together and aim to promote the quality of the SDM process (Montori et al., 2017; Stacey et al., 2017).

We set out to co-create a theme and practice-specific ethics support tool to foster SDM and the joint handling of SDM-related ethical challenges in GAMC for adults. In doing so, this study seeks to make a questioning and critical yet constructive contribution to the dialogue about what *good* SDM in GAMC entails, both within and outside the consultation room.

Methods

Setting

We developed the GenderJourney in the context of a larger project on SDM-related ethical challenges and CES in Dutch GAMC (2018 – 2022). Its development was informed by previously conducted qualitative (Gerritse et al., 2018, in press) and conceptual research (Gerritse et al., 2021).

Dutch GAMC is currently offered by three multidisciplinary University Medical Centers (UMCs) and, increasingly, nonacademic mental healthcare centers working in partnership with somatic healthcare providers and UMCs. Dutch GAMC guidelines largely follow the Standards of Care of the World Professional Association for Transgender Health (Coleman et al., 2012, 2022).

Design

Given the theme of SDM and in line with others developing CES tools (de Snoo-Trimp et al., 2022; Hartman et al., 2018; van Schaik et al., 2022), we used a participatory development design. Participatory research aims to solve challenges within a specific context and includes end users throughout the development process (Abma et al., 2019). Such an approach may address stakeholders' needs more adequately, facilitate implementation (Goodyear-Smith et al., 2015), and empower end users (Abma et al., 2019).

Concretely, we organized a series of co-creation workshops (WSs) (Abma et al., 2019) with TGD clients and HCPs. We distinguished four design phases. In *phase one,* we identified the needs of the participants. We agreed on the tool's aims, content, and design in phase two. In *phase three*, we co-created the tool in an iterative developing, testing, and adjusting process. In *phase four,* we presented and tested the final version of the GenderJourney.

Theoretically, these co-creation workshops were informed by a dialogical approach to empirical ethics (Widdershoven et al., 2009) which prescribes that both the empirical research process and the process of reaching normative conclusions are organized in a dialogical way. The latter entailed that the (normative) conclusions about the aims, content, and design of the tool were made by and shared among end users and researchers in dialogue.

Participant recruitment and selection

We included 12 participants: six TGD clients and six mental health professionals (MHPs). We recruited TGD clients through the participating academic and nonacademic GAMC institutions and the Dutch TGD client organization. We included TGD clients who: (1) started GAMC <10 years ago, (2) were not currently involved in decision-making regarding GAMC interventions (to foreground their experiential knowledge and minimize conflicts of interests), (3) were able to provide informed consent, and (4) spoke Dutch. We purposively sampled for gender identity, age, and experience with academic and/or nonacademic GAMC. All six TGD clients who expressed an interest and met inclusion criteria agreed to participate upon request. See Table 1.1 for characteristics and WS attendance.

MHPs were recruited through a member of the steering group of the larger project, who informed potential participants about the study. We focused on MHPs as their role in SDM is both central and contested. We included MHPs with > 1 year of work experience in Dutch GAMC. We purposively sampled for years of experience in GAMC and employment in academic and/or nonacademic GAMC. Of the six MHPs we approached, one MHP retired, and another faced time constraints during the project. Therefore, we recruited two MHPs who were new to the project from the participating academic GAMC institution. See Table 1.2 for characteristics and WS attendance.

Table 1. Participants' characteristics and WS attendance

1. Characteristics and attendance of TGD clients

Name*	Gender	Age range	(Non)academic GAMC	WS2	WS4	WS5	WS6
Tim	TM/NB	40-50	Academic	X	X	X	
Daan	TM	20-30	Nonacademic	X	X		X
Noah	TM	40-50	Academic	X	X	X	
Emma	NB/TW	60-70	Academic	X	X	X	
Frouk	TW	50-60	Both		X		X
Julia	TW	20-30	Both	X	X		X

2. Characteristics and attendance of MHPs

Name*	Experience	(Non)academic GAMC	WS1	WS3	WS5	WS6
Maria	5-10 years	Academic	X	X	X	
Stefan	10+ years	Academic	X	X	X	
Tinka	10+ years	Academic	X	X	X	
Barbara	5-10 years	Academic	X	X		X
Ellen	<5 years	Nonacademic		X		X
Marieke	<5 years	Nonacademic	X	X		X

Abbreviations: WS, workshop; GAMC, gender-affirming medical care; WS, workshop; TM, trans man; NB, non-binary; TW, trans woman. *Names are pseudonyms.

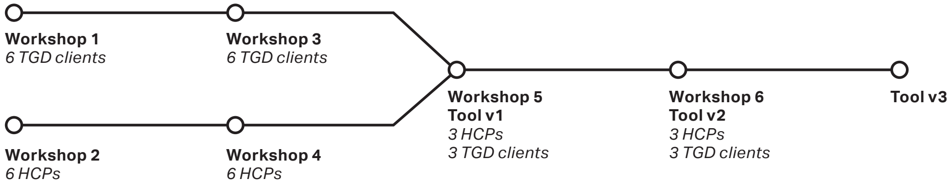
Data collection and analysis

We held six WSs between March and October of 2022. WS5 took place in real life. The other WSs were held online via Microsoft Teams due to the COVID-19 pandemic, at the request of some of the participants, and to explore both online and face-to-face use of the tool, given that Dutch GAMC is increasingly offered in a hybrid manner. WSs lasted two to three hours. In the first four WSs, TGD clients and MHPs convened twice in a homogenous, alternating fashion (i.e., TGD clients in WS1 and WS3 and MHPs in WS2 and WS4) to foster social safety within the groups. Next, we allocated TGD clients and MHPs to either WS5 or WS6 (i.e., two heterogenous groups consisting of three TGD clients and three MHPs). See Figure 1 for an overview of the data collection.

Figure. Overview of data collection

The WSs were structured as follows: we started WSs by outlining the session's aims and presenting provisional findings. In WS1 and WS2, these were the findings of previously conducted studies (Gerritse et al., 2018, 2021, in press) summarized in the introduction. In WS3 and WS4, these comprised the findings from WS1 and WS2, and in WS5 and WS6, the findings of WS3 and WS4. These presentations were followed by questions, dialogue, and feedback from the participants. Furthermore, in WS5, we tested the 1st, and in WS6, the 2nd version of the tool. In this way, a cyclical-iterative co-creation process emerged.

During the WSs, we took extensive notes about the process, participants' input, consensus/dissensus, and relevant quotes. In the online WSs, we also used Google Jamboard, a tool for visual collaboration, as a data collection method. Furthermore, we invited participants to give input after the WSs via Google Jamboard or e-mail and planned individual sessions with the absent participants during WS1 (n=1) and WS2 (n=1).



Abbreviations: WS, workshop; TGDC: transgender and gender diverse client; MHP, mental health professional.

After each WS, we collected all empirical data (notes, comments on Google Jamboard, received e-mails) and drafted a detailed report. We presented a summary of this report—along with exemplary quotes selected based on (ethical) significance and clarity—to participants during the following WS for member check and discussion.

Ethical considerations

The Medical Ethics Committee of the Amsterdam UMC, location VUmc, declared that under Dutch law, a full ethical review of the study protocol was unnecessary (IRB00002991, April 21, 2020). We emphasized that participation was voluntary and that participants could withdraw at any moment. Participants gave written and oral informed consent before the first WS and received a gift card after each WS.

Research team

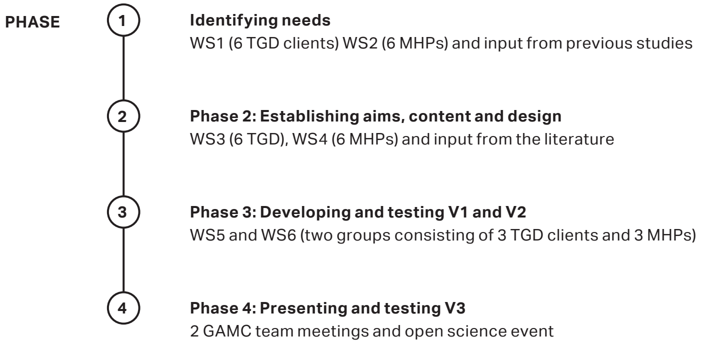
KG is an M.D. with experience in GAMC, a trained ethicist, and a Ph.D. candidate. CM is a healthcare consultant and TGD community advocate. MB and AdV are senior researchers and psychiatrists in GAMC. BK is a senior researcher in medical psychology focusing on GAMC. BM is a senior researcher and ethicist providing and researching CES in GAMC.

Results

In this section, we describe the development process of the GenderJourney. We distinguished four phases: (1) identifying needs, (2) establishing aims, content, and design, (3) developing and testing v1 and v2, and (4) presenting and testing v3 of the tool. Table 2 provides an overview of the phases and steps.

Figure 2. Overview of the development process

Abbreviations: WS, workshop; TGD, transgender and gender diverse; MHP, mental health professional; GAMC, gender-affirming medical care



Identifying needs
WS1 (6 TGD clients) WS2 (6 MHPs) and input from previous studies

Phase 2: Establishing aims, content and design
WS3 (6 TGD), WS4 (6 MHPs) and input from the literature

Phase 3: Developing and testing V1 and V2
WS5 and WS6 (two groups consisting of 3 TGD clients and 3 MHPs)

Phase 4: Presenting and testing V3
2 GAMC team meetings and open science event

Phase 1: Identifying needs

This phase centered on elucidating end users' needs. In WS1 (TGD clients) and WS2 (MHPs), we introduced and discussed the overarching co-creation process (i.e., to develop a tool to foster SDM in GAMC). We presented and discussed findings from previously conducted qualitative studies on the ethical challenges and norms of stakeholders in GAMC (Gerritse et al., 2018, in press) and facilitated a dialogue on the needs the tool should address (See Table 2 for the needs and exemplary quotes).

Table 2 Output of WS1 and WS2: Needs and exemplary quotes.

Need	Exemplary quote
(1) Share decisional responsibilities more	"You [i.e., the client] decide, but know what you're deciding because you have to live with it. The tool could help to work towards actually sharing that responsibility" (Maria, MHP).
(2) Further support personalized decision-making	"Clarifying the care request is vital. We really should let go of the idea of a norm or standard. I hope that the tool can help to communicate to counter presuppositions" (Julia, TGD client).
(3) Allow more space for the non-linear character of GAMC	"It's good to emphasize that [a medical transition] is not a linear process, but that you can change course at every step along the way. It [the tool] should allow space for change" (Tinka, MHP).
(4) Offer more clarity regarding the decisional process	"During your transition, you run into all kinds of things that are unclear regarding how decisions are made. …The tool should offer clarity regarding what the decision-making process is or could be" (Tim, TGD client).
(5) Discuss (mutual) expectations more explicitly	'shouldn't we start the conversation with: "What is it like for you to be here? What are your experiences with other caregivers? What are your expectations concerning how we're going to make decisions?" (Barbara, MHP).
(6) Discuss decisional roles and values more explicitly	"I think I've got more than a double role [i.e., guiding and assessing]: supporting, informing, investigating, gatekeeping, helping. These roles intermingle, differ from person to person, and can change during the client's process. Talking more about these roles with clients would be really helpful" (Tinka, MHP).
(7) Share (ethical) uncertainties and fears more	"It's interesting and valuable to hear the clinician's side of the story and to see that they struggle with all kinds of things too. They talk about that amongst each other, but why can't they be more open and share their doubts in the consultation room?" (Tim, TGD client).
(8) Talk about and handle (ethical) dissensus	"Who has what kind of responsibility? Where does my responsibility as a clinician end, for example, when my client and I have different ideas about how to proceed?" (Stefan, MHP).

Abbreviations: MHP, mental health professional; TGD, transgender and gender diverse; GAMC: gender-affirming medical care.

Phase 2: Establishing aims, content, and design

Next, in WS3 (TGD clients) and WS4 (MHPs), we presented and discussed the tool's provisional aims,[34] which we drafted based on the findings of WS1 and WS2. See Table 3 for the provisional aims and exemplary responses.

Table 3. Output of WS3 and WS4: Provisional aims and exemplary responses

Provisional aims	Exemplary response
(1) Elucidate clients' care requests and treatment goals	"[The tool should] help to formulate, like, what is my identity, what suits me, and how can I can move towards that. That should be the starting point of the decision-making process" (Frouk, TGD client).
(2) Provide an overview of the corresponding decision-making process and moments	"Given the diversity of treatments and treatment wishes, it is critical to get an overview of the personal decisional path for a client" (Barbara, MHP).
(3) Offer clarity concerning the possibilities and boundaries of the MHP's decisional roles	"I think it's really important to be clear about your boundaries … concerning what you can and cannot offer [as an MHP] and in terms of treatment options" (Marieke, MHP).
(4) Make expectations and values regarding decisional roles more explicit	"People [i.e., clients] often need a lot of information at first and are OK with someone [i.e., a clinician] who's a bit more stand-by and not as involved later on. That's fine. It's good to ask: 'How much would you like your clinician to be involved in that particular decision?'" (Julia, TGD client].
(5) Identify and discuss SDM-related ethical challenges	"We should really strive towards making challenges [concerning decision-making] more explicit: what is the bottleneck?" (Tinka, MHP).

Abbreviations: TGD: transgender and gender diverse; MHP, mental health professional.

Participants readily agreed with the provisional aims of the tool. Subsequently, we brainstormed in WS3 and WS4 about the implications of the established aims for the tool's content and design. We presented three tools/instruments used within and beyond (Dutch) GAMC as dialogue prompts, i.e., the Genderbread person (http://www.genderbread.org/), GenderAid (Mokken et al., 2020; Özer et al., 2018) and River of Life exercise (Parker et al., 2020). See Table 4 for respondents' input on content, design, and exemplary quotes. Respondents underscored the importance of a visually attractive and accessible tool to meet the established aims. They expressed that an overly cognitive, analytical, and verbal tool would run the risk of not meeting the needs and capabilities of certain end users, e.g., those with cognitive disabilities or autism spectrum disorder.

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[34] We used working definitions of needs and aims, with the former referring to dissatisfactions the tool should address, and the latter to desires, wishes, or aspirations for the tool. We identified a significant overlap.

Table 4. Output of WS3/WS4: Provisional content and design and exemplary quotes

Provisional content/design	Exemplary quotes
1. Visualize a (non-linear) decision-making process through the metaphor of a river or sea	"A river flows in just one direction, while you could make the same round twice, or go back to an island you've passed because you're not really done there" (Julia, TGD client).
2. Visualize decision-making options and moments through the metaphor of islands	"Could you attune [the river] to clients? That you don't presuppose, like, first this, then that. You could look at it like Homer's odyssey: there are different islands, but you [i.e., the client] can decide which ones you'll visit and when" (Daan, TGD client).
3. Visualize decisional roles and conflict through the metaphor of a boat or vessel	"I think the idea of a GenderJourney, a journey you're making together, where you discuss roles, sounds really great. Am I the [client's] travel guide? Or travel companion? Who decides on the next destination and route? Who's at the helm?" (Stefan, MHP).
4. Islands should encompass both medical and non-medical interventions	"I think [the islands] could be an important aid in giving clients more agency, also concerning what they can do themselves. These [i.e., activities that correspond with a client's care request] aren't just medical steps, of course" (Maria, MHP).

Abbreviations: TGD: transgender and gender-diverse; MHP, mental health professional.

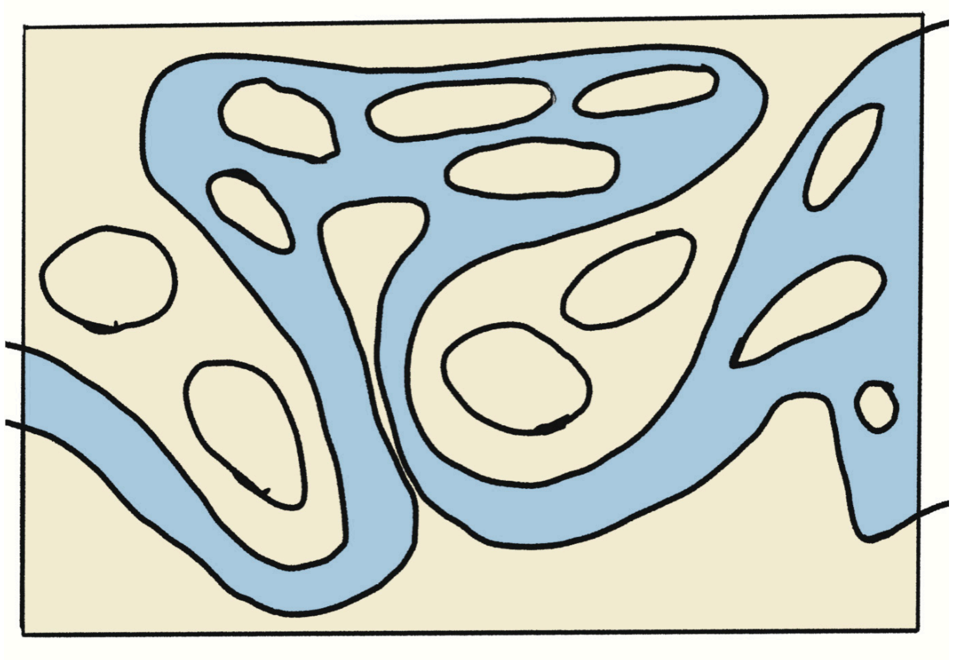
Phase 3: Developing and testing v1 and v2

In phase 3, we developed, tested, and adjusted the tool in two heterogenous WSs (i.e., WS5 and WS6 both consisted of three MHPs and TGD clients). Stefan suggested the working title "GenderJourney" to emphasize the non-linear and open-ended character of SDM in GAMC.

Based on the input of WS3 and WS4, we established the first version consisting of three consecutive parts: (A) elucidating the client's care request and visualizing the corresponding decision-making process and moments, (B) supporting the discussion of expected/preferred decisional roles and (C) facilitating the explication of and dialogue about SDM-related ethical challenges.

In collaboration with a professional graphic designer (http://rtiiika.com), we created a visual map consisting of a river with various islands (see Fig. 2). Furthermore, we drafted a brochure aimed at TGD clients, which included information about SDM, SDM in the context of GAMC, provisional instructions for the GenderJourney and "first aid" for SDM-related ethical challenges.

Figure 2. First version of the GenderJourney



In WS5 and WS6, we subsequently presented and piloted the first and second versions of the GenderJourney. See Table 5 for a summary of the resulting feedback on its context of use and content/design.

Table 5. Summary of feedback received in WS5 and WS6

WS5/WS6	Feedback on (context of) use
WS5	1. Participants appreciated how working together on the map and sitting next to each other, rather than opposite, fostered a sense of collaboration between the TGD client and MHP. 2. Participants needed guidance on when and how to introduce and use the tool. 3. The dyads' diverse use of the tool raised the question of how uniformly the tool should be used. Participants appreciated its open-ended character but agreed that a summary of guiding instructions should be included on the map. 4. Participants noted how using the tool laid bare (institutional/organizational) barriers to SDM (e.g., multidisciplinary decision-making meetings and criteria in clinical guidelines), raising a discussion about how the tool should relate to these barriers.

WS6	1. Participants agreed that MHPs and TGD clients must first get acquainted, as establishing a client-clinician relationship should take precedence. Participants held that the tool could best be introduced voluntarily by either MHP or the client in the 2nd or 3rd consultation. 2. Participants valued the structure of the steps and instructions in v2. Many expressed an appreciation for the explicit link between the GenderJourney and the "First aid" for ethical challenges" section. 3. MHPs noted how the map helped them to explicitly visualize, explain and discuss specific barriers to SDM, e.g., multidisciplinary decision-making meetings and the role of MHP as a "gatekeeper" in decision-making. It also aided them in jointly relating to these barriers to allow for collaboration even in the case of conflicting visions/values (e.g., regarding what good care or decision-making entails).
WS5/WS6	Feedback on content/design
WS5	1. Participants discussed whether and to what extent treatment modalities and decisional roles should be included on the map. They agreed that including some categories and/or examples as prompts would be beneficial. 2. Participants stressed how SDM-related ethical questions, doubts, and challenges on both sides of the dyad are inherent to GAMC and agreed that a "doubt" island should be included on the map. 3. Participants agreed that the river wrongly suggested that a gender transition is a linear process and proposed using the metaphor of a sea or ocean with unnamed islands.
WS6	1. Participants expressed how the ocean metaphor and suggested open-endedness did more justice to their lived and professional experiences with GAMC. 2. Participants appreciated the "doubt" island and stressed the importance of normalizing (the expression of) ethical doubt and challenges on both sides of the dyad. Some suggested expanding this island to include "reflection." 3. Especially TGD clients shared how the term "shared *decision*-making" felt too narrow and alienating. They proposed to use "collaboration" to stress the ground/prerequisites for shared decision-making and handling of (ethical) questions and challenges.

Significant changes from the 1st to the 2nd version of the tool (based on WS5) were the inclusion of (1) brief instructions and (2) exemplary (treatment) options and decisional roles on the map. Furthermore, we (3) changed the river into an ocean, and (4) included a "doubt" island. A major change from the 2nd to the 3rd version of the tool (based on WS6) was to change the language from "shared *decision*-making" to client-clinician *collaboration,* as participants felt the former term to be too narrow and clinical.

The final tool (see Figure 3 and Supplementary files 1 the English and Dutch versions, respectively) consists of three parts and is developed for use in the consultation room between HCPs, TGD clients, and other stakeholders but may also be used individually by TGD clients. To facilitate usage, we developed the brochure for TGD clients (see Table 6 and Supplementary files 3 and 4 for the English and Dutch versions, respectively) and instructions for MHPs. In short, the tool starts by explaining when and why to use the GenderJourney. Part A aims to clarify the client's care request and route, i.e., what steps the client has made and what (non)medical steps they believe are necessary, and to prioritize these steps. Part B seeks to foster a dialogue between the TGD client and HCP about (expected/ideal) decisional roles and collaboration. Part C stimulates evaluation, normalizes SDM-related ethical challenges, and refers to support. Finally, the "First aid for ethical challenges" section (see Table 7 and Appendix 2) aims to identify and formulate the SDM-related ethical challenge, involved stakeholders, and potentially conflicting values. It also seeks to help stakeholders in weighing these values and handling dissensus.

Figure 3 The third and final version of the GenderJourney.

Table 6. Instructions for the final version of the GenderJourney in the brochure for TGD clients

1. Introduction	The GenderJourney helps you to get an overview of your (medical) transition. It also guides the conversation between you and your healthcare provider about what is important when making decisions together. Three reasons to use the GenderJourney • **Plotting the course:** c*larifying your care request and ideas about the route and destination* • **Defining the roles:** *discussing expectations, roles, and doubts about decision-making* • **Taking a step back**: *evaluating and dealing with potential challenges* • **What do you need?** *The GenderJourney, printed in A3 or online, pens, markers* *Please note! The GenderJourney does not tell you what (medical) treatment is best for you or how you should decide with your healthcare provider. It can help you to discuss this and find out what is important to you.* *Please note! What is important to you about your GenderJourney and your collaboration with your healthcare provider may change over time, depending on the particular (treatment) step. How you and your healthcare provider decide about hormone treatment can differ from surgeries. It's good to keep this conversation going!*
2. Three reasons to use the genderjourney	**Plotting the course** clarifying your care request and ideas about the route and destination
	Dividing roles discussing expectations, roles, and doubts about decision-making
	Taking a step back evaluating and dealing with potential challenges
3. Plotting the course	**What brings you here?** *Write or draw your care request (destination) on the map* Your GenderJourney is a process: there are many possible routes and destinations. What is your care request at this moment in time? For example, self-acceptance and feeling better in my body. It's OK if you don't know yet. Your request can also be to explore what it is you need.
	Where are you now? *Draw your vessel on the map* Have you already taken any steps? For example, coming out to friends
	Which steps do you think you need? *Name the islands* There are many options, for instance: an exploration of your gender identity/expression, peer support, medical-surgical, psychological, social, and legal. Maybe you need something different. Perhaps you're in doubt, or you don't know yet. In that case, discussing your doubts or what you don't know could be the next step.
	What is your desired route at this moment? And your first or next destination? *Draw and describe your ideal route and first destination, "X."* What does your HCP think about your envisioned route and first/next destination?
4. Dividing the roles	**How will you get there?** On your way to "X," you and your healthcare provider can have different roles. For example, you can ask questions and tell your provider about your feelings, doubts, or treatment goals. Your provider may inform, support or critically question you.
	How can your healthcare provider best help you to reach "X"? *Where would you place your healthcare provider on the map (for example, at the helm, ashore)?* **Ideally, what role(s) would your healthcare provider have?** *Reflect on this with your healthcare provider*
	What can your healthcare provider do for you, and what is not? *Ask your healthcare provider* **What policies must be considered on your way to "X"?** *Ask your healthcare provider. What do you and your provider think about these policies?* **What is important to your healthcare provider on your way to "X"?** *Ask your healthcare provider*
	What is your desired speed? *Encircle your desired speed on your way to "X"* Some people hurry to get to their first destination, while others like to take their time. How's that for you?
5. Taking a step back	**Are you headed in the right direction?** During your GenderJourney, it's helpful to check if you're headed in the right direction concerning your transition and collaboration. How do you and your provider feel about your journey and partnership? Are changes necessary? If so, what? (Are you stuck? Or not on the same page with your healthcare provider? See the "First aid for questions and challenges" section in the brochure)

Table 7. Instructions for "First aid for ethical challenges concerning collaboration" in the brochure for TGD clients

1. First aid for ethical challenges regarding collaboration	You and/or your healthcare provider may have questions about how you work and decide together. It's important to talk these through. The following steps can guide the conversation. Hopefully, they'll help to answer your question or deal with the challenge.
2. Starting point: What is the ethical challenge?	What are you or your healthcare provider confronted with? Is there any doubt or uncertainty about the way you work together? Do you have different viewpoints on what is appropriate and which role fits the current moment?
3. Do you recognize a theme?	Ethical challenges regarding collaboration and decision-making often involve self-determination, protection, trust, honesty, responsibility, disagreement, dependency, or communication. For example: • **Self-determination**: I should decide, but I want to do that together with my healthcare provider • **Responsibility**: Who should decide whether the risks are acceptable? The provider or the client? • **Honesty**: Should I be honest with my healthcare provider when I doubt or disagree with something? • **Disagreement**: How do we deal with disagreement (f.e., about supportive therapy) and come to a decision? • **Dependency**: To what extent may a client and/or healthcare provider go against the team's advice?
4. Who is involved?	What is important to you and your healthcare provider about the challenge? Can you both express your priorities and concerns?
5. What happens next?	According to you and your healthcare provider, what should happen next? In case of a disagreement **Do you disagree?** Do you agree about what's important, but do you disagree about what needs to happen? Or do you disagree about what should happen because your priorities are different? Do you understand what's essential to the other? Is it possible for both of your concerns to be met?
6. Weighing up the options	What is decisive to you and your healthcare provider concerning the question or challenge? What do you think needs to happen? In case not everything you and the other find important can be done: are there ways to do justice to the things that are receiving insufficient attention at the moment?
	Do you still disagree?
	Sometimes there's no clear-cut answer to your question or solution to your challenge. You and your healthcare provider may still have different ideas about what's important concerning a decision or what your collaboration should look like. Fortunately, there are options: exploring alternatives; including relatives, friends, or partners; writing down your thoughts and sharing these; requesting a Moral Case Deliberation, mediator, spiritual care worker, member of the client council, or independent healthcare professional; filing an official complaint; etc.

Presenting and testing v3

Finally, in *phase four,* we presented the final version of the tool in three different settings. First, we introduced the tool to a total of +/-80 HCPs (both MHPs and non-MHPs) during live team meetings of two participating GAMC institutions. After the presentation, potential end-users tested the GenderJourney in four workshop sessions with +/- 20 participants. In their feedback, HCPs appreciated how the tool provided a visual overview of the decision-making process in GAMC and facilitated a dialogue on values relevant to both GAMC and decision-making. Furthermore, HCPs valued the means to identify and handle SDM-related ethical challenges. Some wondered whether GenderJourney's language, open-ended character, and cognitive requirements match the abilities of clients with co-occurring cognitive disabilities and/or autism spectrum disorder. Others pointed out that the tool did not align with the structured character of their practice or could wrongly imply that the client is granted full decisional self-determination. Furthermore, we presented the tool at an online science event of one of the participating GAMC institutions to +/- 80 TGD end users and other interested parties.

Discussion

This study describes the participatory development of an ethics support tool to foster (dialogue and reflection on) SDM in GAMC for adult TGD clients. The final tool centers on the following elements of the SDM process: (1) deliberation, especially the clarification of the client's treatment request; (2) establishing (consensus as to) what specific decision is at stake; (3) expounding and discussing corresponding (values pertaining to) decisional roles. Furthermore, the tool aids in (4) elucidating and handling SDM-related ethical challenges.

GenderJourney's participatory development, thematic focus, and practice sensitiveness resemble other ethics support tools (de Snoo-Trimp et al., 2022; Hartman, Metselaar, et al., 2019; van Schaik et al., 2022). They also align with what Hartman et al. (2018) call an "integrative approach to CES," i.e., "an approach in which both the development and the specific use of CES are closely connected with the local circumstances and the involved stakeholders' (pp. 10–11). This entails that the development and dissemination of CES occur within the actual care practices and requires the researcher to act as a facilitator (Hartman et al., 2018; Hartman, Widdershoven, et al., 2019).

GenderJourney also differs from the abovementioned ethics support tools. The latter often start with and require an experienced *ethical question or challenge,* i.e., a situation in which a stakeholder does not know, is uncertain, or disagrees with another stakeholder about what is good or right (de Snoo-Trimp et al., 2022; Hartman et al., 2018; Molewijk et al., 2008; van Schaik et al., 2022). However, during the WSs, both HCPs and TGD clients also expressed that *good* SDM in GAMC should be attuned to the person/dyad and decision at stake and a need to support the latter. Previous empirical research illustrates how this attunement is hampered by stakeholders not regularly sharing or deliberating values and norms pertaining to decision-making, partly due to precarious client-clinician trust, collaboration, and communication (Dewey, 2015; Gerritse et al., 2018; shuster, 2021). Thus, the challenge was to develop a responsive and sensitive tool for this specific context.

To that end, our ethics support tool took inspiration from conversation aids (Elwyn et al., 2010; Stacey et al., 2017). Elements of the SDM process such aids address considered relevant by our participants were: (1) decision explication; (2) elucidation and discussion of decisional roles; (3) open communication; and (4) supportive (i.e., trusting and accepting) client-clinician relationship. GenderJourney also differs from conversation aids in important ways. First, GenderJourney includes a section to support handling SDM-related challenges and dissensus. Next, we did not seek to implement a particular normative SDM model in the field of GAMC. For example, in developing a conversation aid for people with intellectual disabilities in the palliative phase, Noorlandt et al. (2021) departed from a previously established SDM model (van de Pol et al., 2016). Our approach was more inductive as we centered on the variety of our participants' needs and moral considerations.

In our study, paradoxically, the often-criticized open-endedness and normative ambiguity of SDM was a helpful heuristic device. It allowed us to identify stakeholders' various decisional ethical challenges and laid bare how values and norms regarding decision-making are dynamic, time-, decision- and context-specific. This suggests that the question of what *good* SDM is cannot be answered by a set of a priori values or norms but should be established by stakeholders in practice, time and again. An iterative and open dialogue to reflect on what *good* SDM entails for *these* stakeholders at *that* moment in *this* context is thus an integral part of fostering *good* SDM. This is in line with dialogical ethics, which holds that ethical expertise (e.g., on what *good* SDM is) develops through an exchange of stakeholders' perspectives on a specific situation based on their experiential knowledge and context-sensitive moral intuitions (Inguaggiato et al., 2019). The latter implies that stakeholders' values and norms concerning what good SDM is may differ and come into conflict. Rather than viewing SDM-related ethical challenges and dissensus as a threat to SDM that should be avoided at all costs, we believe they ought to be taken seriously and made more explicit as they indicate the values and norms at stake and provide the grounds for co-constituting *good* SDM.

Strengths, limitations, and future studies

To our knowledge, this is the first CA or CES tool to promote SDM in the field of GAMC for adults. The strengths of this study are that TGD clients and MHPs participated throughout the development process, that the latter included the actual use of (various versions of) the tool, and that we have made our normative and theoretical assumptions explicit. The study is not without limitations. First, the tool needs further implementation and feasibility evaluation. We particularly encourage qualitative, responsive evaluation studies (Abma et al., 2019), as their methodology aligns with our participatory approach and allows end-users to formulate evaluation criteria collaboratively. Such studies would benefit from including stakeholders beyond the MHP-TGD client dyad, such as other multidisciplinary HCPs, families, and partners. Furthermore, future studies should investigate GenderJourney's impact on (handling) SDM-related ethical challenges and synergies/discords with other CES instruments and SDM tools.

Conclusion

This paper presents a visual ethics CA to support SDM in GAMC for adults called GenderJourney. We used a participatory design and included end users (TGD clients and MHPs) throughout the development process. GenderJourney seeks to aid TGD clients and MHPs to (1) elucidate the client's care request and clarify the decision-making process and moments; (2) share and deliberate on (values related to) preferred decisional roles and collaboration; and (3) identify and handle SDM-related (ethical) questions and challenges. Future studies should focus on implementing GenderJourney and evaluating its impact on SDM in clinical practice.

Practice implications

Stakeholders in GAMC can use GenderJourney to support the dialogue on what good SDM entails and the identification, discussion, and handling of SDM-related ethical challenges. The tool invites stakeholders to learn from, rather than "solve," such challenges and dissensus. GenderJourney could be translated and adapted for international use in diverse GAMC settings (e.g., for TGD children and youth), where it may also facilitate (deliberation on) guidelines for SDM. Finally, although the tool is theme- and practice-specific, it may inspire those working in other morally contentious SDM contexts.

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Credit authorship contribution statement

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Declaration of interest

None.

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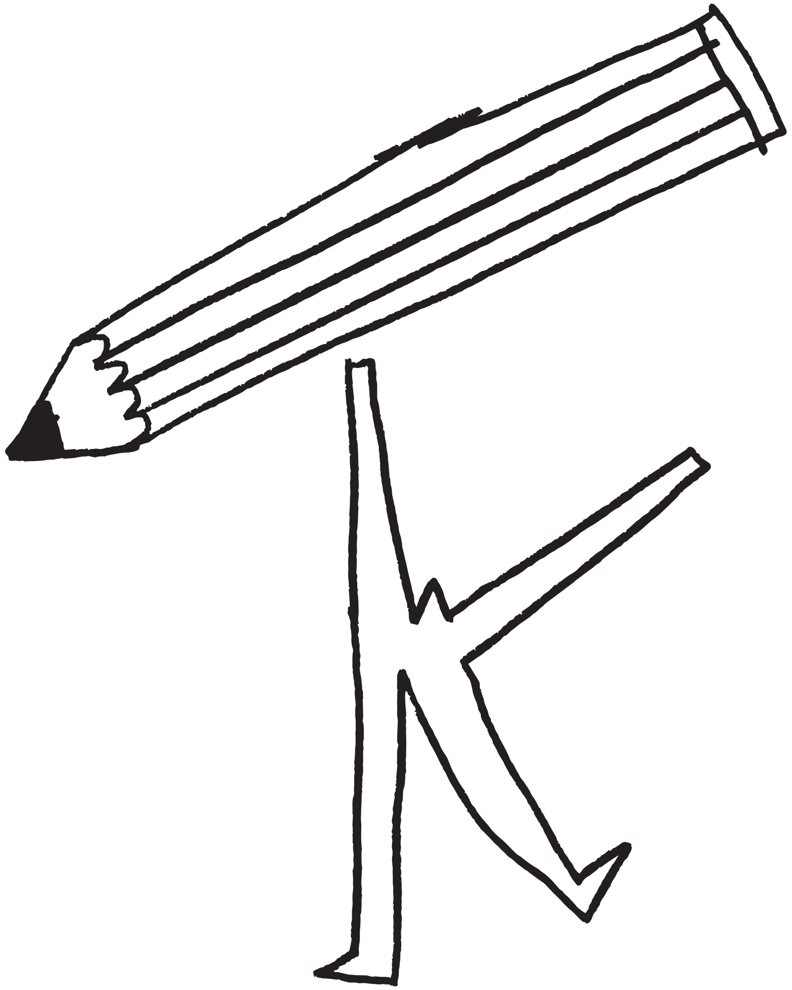

Chapter 8

General discussion

General discussion

The discussion concerning decision-making for GAMC is thorny and ongoing. This thesis sought to make a critical and constructive contribution to this discussion and support stakeholders in grappling with the ethical issues they face in practice. To these ends, we gained insight into the moral and conceptual landscape of shared decision-making (SDM) in adult GAMC. We employed an emerging research design, including descriptive ethics, conceptual analysis, and various qualitative methods. These empirical and conceptual investigations informed the development part of this thesis, i.e., the co-creation of an ethics support tool that aims to foster (a joint deliberation between HCPs and trans* clients about) *good* shared decision-making (SDM) and the handling of concomitant ethical challenges. This participatory development study was theoretically grounded in dialogical empirical ethics and included HCPs and trans* clients throughout the development process through co-creation workshops.

In what follows, we reflect on our findings by picking up three discussion points, which we end by suggesting practice implications and directions for future research. We start with a section on GAMC in light of SDM. Here, we elaborate on the ways (ontological and epistemic) uncertainties concerning GI/GD challenge HCPs' experienced responsibility not to harm trans* clients. The following section focuses on SDM in light of GAMC. Here, we describe how our empirical findings and pragmatic-hermeneutic clinical ethics may inform the ambiguous normative underpinnings of SDM. In the third section, we reflect on pragmatic-hermeneutic CES and ethics support tools based on our experiences with developing the GenderJourney. We stress the importance of CES in the current context of polarization in GAMC. We also highlight some critical questions and challenges relating to the normative implications of a hermeneutic-pragmatic approach to CES and ethics support tools.

Reflections on non-maleficence and the prevention of regret

This section elaborates on SDM in GAMC and challenges the centrality of non-maleficence, preventing regret, and, more generally, consequentialism. We argue that the experienced duty of HCPs to do no harm should be weighed against more than the apparent infringement to trans* clients' right to self-determination. Specifically, we believe that this thesis laid bare unforeseen (and unintended) harms of the impetus to "do no harm" to the client-clinician decision-making process. Given the serious consequences of the latter on the realization of good care, we believe these harms should be considered. We start this section by presenting some empirical findings and sketching the historical background of non-maleficence and "regret prevention work" in GAMC.

Our empirical findings showed that HCPs face a fundamental tension in decision-making between respecting trans* clients' self-determination and experiencing a duty to non-maleficence (Chapters 2, 4). Like others (J. M. Dewey, 2015; MacKinnon et al., 2020; shuster, 2021), we found that HCPs face questions such as: How should we divide decisional roles with clients? Who ought to determine whether potential complications are permissible? When is it ethically acceptable or necessary to delay or withhold GAMC?

Chapter 5 explained these questions in the context of SoC7 recommending (weak) paternalistic duties in decision-making to exclude clients who cannot cope, might regret, and/or seek to halt or revert (irreversible) medical interventions. For example, SoC7 spoke of "[c]ases … of people who received hormone therapy and genital surgery and later regretted their inability to parent genetically related children" (Coleman et al., 2012, p. 196) and described how since the SoC have been in place, cases of regret have remained low (p. 229). Likewise, SoC8 recommend that HCPs should only initiate GAMC in those clients showing "marked and sustained" GI, as a "stable gender identity" is associated with higher satisfaction and lower rates of regret (Coleman et al., 2022, p 536). Indeed, SoC8 state that "the percentage of people seeking to halt or reverse permanent physical changes should remain static and low" (p. 541).

We can arguably better understand HCPs' impetus to "do no harm" and "prevent regret" against the background of the history and emergence of GAMC. Until the 1950s, the experience that one's gender did not align with one's birth-assigned sex was considered a psychiatric condition warranting institutionalization aimed at the re-alignment of the mind to the body, i.e., "the corrective approach" (Bakker, 2018; MacKinnon et al., 2021; shuster, 2021). In the 1950s and 1960s, the incongruence between sex and gender was increasingly reconceptualized as a treatable medical condition, giving rise to the "affirmative approach," i.e., medical interventions that affirm and support the expression of one's gendered sense of self. Until today, the history of GAMC could be read as a battle for its (social and biomedical) legitimacy. Local (Bakker, 2021) and (inter)national (Bakker, 2018; shuster, 2021) publications recount numerous stories of the ways clients, HCPs, and other advocates have had to maneuver to safeguard the provision of GAMC in the medical realm and society at large. The aim of the first SoC of what was then called the Harry Benjamin International Gender Dysphoria Association (now the World Professional Association for Transgender Health [WPATH]) was bifold: to offer guidance in and improve the provision of GAMC, but also to protect HCPs and their institutions (shuster, 2021). All this to say, the fear of legal and social repercussions and professional ostracization among those providing GAMC was—and to some extent *is*—rife (Bakker, 2018, 2021; shuster, 2021).

As GAMC professionalized and institutionalized, a predominantly "trans- and heteronormative" notion of what is now classified as "Gender Incongruence (GI)" (World Health Organization [WHO], 2018) or "Gender Dysphoria (GD)" (American Psychiatric Association [APA], 2013) emerged which understood gender as binary and medical transition as one-directional, i.e., from male to female and vice versa (MacKinnon et al., 2021). These normative notions were enshrined in the eligibility criteria for GAMC in WPATH SoCs (MacKinnon et al., 2021; shuster, 2021), diagnostic and classificatory systems (Chapter 6; Beek et al., 2016), and anchored in law. For example, as we wrote in Chapter 2, until July 2014, sterilization was a prerequisite to have one's legal gender recognized by Dutch law (art. 1:28 subsection 1 DCC Jo art. 1:20 subsection 1 DCC). Those identifying outside of the heterosexual matrix, not meeting normative notions of GI/GD, or requesting variations from what was called a "complete sexual reassignment" were a priori rejected, as stipulated by the (local) guidelines in place at the time (Cohen-Kettenis & Gooren, 1999). Arguably, it is against this background that the enterprise of establishing who is "truly trans" and "stable enough" to prevent harm[35] arose (Bakker, 2018; MacKinnon et al., 2020, 2021; shuster, 2021).

Our empirical findings highlight how the principle of non-maleficence and regret prevention work may have unforeseen (and unintended) consequences for the client-clinician relationship. We hypothesize that this is partly due to the strategies HCPs employ to cope with uncertainties inherent to GAMC, particularly regarding GI/GD. Chapter 4 described how HCPs' commitment to non-maleficence is challenged by uncertainties regarding the presence and boundaries of its object of care. These uncertainties impede HCPs' gauging of whether clients have GI/GD, will benefit from GAMC and, as a consequence, decision-making. Chapter 4 also described that HCPs employ different strategies to cope with these uncertainties. While some readily acknowledge them (e.g., "I don't have a crystal ball," "I can't truly determine whether a client is gender dysphoric"), others defer or seek ways to contain them. One such method is for HCPs to refer to ostensibly neutral but value-laden qualifiers such as "good-functioning" and "complex" clients. These qualifiers provided a prima facie justification for more laissez-faire or paternalistic approaches to decision-making, respectively. Their underpinning rationale, however, often remained implicit (Chapters 2, 4). Similarly, we found that uncertainties concerning GI/GD (e.g., whether or not a client who claims so actually has it) propel implicit normative assumptions about what GI/GD is and what kinds of medical interventions it (does not) warrant (Chapter 4). "Non-traditional" treatment requests, e.g., a mastectomy without nipple replacement, were sometimes characterized as "strange [raar]" or "inconceivable [oninvoelbaar]" and consequently dismissed as a potential treatment and object of decision-making (Chapters 2, 4).

These (implicit) normative assumptions outlined above may hamper the SDM process. Chapters 4 and 6 described how they risk contributing to the "reification" of GI/GD, i.e., solidifying the clinical construct of GI/GD as an entity *causing* certain symptoms, *underlying* specific treatment requests, which may be *discerned* by HCPs from *other* (mental) health conditions. The impact of the reification of GI/GD on decision-making in the consultation room[36] should not be underestimated. There, it risks producing (largely implicit) normative images of "straightforward" GI/GD presentations and "good-functioning" clients as opposed to "complex" clients with co-occurring mental health problems. Chapter 2, for example, described how trans* clients with a so-called "early-onset" presentation of GI/GD are rendered more intelligible, convincing, and, consequently, suitable for more informative and deliberative approaches to decision-making.

Due to their impact on client-clinician trust and collaboration, these specific normative images may significantly hamper decisional deliberation. Chapter 3 detailed how, due to the above, some clients face a double bind in decision-making where they fear being open and honest with their HCP potentially jeopardizes (the duration or outcome of) the decisional process.[37] Like MacKinnon et al. (2020), Chapter 4 found that trans* clients engaged in diverse balancing acts to convince their HCPs: rehearsing (parts) of their gender development narratives, omitting specific treatment-related values (e.g., regarding fertility or a non-binary identification), and showing gender-related distress, while downplaying co-occurring mental health concerns. This dynamic echoes sociological work (e.g., Lane, 2020; Werner & Malterud, 2003) demonstrating how clients may feel compelled to convincingly enact their "sick role" to legitimize, in our case, their claims of having GI/GD, needing GAMC, and being competent to engage in SDM. Our findings highlight how this dynamic may have serious ethical consequences for the client-clinician partnership and the possibility of good decision-making: Due to fear and distrust, not all relevant information, values, and ethical challenges may be shared, considered, and deliberated (Chapters 2-4).

Beyond the challenges for decision-making, we believe that the above-described dynamic also challenges (the possibility of) arriving at good GAMC. We relate this to two specific characteristics of GAMC: its personally transformative nature and the epistemic privilege of trans* clients regarding their gendered experience. First, empirical work (Chapter 3; Beek et al., 2015; Huisman et al., 2022; Valentine, 2007) illustrates the myriad ways in which trans* clients experience their gender identity, the diversity of their treatment requests, as well as the divergent effects of GAMC on relationships, mental health, and sense of self. Indeed, beyond (but also due to) its physical effects on sex characteristics, GAMC affords trans* people a different being-in-the-world and identity. The existential (Ashley, 2022) and personally transformative (McQueen, 2017a, 2017b) nature of GAMC make for inherently unforeseeable effects: good decisions may be harmful and/or regretted later because the proof of the pudding is in the eating. Second, and relatedly, as "gender uniquely pertains to personal identity and self-realization," trans* clients arguably have an "epistemic privilege" vis-à-vis (their) GI/GD (Ashley, 2022, p. 1).

As HCPs' commitment to non-maleficence may preclude trans* clients from speaking openly and honestly in consultation rooms, it may seriously backfire. Without a validated marker, "scan," or other means to "measure" GI/GD, the latter may complicate not only the decision-making process but also the realization of good GAMC (Chapter 4). Remember, for example, Stefan (Chapter 4), who recounted a story of a client who concealed symptoms of a Dissociative Identity Disorder, or Daan (Chapter 3), who did not feel free to talk to his HCP about the ramifications of his wish to carry a child as a trans man on GAMC.

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[35] This includes harm to trans* clients, but also to HCPs, institutions, the legitimacy of GAMC and arguably hetero- and cisnormative socio-cultural values.

[36] On a macro-level, recent attention to so-called "rapid-onset gender dysphoria" (ROGD) illustrates how the reification of GI/GD may also instill barriers to decision-making or foreclose GAMC altogether (Ashley, 2020). The idea of ROGD as a clinically relevant subgroup of especially young trans men suddenly—and mistakenly—presenting with GI/GD purportedly caused by social contagion, mental health problems, (sexual) trauma, or internalized homophobia has already had far-reaching policy implications. For example, it has been mobilized to warrant blanket paternalism and curb and ban the provision of GAMC to (especially adolescent and young adult) trans* people in some parts of the United States and Europe (Ashley, 2020; Turban et al., 2021).

[37] This may also contribute to "double stigma" to trans* clients with both GI/GD and co-occurring mental health concerns (see Cooper et al., 2021).

We believe that the harm caused by HCPs' commitment to "do no harm" warrants the ethical question of to what extent HCPs should seek to prevent it. In light of the above, we agree with McQueen (2017b), for example, that it is questionable whether the possibility of post-treatment regret should have a bearing on the decision-making process. Without reliable predictors, post-treatment regret is an unpredictable outcome that cannot be entirely prevented by stringent decision-making approaches (Expósito-Campos, 2021; MacKinnon et al., 2021).

Practice implications and suggestions for future research

Our takeaway for clinical practice is this: We do not argue that HCPs have no obligation to prevent harm in decision-making whatsoever. While we do believe that the principle of non-maleficence in decision-making should account for the potential damages caused by HCPs' commitment to it, we also agree with Expósito-Campos (2021) that it remains their responsibility to discuss potential benefits and harms, deliberate and ensure that clients' decisions are thoughtful and informed. Yet, even when such obligations have been diligently met, some harm may be inevitable, and some clients may come to revise their decisions concerning GAMC over time—which may or may not be associated with feelings of regret. To reiterate Expósito-Campos, "*prevention and support are not exclusionary terms* [italics in original]" (2021, p. 276). In light of the potential (irreversible) effects of GAMC, "the logic of prevention" is understandable but should not equate the occurrence of harm, specifically regret, to clinical failure or flawed decision-making.[38]

We believe that rather than seeking to prevent it at all costs, the possibility of harm, such as regret, should be normalized and deliberated on throughout the decision-making process. More generally, we believe that HCPs and trans* clients should make their (implicit) intuitions, rationales, and justifications underlying their normative positions concerning SDM more explicit. These should include conceptual and ontological assumptions regarding the object of care, GI/GD. The central normative question then becomes: What should be the moral responsibility of HCPs (and clients) regarding SDM, particularly non-maleficence, and the possibility of post-treatment regret, and why?

We recommend further qualitative, ethical, and conceptual research into non-maleficence and regret in GAMC and their normative implications for SDM. Notably, in the context of ethical challenges related to SDM, we believe a dialogical empirical-ethical research project (Widdershoven et al., 2009) into "regret" is timely and worthwhile: How do HCPs and trans* people conceptualize regret? What are the experiences and needs of those regretting GAMC or caring for them? What should be the consequences of the potential occurrence of regret on the decision-making process? Furthermore, we advocate the development, implementation, and evaluation of CES in GAMC to aid HCPs and clients in grappling with questions on the moral responsibility of stakeholders regarding SDM, particularly regarding non-maleficence and regret.

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[38] Indeed, the empirical findings of MacKinnon et al. (2022) serve as a potent reminder that life after detransition may be challenging but "can be livable, meaningful, and fulfilling (Expósito-Campos, 2021, p. 276).

The normative ambiguity of SDM and the plea for a dialogical approach

This section elaborates on the heritage and inherent normative ambiguity of SDM. We describe how our empirical findings and pragmatic-hermeneutic ethics may put more conceptual and normative flesh on the bones of SDM. Specifically, we argue that good SDM in GAMC necessitates various renditions of, an openness toward, and dialogue about what good SDM may entail for *these* stakeholders concerning *this* intervention at *that* moment and in *this* context. We believe that such a take on good SDM does more justice to stakeholders' diverse and dynamic values and norms regarding good SDM and contextual and decisional characteristics specific to SDM in GAMC.

Although the central tenets of SDM are widespread and generally agreed upon, myriad interpretations have been put forward (see Makoul & Clayman, 2006). Notwithstanding this conceptual equivocality, over time, particularly the three-talk SDM model of Elwyn et al. (2017) gained momentum. Elwyn holds that the primacy of SDM rests on the assertion that self-determination is a highly desirable goal and that clinicians should aim to support clients in attaining it (2016). According to Elwyn, however, "[s]elf-determination in the context of SDM does not mean that individuals are abandoned. SDM recognizes the need to support autonomy by building good relationships and respecting both individual competence and interdependence on others" (Elwyn, 2016, p. 79). He puts forward both "self-determination theory" (Ryan & Deci, 2000) and "relational autonomy" (Mackenzie, 2008) as the theoretical foundations for SDM, with relational autonomy referring to the view that we are not wholly free, self-governing agents, but that actions and decisions invariably relate to our social relationships and mutual dependencies (Mackenzie, 2008). The reference to both self-determination and relational autonomy is suggestive of a normative ambiguity: How should these differing notions of client autonomy be weighed and fleshed out in practice?

Our empirical findings and theoretical perspective may elucidate this question. Many researchers investigating and/or implementing SDM in a specific care practice do so by deductively applying a pre-existing SDM model (e.g., Elwyn, 2016; Stiggelbout et al., 2015). A risk of a top-down interpretation (and implementation) of SDM is that it reduces and simplifies the messiness and complexity of the clinical encounter (in GAMC and elsewhere) and overlooks the specific decisional context. We opted for a more inductive and dialogical approach, asking: What does *good* SDM in GAMC entail? The conceptual openness with which we approached SDM reflects our view that good SDM should be closely intertwined with the decision and context at stake (Chapters 3, 4, 7). In our view, good SDM cannot be determined by applying a set of a priori values and norms but should be established by stakeholders in practice, time and again.

This conviction is theoretically informed by a pragmatic-hermeneutic take on clinical ethics (J. Dewey, 1957; Hartman et al., 2020; Inguaggiato et al., 2019; James, 1907; Widdershoven & Molewijk, 2010). According to these schools of thought, norms and values are not doctrines but instruments that attain their meaning within the practices they are put to use. They thus require interpretation and application to a specific situation. In other words, every decision may entail fundamentally different "facts," which may, in turn, be valued and judged divergently by the stakeholders involved. For example, we found that clients' (implicit) conceptual assumptions regarding GI/GD impacted their principles and values related to SDM and underpinned diverse norms regarding good SDM (Chapter 3).

Seen through a pragmatic-hermeneutic lens, the diverse and dynamic nature of HCPs' and clients' decisional values and norms related to good SDM (Chapters 3, 4) and the adoption of a variety of decision-making approaches (Chapters 2, 4) is not surprising or problematic, but the consequence of stakeholders reconsidering their moral presuppositions and convictions related to SDM in light of the particular decision and situation at hand. The latter arguably lies at the core of a pragmatic-hermeneutic and dialogical understanding of good SDM (Hartman et al., 2020; Widdershoven & Molewijk, 2010).

By emphasizing the singular and contingent character of each decision and not assuming stakeholders' (interpretations of) norms and values about decision-making, a pragmatic-hermeneutic approach to SDM may better capture the decisional and normative complexity of GAMC than, say, a priori principles such as "respect for self-determination," "beneficence," and "non-maleficence." Indeed, we argue that jointly shaping SDM and attuning to the "timely, the local, the particular, and the contingent" (Abma et al., 2010, p. 245) is a way of co-creating good SDM.[39]

Attending to "the timely, the local, the particular, and the contingent" to establish good SDM requires collaborative work, communication, and attunement on both sides of the dyad. A pragmatic-hermeneutic approach to clinical ethics may provide more theoretical depth to these processes. Both pragmatism and hermeneutics emphasize how our understanding and valuation of the world are inherently based on our specific point-of-view and pre-understandings (Gadamer, 1975; Hartman et al., 2020; Inguaggiato et al., 2019; James, 1907; Widdershoven & Molewijk, 2010). While this might seem suggestive of a rejection of objectivism (i.e., a "god perspective" or "singular truth") and acceptance of relativism (i.e., all perspectives are equally valid), this is not necessarily so (Widdershoven & Molewijk, 2010). Instead, hermeneutics and pragmatism underline the importance of openness toward others' perspectives for moral learning. Through the exchange of views, stakeholders may arrive at what Gadamer called a "fusion of horizons:" not a "god perspective" but the enrichment of one's situated perspective with those of others (Gadamer, 1975).

This latter process requires a certain attitude and the willingness to engage in dialogue. For hermeneutics, this entails that stakeholders acknowledge the limits of their perspectives, the fundamental differences between theirs and others," and an intention to bridge the gap between the two (Widdershoven & Molewijk, 2010). This bridging comes about in a critical but constructive dialogue in which one is willing to "move" and "be moved by" others. Similarly, philosophical pragmatism argues that moral learning necessitates an attitude in which stakeholders are amenable to (1) shift their attention from principles and theory to the concrete issue at stake; (2) accept the fallibility of one's moral principles and intuitions and focus on their "cash value," i.e., practical consequences; and (3) to strive toward inter-subjective solutions through a shared and democratic inquiry (Inguaggiato et al., 2019).

Although the above might suggest otherwise, our empirical findings and theoretical approach indicate that this dialogue and inquiry does not have to be an (overly) cognitive and rational endeavor. For example, while developing the GenderJourney (Chapter 7), respondents noted that an overly analytical and verbally-oriented tool would run the risk of not meeting the needs and capabilities of certain end users, e.g., those with cognitive disabilities or autism spectrum disorder. This notion aligns with pragmatism and hermeneutics, which do not grant a priori importance of one value or epistemic source over others. Indeed, our theoretical understanding of good SDM stresses how both HCPs and trans* clients bring to the consultation room unique and limited sources of (moral) knowledge, e.g., lived and clinical experience, technical, body- and self-knowledge in relation to SDM (Elwyn et al., 2016; Makoul & Clayman, 2006; Stiggelbout et al., 2015).

Practice implications and suggestions for future research

In practice, bridging the fundamental differences between HCPs and trans* clients may be a complicated or even unattainable ideal. Indeed, Chapters 2-4 highlighted the contingency of clients' ability to participate in SDM on socio-economic and cultural circumstances and potentially co-occurring mental and medical concerns. Furthermore, we found that HCPs and clients differed considerably in their willingness to engage in SDM and held divergent normative intuitions about SDM (Chapters 2, 4). Calling for shared and democratic inquiry as the moral basis for SDM puts the burden on both sides of the dyad. Yet, our empirical findings arguably raise the question of whether this is attainable and ethically justifiable in the context of client-clinician power differentials (Chapters 2-4). We elaborate further on this point below. For now, we suggest that acknowledging that the consultation room is not a level playing field (i.e., power differentials) puts a prima facie duty for elucidating their and clients' SDM-related values in the court of HCPs.

Directions for future clinical research include mapping pitfalls and best practices of clinicians regarding the elucidation of their and their clients' SDM-related norms and values: what (verbal, written, and/or creative) methods are effective with what subset of trans* clients? How can these practices be valorized and made more accessible? Future conceptual and normative research into SDM should flesh out what pragmatic-hermeneutic ethics (and other ethical theories, such as care ethics) entail for SDM. Such research should home in on rather than bypass the complexity and messiness of clinical practice and grapple with the diversity of stakeholders' willingness and ability to engage in SDM.

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[39] And perhaps GI/GD and GAMC, too. Fleshing out a dialogical, pragmatic-hermeneutic approach to the object of care and GAMC itself is beyond the scope of this Discussion. Chapter 6 does illustrate, however, how in the consultation room, one of the ways in which GI/GD may be enacted, is through joint narration.

Reflections on integrative CES and the development of the GenderJourney

This section reflects on a pragmatic-hermeneutic approach to CES, particularly ethics support tools. We stress the importance of CES in the current context of polarization of normative positions in GAMC, argue why the GenderJourney is a form of *integrative* CES (Hartman et al., 2020), and highlight some of the challenges of pragmatic-hermeneutic CES and ethics support tools based on our experiences while developing the GenderJourney.

During the research described in this thesis, social and academic discourse concerning (decision-making in) GAMC polarized considerably. On the one hand, a group of stakeholders argue that the role of HCPs, especially MHPs, in decision-making forms an unjust barrier to trans* clients' self-determination (e.g., Ashley, 2019; Cavanaugh et al., 2016; Schulz, 2018). Contrarily, others (e.g., Evans, 2021) believe that the principle of non-maleficence is insufficiently protected in current decision-making practices. Our findings showed how, on the micro-level of the consultation room, power differentials and normative contestations may contribute to the solidification of normative assumptions on both sides of the dyad and, consequently, a reluctance to engage with others and partake in a dialogue about what good SDM, as well as good GAMC, entails (Chapters 4, 5). This particularly concerned sharing and jointly investigating concomitant ethical doubts and uncertainties.

As this thesis illustrated, CES may help analyze the key points within these debates critically yet much more constructively (Chapters 2, 7). CES enables stakeholders to move beyond merely voicing opinions and criticisms. It does so by elucidating their normative (pre)suppositions and supporting them in explicit moral deliberation, e.g., by appreciating their and others' relevant values and norms. As such, CES may improve the quality of care, cooperation, and moral competencies (Rasoal et al., 2017). In GAMC, CES contributed to making HCPs more aware of the moral dimensions of their work, increased their ability to respond to ethical challenges, and, importantly, promoted mutual respect and open communication (Feldman et al., 2022; Hartman et al., 2019; Mabel et al., 2019). Particularly focused on recognizing and bracketing normative presuppositions and value judgments, we believe (and have illustrated how) a pragmatic-hermeneutic take on CES may provide an antidote to the impact of the polarized debate in the consultation room in GAMC (Chapters 2, 7; de Snoo-Trimp et al., 2022; Hartman et al., 2019, 2020; Vrouenraets et al., 2020).

We argued in Chapter 7 that the GenderJourney can be understood as *integrative* CES, i.e., a form of CES with theoretical roots in pragmatism and hermeneutics embedded in actual care practices and attuned to the needs of its end-users. After expounding on the former, we illustrate how (the development process of) the GenderJourney also advances integrative CES itself. The GenderJourney meets the five key characteristics of integrative CES outlined by Hartman et al. (2020). First, the GenderJourney (1) is *positioned within the actual care practice* of GAMC, where it may help to make invisible moral frameworks, normative assumptions, and intuitions concerning SDM more explicit. Second, it (2) *involves new perspectives* both in the development process, and its purported use: including HCPs and clients in development and dialogue is arguably indispensable given the theme of SDM and as their (hitherto unexamined) perspectives enable moral learning. Third, throughout the development, we sought to (3) *create co-ownership* of GenderJourney's use and follow-up, not only by including end-users of the tool in the co-creation workshops but also by regularly liaising with board members and senior clinicians and researchers of the Amsterdam UMC Center for Expertise on Gender Dysphoria (CEGD) to ensure that the tool met stakeholders' needs and practice. Through its practical and normative open-mindedness, the GenderJourney also promotes co-ownership between HCPs and clients in the consultation room, where it may serve various practical needs and aims and help to establish different renditions of good SDM. Fourth, we have been (4) *mindful of GenderJourney's follow-up throughout the development process* and are working toward implementing and evaluating the GenderJourney using responsive evaluation (Abma et al., 2019). In the consultation room, the GenderJourney explicitly encourages iterative use and evaluation between HCPs and clients. Finally, the GenderJourney was (5) *developed through an emerging design.* Integrative CES cannot be planned from start to finish, and a flexible and creative design is essential to respond to changing needs and insights (Hartman et al., 2020). Arguably, we applied this axiom not only to the development of the GenderJourney but also to integrative CES.

An important new advancement of integrative CES concerned the development of an ethics support tool for both HCPs and clients. Indeed, what is unique about GenderJourney's development process is the methodical and normative move to include both HCPs and trans* clients as co-creators. Broadening the scope of co-creators was indispensable, given the theme of SDM. In fact, GenderJourney's co-creation workshops were an (in)direct way for HCPs and trans* clients to jointly engage in, work on, and grapple with SDM.

This process allowed us to better attune the *focus* of the GenderJourney to the needs of end-users. For example, CES tools often start with and presuppose an experienced ethical question or challenge (de Snoo-Trimp et al., 2022; Hartman et al., 2018; Molewijk et al., 2008; van Schaik et al., 2022). We found that stakeholders' CES needs were broader, e.g., clarifying the facts or decisions at stake or establishing a good (enough) client-clinician relationship. Moreover, ethics support tools tend to foreground moral/argumentative reasoning, while stakeholders emphasized how ethical challenges concerning SDM arise *within* the client-clinician relationship and are often experienced as affects and emotions. A cognitive tool directed solely at explicitly formulated ethical challenges of SDM thus ran the risk of insufficiently addressing both the relevant context and stakeholders' CES needs.

To do justice to the latter, we aimed to *locate* the GenderJourney directly within the client-clinician relationship to foster moral learning, deliberation, and handling ethical challenges *in vivo*. This localization entails a more integrative form of CES as the tool is embedded in the consultation room and takes the client-clinician relationship and the client's journey as its (principal and theoretical) vantage point rather. Our rationale was that better, trusting collaboration and transparent, effective, context-informed communication would help to short-circuit eventual SDM-related ethical challenges and foster the dyad's resilience to make such challenges more explicit, discuss, and tolerate them (Feldman et al., 2022). Beyond this pragmatic argument, localizing the GenderJourney within the consultation room arguably better accounts for the notion that SDM-related ethical challenges are shaped in and by the client-clinician relationship.

Practice implications and suggestions for future research

In what follows, we describe three questions GenderJourney's development process raised. These questions challenge the normativity of a hermeneutic-pragmatic approach to CES, particularly its emphasis and dependency on an egalitarian and democratic dialogue to reach and justify normative conclusions. Our experiences show how these assumptions are not self-evident. We translate these questions into directions for future research.

First, what if stakeholders do not want to engage in dialogue? We argued that the polarized state of the discussion concerning (decision-making in) GAMC warrants more explicit moral deliberation and dialogue. However, it also prompted a situation where some stakeholders refused to talk with one another, with normative positions appearing incommensurable. To illustrate, during the so-called "trans summer of rage" of 2021, transgender activists affiliated with "Trans Zorg Nu! [Trans Care Now!]" demanded radical self-determination and the total depathologization of GAMC. During protests outside of the doors of the CEGD, they chanted: "Fuck de VU, trans zorg nu! [Fuck the CEGD, trans care now!]." They did not follow up on invitations to elaborate on and discuss their manifesto (see Trans Zorg Nu!, 2021). Simultaneously, conservative Dutch voices considered GAMC for youth immoral and argued against the criminalization of conversion therapy (Voorzij, n.d.).

Indeed, "[in] our pluralist society, people may be unwilling to [engage in a democratic dialogue]. For instance, participants may seek to adhere to principles without "unstiffening" them" (Inguaggiato et al., 2019, p. 435). Some may argue that due to power differentials, the dialogue will never be truly democratic and hence choose to pass up on it (Trans Zorg Nu! 2021). The above raises two questions that remain relatively underexplored in the extant literature on SDM and (pragmatic-hermeneutic) CES: In the absence of a democratic attitude or willingness to engage in dialogue, should stakeholders be brought to the same table, and if so, how? Follow-up research should identify stakeholders' motivations for not wanting to engage in dialogue in the context of (developing) CES. Studying and developing ways to account for voices absent from the dialogue would be worthwhile. This holds especially for a pragmatic-hermeneutic approach to CES, as it takes dialogue as the justificatory locus of normative conclusions.

Next, CES strives toward epistemic justice. A question we faced during the development of the GenderJourney is whether and to what extent a pragmatic-hermeneutic CES tool can account for the ways client-clinician power differentials may hamper the latter. As noted by Elwyn, "[one] of the most critical issues [in SDM] is the role of power. A person who seeks help immediately positions themselves in the role of a supplicant [with the] … associated vulnerability and dependence" (2021, p. 1594). Chapters 2-6 illustrate how client-clinician power differences in GAMC may thwart the dialogue and collaboration necessary to arrive at good SDM and, consequently, good GAMC. In traditional CES, such as MCD, the facilitator seeks to acknowledge and counteract power differentials to foster a shared intersubjective inquiry (Inguaggiato et al., 2019). Similarly, the GenderJourney aims to facilitate the unveiling of decisional power differentials and encourage a dialogue about how stakeholders relate to them. Follow-up research should address whether the GenderJourney and pragmatic-hermeneutic ethic support tools, more generally, can do justice to both "loud" and "dim" voices in practice (Hartman et al., 2018).

Third, and relatedly, a central question we faced during the co-creation workshops was how the GenderJourney should relate to structural and/or institutional barriers to good SDM. For example, various participants commented that being dependent on multiple steps/levels of multidisciplinary decision-making, the need for a formal diagnosis, and clinical guidelines or insurers hampered good SDM in practice. As such, Noah (trans* client) questioned the usefulness of an ethics support tool altogether, as he felt more structural changes were warranted. Alternatively, Barbara (MHP) noted how using an initial version of the GenderJourney in practice also laid bare structural impediments to SDM and found it helpful in being more transparent and honest about (how she relates to) these impediments in the consultation room. The latter is reminiscent of Hartman et al. (2018), who found that their ethic support tool stimulated HCPs' reflection on the validity and usefulness of clinical guidelines. Together, these comments illustrate *and* question the efficacy of ethics support tools and challenge the tendency of the latter to focus on the "problem" rather than the problem's contextual and systemic roots. We emphasize that ethics support tools are *tools* rather than ethical cure-alls. To avoid ethics support tools merely touching upon local and isolated ethical challenges, the underlying structure, policy, and context of these challenges should be considered. We argue that ethics support tools should address such broader factors (e.g., by making them more explicit so stakeholders may position themselves in relation to them) but also be positioned in a way that allows for their development and use to inform structural and institutional change.

Concluding remarks

The number of those seeking GAMC is increasing exponentially, fueling debates and culture wars concerning the rights of trans* people, the validity of GAMC, and decision-making approaches for GAMC. In this convoluted context, stakeholders in gender identity clinics face myriad ethical challenges related to the question: What is *good* SDM? With a wide aperture and a 5-year shutter speed, this thesis outlined the ethical and conceptual complexities of SDM in GAMC. Employing various methods and theoretical approaches, we provided a thorough overview and understanding of the ethical challenges experienced by stakeholders in practice, as well as the context in which these challenges arise. The resulting image is a testament to the inherent moral, normative, and contextual dimensions of GAMC and foregrounds the importance of addressing the ways SDM and its concomitant ethical challenges are inextricably linked to the actual content and context of the decisions at stake.

Ongoing deliberation on what good SDM should entail is vital. Indeed, our empirical findings and a pragmatic-hermeneutic approach stress that good SDM in GAMC necessitates various renditions of, and an open dialogue about what it may entail for *these* stakeholders concerning *this* intervention at *that* moment and in *this* context. Not only in the consultation room—where norms and values pertaining to decision-making are varied, dynamic, (ostensibly) contradictory, and often implicit—but also within institutions and society at large.

This thesis offers insight and support to those in clinical practice and provides a basis for future research on SDM and CES in GAMC. Its findings could also be relevant for those in care practices that, like GAMC, involve decisions characterized by ontological ambiguities, epistemic uncertainties, and normative contestations. Finally, we believe this thesis is relevant to those developing, providing and researching CES and CES tools, both in and outside GAMC. By jointly creating CES with HCPs and trans* clients in GAMC, we sought to advance CES and contribute to good SDM. We hope that the findings and tool presented in this thesis provide a foothold for ongoing, critical-constructive dialogues toward better SDM in GAMC and beyond.

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Epilogue

my (KG's) fascination for gender-affirming medical care was partly borne out of academic interest in bioethics and the impression—while starting medical school—that the myriad ethical and conceptual questions in this care practice remained underexplored. My interest in trans* care also stemmed from my having a queer sexual identity and the feminist belief that we ought to be attentive to, care for, and empower others within the LGBTQ+ community, especially vis-à-vis (inequitable) healthcare systems.

My conviction of the relevance of this research only intensified as I started as an MSc research intern and, later, as a junior medical doctor for the Amsterdam Center of Expertise on Gender Dysphoria (CEGD). I had emphatically told myself and the supervisor of my MSc thesis (rewritten as Chapter 2) I would not enter this "moral minefield" as a clinician: I believed that the paternalism and implicit (binary) normative assumptions concerning gender I observed as an intern would preclude me from offering what I thought was good care. Yet, here I found myself with my feet in the mud, where I felt the ethical challenges described in this thesis: as bigger or smaller knots in my stomach and chest as I biked to work, during supervision and multidisciplinary meetings, while facilitating moral case deliberations, and in the consultation room.

Next to rationalizing them by my being a novice, I considered these (bodily) experiences manifestations of values at stake. Martha Nussbaum (2001) reminds us that "[e]motions … involve judgements about important things, judgements in which, appraising an external object as salient for our own well-being, we acknowledge our own neediness and incompleteness before parts of the world that we do not fully control" (p. 17). Below, I present some knots, questions, and critical incidents I experienced over the years. I do not aim to provide an exhaustive overview; instead, these incidents serve to illustrate how I, and we, as researchers, were entangled in the practice we researched.

The first critical incident concerns a role conflict of the clinical ethicist-researcher. While drafting the manuscript for Chapter 2, there were concerns within the CEGD regarding the public reception of certain quotes. They requested the redaction of two expressions they considered "overly primary" and potentially harmful for the CEGD and, consequently, trans* clients. On the one hand, I believed this request raised serious concerns about my academic freedom. On the other hand, I felt a moral responsibility to respectfully attend to (the interests and vulnerabilities of) our participants. This dilemma was complicated by a tension inherent in the role of clinical ethicists. As Hartman et al. noted about the collaboration between the CEGD and ethics support staff of the department of Ethics, Law, and Humanities of the Amsterdam UMC: "There is a sensitive balance between, on the one hand, being critical and explicitly normative and, on the other hand, maintaining the relationship and trust that the clinical staff put in ethicists as critical observers" (2019, p. 257). Indeed, without trust, the doors close, and the walls go up. Throughout this research, the research team and I navigated the (ever-changing) line between maintaining trusting relationships and overt criticism and critique. Consequently, the story this thesis can tell is one predominantly produced by a descriptive and emic perspective on our interlocutors' beliefs, values, and norms. This is not to say that it is rendered toothless. In fact, the ongoing conversations about the organization, findings and output of this research within the CEGD evidence how research can be a tool for ethics support insofar as one of its main aims is to increase awareness, sensitivity, and a critical yet constructive dialogue on (implicit) normativity and morally pressing issues.

The next set of knots pertains to my double role as clinician-researcher. The following critical incident took place on my first day of work. My clinical supervisor fell ill, and another junior doctor showed me around the clinic. As I (re-)introduced myself to clinicians and support staff, I felt confused: are these my colleagues, research participants, or both? Who and what am I to them? Should I ask for consent if I jot down impressions of a conversation (overheard) by the coffee machine? Discussions about these questions within our research group laid bare fundamental differences in methodological assumptions: one supervisor asked the rhetorical question: "Your data collection doesn't start until you've had people sign the informed consent sheet and started the tape recorder, right?" This remark proved a catalyst for discussions broadly aimed at disciplinary and methodological reflexivity, the fundamental question being: What methods can and are we allowed to use, and why?

Another set of questions concerned epistemological reflexivity: the impact of our various (double) roles and positionalities as research team members on what knowledge we could generate. I wondered: How does my being a clinician impact what professionals and trans* clients feel comfortable divulging during the interviews? How does my gradual shift from "fly on the wall" to "going native" (as one of the professionals said about a year into my clinical work: "you're one of us, now") play a part in this? Being a clinician likely enhanced my responsiveness to practice, but also increased the likelihood of interviewer bias. For example, during the interviews with clinicians, I found myself asking questions they (and I) considered self-explanatory and obvious given my clinical experience. At the same time, my being a clinician proved beneficial in building rapport with professional respondents. I became more acutely aware of the latter as I analyzed their interview transcripts with a trans-identified member of our research team. He noted how the respondents divulged their frustrations and experiences rather frankly, and wondered whether he would have been met with the same honesty (which they deemed unlikely). We hypothesized how the reverse probably held true for us interviewing and building rapport with trans* clients. What's more, both of us noticed how our reading of and response to the transcripts differed: the experiences of trans* clients being somewhat of a black box to me and those of clinicians to him. Talking about these stark and subtle differences helped us think through the impact of our personal and professional positionalities on the data we were able to generate, and informed both practical and methodological decisions we took later on.

Finally, this thesis is inextricably linked to my clinical experiences. My double role as a clinician-researcher provided both unique opportunities and (ethical) challenges. For example, beyond holding up as I was adjusting to the role of a medical doctor—thankfully without a white coat—I soon found myself confronted with my presuppositions regarding trans clients' decisional needs and normative convictions: while I thought many would take offence at my being a "gatekeeper" (some did), I also found (apparent) contradictions, uncertainties, and layered wishes. If anything, the three years I spent in the trenches of transgender healthcare impressed on me a deep sense of the intricacy—I would almost go as far as to call it the impossibility—of what is (implicitly and perhaps socially) expected from clients and professionals in gender-affirming care, i.e., to offer a sense of certainty amid uncertainty (see Chapters 2-6). This research was both a burden and a relief as it forced me to make this not-knowing and (moral) uncertainty explicit (and come to terms with it psychologically as a somewhat conflict-avoidant, perfectionistic novice). Paradoxically, this sobering coming to terms allowed me to bear and learn from the knots in my chest and opened the door for empathy and contact with my clients, colleagues and self as well as the theme of the research.*

While we decided early on that, due to privacy reasons and considerations of consent, our many personal impressions, critical incidents, questions, and dilemmas would not be included in the dataset, this thesis is steeped in them. In a way, this thesis could be read as a critical self-reflection (Mol, 2008), not just on the research team and me but on the field of GAMC in the Netherlands. Through its collective knot-untying, I hope it contributes to what Harry Kunneman (2017) calls a "mound in the swamp" [terp in het moeras], a foothold from which to acknowledge, appreciate and learn from the soggy complexities of and "instructive friction" [leerzame wrijving] between ourselves, others, and the world.

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Summary

This thesis has two central aims. First, to gain insight into the moral and conceptual landscape of gender-affirming medical care (GAMC) for transgender (trans*)[40] adults, specifically concerning shared) decision-making (SDM). Second, to (2) co-create an ethics support tool to foster (a joint reflection on) *good* SDM and aid healthcare professionals (HCPs) and trans* clients in recognizing and handling its concomitant ethical challenges. To these ends, we addressed the following research questions:

- Which ethical challenges do HCPs working in a multidisciplinary GAMC center in the Netherlands experience? (Chapter 2)

- What are the ethical challenges and norms concerning SDM of adult trans* clients who received GAMC in the Netherlands? (Chapter 3)

- What are the ethical challenges and norms concerning SDM of HCPs providing GAMC to adult trans* clients in the Netherlands? (Chapter 4)

- What are the conceptual assumptions regarding decision-making and client autonomy in two care models for GAMC, and what are their key ethical challenges? (Chapter 5)

- How do HCPs in GAMC "enact" Gender Dysphoria in daily practice, and what normative assumptions concerning GD do these enactments reflect? (Chapter 6)

- What ethics support tool can foster (a joint deliberation and reflection about) *good* SDM in GAMC and help stakeholders to recognize and handle its concomitant ethical challenges? (Chapter 7)

Chapter 1 introduced the research aims against the background of GAMC, SDM, and the need for theme- and practice-specific CES. Trans* individuals have gender identities or expressions that differ from their sex assigned at birth. Increasingly, trans* people seek GAMC: interventions such as feminizing (de-masculinizing) and masculinizing (de-feminizing) hormones and/or surgeries. GAMC may improve the quality of life of trans* people by affirming and expressing their experienced gender, thereby alleviating what is currently classified as "Gender Incongruence (GI)" or "Gender Dysphoria (GD)." Since the late 1970s, stakeholders have worked toward developing standards of care and establishing the guiding ethical principles of GAMC, such as physical health, mental well-being, self-actualization, and safety. Still, both HCPs and trans* clients appear to experience ethical challenges related to the question: What is *good* decision-making?

Increasingly, stakeholders in GAMC call for more *shared* decision-making (SDM). SDM emphasizes the importance of personalized care, shared ownership in decision-making, and responsibility for choosing (or deferring) treatment. SDM is becoming ever more prominent in healthcare (policy) and is considered the ideal decisional model, especially for so-called "preference-sensitive decisions," i.e., decisions where more than one reasonable treatment option is available. GAMC is a preference-sensitive care practice *par excellence*. Indeed, given the ever-expanding availability of GAMC options and the diversity of clients' needs and values regarding their medical transition, the growing appeal for SDM in GAMC is not surprising. Yet, SDM is normatively and conceptually ambiguous, raising the question of what SDM actually is and how it should be attuned to the specifics of GAMC.

These questions on SDM are becoming more pressing in the context of increasing referrals to and waiting lists for GAMC. The increasing number of those seeking GAMC entails that more people are (and will be) confronted with such questions. Additionally, some see the "gatekeeper role" of mental health professionals (MHPs) in decision-making as one of the causes of the growing waiting lists and hence dispute it. Moreover, questions about SDM arise in a polarizing social and academic discourse on gender diversity in general and (decision-making in) GAMC in particular: the voices arguing for radical self-determination or, conversely, the restriction or criminalization of GAMC are getting louder. The above makes the question of what constitutes good SDM in GAMC not only contested and uncertain but also highly urgent.

Clinical ethics support CES aims to help stakeholders deal with ethical issues in clinical practice. Thereby, it seeks to improve moral competencies, cooperation, and quality of care. CES may aid trans* clients and HCPs in recognizing and handling ethical challenges about SDM but also help establish a reference for what good SDM in GAMC should entail. Increasingly, CES is offered in GAMC through ethics consultations and Moral Case Deliberation (MCD). CES may also be offered, for example, through the co-creation of theme- and practice-specific CES tools. It could prove fruitful to co-create an ethics support tool focused on the theme of SDM and the practice of GAMC. This thesis examines how HCPs and trans* clients in GAMC may be supported in fostering good SDM and dealing with related ethical challenges. It investigates what type of ethics support tool suits these aims best.

The development of this tool necessitates a thorough understanding of stakeholders' needs and the moral, conceptual, and contextual landscape of SDM in GAMC: What ethical challenges (concerning decision-making) are stakeholders confronted with when providing or receiving GAMC? How do these challenges relate to care models and clinical guidelines? What is the impact of stakeholders' conceptual and normative assumptions regarding GI/GD on (the provision of) GAMC? Research into these questions is sparse yet vital to inform the co-creation of a theme and practice-sensitive CES tool and to further the dialogue on what *good* SDM in GAMC entails. We grapple with these questions in the first two parts of this thesis. Part A describes the ethical challenges and norms of HCPs (Chapters 2, 4) and trans* clients (Chapter 3). Part B elucidates the conceptual and normative assumptions regarding decision-making and client autonomy

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[40] Transgender (trans*) is an umbrella term referring to various gender identities, roles, and expressions differing from those (normatively expected from) one's sex assigned at birth.

(Chapter 5) and investigates how HCPs "enact" GD in GAMC (Chapter 6). Informed by the previous chapters, Part C describes the co-creation of GenderJourney, a visual ethics support tool (Chapter 7). In keeping with a pragmatic-hermeneutic and dialogical take on CES, we seek to sensitize SDM ("theory") to the field of GAMC ("practice") and vice versa, with the ultimate aim of improving current decision-making practices in GAMC.

Part A: Mapping stakeholders' ethical challenges and norms

Chapter 2 describes a focused ethnography of the ethical challenges of HCPs working in a specialized multidisciplinary GAMC center in the Netherlands. Over seven months, we observed multidisciplinary team meetings and individual consultations. Furthermore, we analyzed transcripts and reports from MCD sessions. Through a thematic analysis, we found that professionals faced ethical challenges in (1) determining the circumstances under which trans* individuals should be rendered *in*eligible for treatment; (2) shaping the content of treatment in the absence of a firm evidence base and the context of "non-traditional" treatment requests; (3) dealing with the multidisciplinary nature and sequential order of various treatments; (4) establishing the strictness of and possible variations from clinical guidelines; (5) assessing the "presence" and "authenticity" of GI/GD; and finally (6) SDM. Ethical challenges concerning SDM proved especially pressing and urgent. Indeed, HCPs often described balancing an experienced duty to non-maleficence and a commitment to respecting clients' self-determination. In practice, this balancing act led to diverse moral and ethical questions, such as: Should we start treatment when a client does not oversee or cope with the consequences of treatment? Who should decide whether a "non-traditional" treatment request is permissible? What are the moral boundaries of the treatment options?

Chapter 3 and **Chapter 4** aim to descriptively elucidate the decisional ethical challenges and norms of trans* clients and HCPs, respectively. We conducted 10 semi-structured interviews with adult Dutch trans* people who received GAMC and 11 semi-structured interviews with HCPs working in two distinct Dutch GAMC settings for adults (academic and non-academic). We analyzed our interview data using thematic analysis. Many (especially trans*) respondents were more inclined to speak about what good or right decision-making ought (not) to be instead of expressing ethical uncertainty or doubt. Therefore, we decided to identify both ethical *challenges* and ethical *norms*. Furthermore, in our analysis, we differentiated between respondents' *explicitly* expressed and *implicit* ethical challenges and norms we ascertained indirectly from the transcripts. Finally, we elucidated the *context* in which the latter emerged.

For trans* clients, we identified the following overarching ethical norms and questions: (1) Clients ought to be in the lead, *but what should this entail?* (2) Harm should be prevented, *but who should be responsible?* (3) The decision-making process ought to be attuned to the client, *but what should this attunement involve?* We italicized the questions above as we saw that clients' diverse decisional values frequently corresponded to divergent ethical norms, of which the practical and ethical consequences regularly varied.

They thus require iterative interpretation and deliberation. We also described how clients' ethical challenges and norms often pertain to the specific context of (power differences within) the client-clinician relationship. Clients also related their ethical norms concerning SDM to implicit and explicit notions about what GI/GD is (not): more laissez-faire in the case of "natural variation" and more paternalistic in the case of a "mental disorder." We also found a strong effect of time, partly related to the transition process itself, i.e., clients' values regarding their treatment and good decision-making often shifted.

HCPs' overarching ethical challenges were: (1) How should we divide and define our decisional roles and bounds? For example, when should we delay or withhold treatment? (2) How should we negotiate decision-making as a (multidisciplinary) team? For example, what is my responsibility in multidisciplinary decision-making? (3) How should we navigate various decision-making temporalities? For instance, what should be the impact of potential future consequences on current decision-making? We found that these ethical challenges were embedded in a context characterized by epistemic and normative uncertainties regarding (1) GAMC's guidelines, evidence, and outcomes and (2) the boundaries and assessment of GI/GD.

Overarchingly, we found that HCPs often implicitly adopted different decision-making models. Similarly, clients appeared to arrive in the consultation room with various needs, fears, and dynamic normative views regarding decision-making but did not regularly share these with their HCPs. Together, these findings illustrated how decision-making in GAMC is best understood as an ongoing dynamic process, constantly—yet often implicitly—negotiated among various stakeholders and distributed across places and times. In our view, the diversity, complexity, and temporally contingent character of stakeholders' decisional ethical norms underscore the need to diversify and explicitly attune decision-making to the dyad, intervention, and context at stake. Therefore, we argue that the first step toward *good* decision-making is to make the content and context of the specific decision and stakeholders' corresponding ethical norms and values more explicit to allow joint dialogue and deliberation. Given its pervasive impact, this endeavor requires attentiveness to how the decisional context (such as the utilized care model) may cultivate or hamper the latter.

Part B: Elucidating conceptual and normative assumptions

Chapter 5 explores clinical ethical challenges concerning decision-making in light of two different care models used in GAMC: the Standards of Care 7 (SoC7) and the Informed Consent Model (ICM). The SoC7 hold that MHPs are best prepared to diagnose GI/GD and assess clients' eligibility for GAMC given their specific training and because GAMC is often intensive and (partially) irreversible. Contrarily, the ICM emphasizes clients' self-determination and minimizes the role of HCPs in decision-making to provide information and obtain informed consent. This Chapter aims to clarify the conceptual and normative assumptions regarding decision-making and client autonomy in these care models and to ultimately better understand key ethical challenges in practice.

Our conceptual analysis shows how SoC7 recommends both assessorial and supportive tasks for MHPs. These dual tasks indicate a tension between weak paternalistic and deliberative decisional assumptions and conflicting conceptions of client autonomy. We describe how this tension contributes to a role conflict on the part of HCPs, which may be met with apprehension, mistrust, and selective information exchange on the part of clients. We conclude that this dynamic may impinge on the client-clinician relationship, undermine decisional deliberation, and, ultimately, the realization of *good* care.

At first glance, the ICM appears to bypass this ethical predicament. However, our analysis illustrates that in the ICM, collaborative decision-making and attuning to clients' individual decisional needs could be hampered by a legalistic and narrow interpretation of informed consent and client autonomy. Our analysis also shows that the conceptual and normative understanding of informed consent in (the various local care models that fall under the rubric of) the ICM is often ambiguous. This ambiguity may lead to questions about what should be considered sufficiently informed consent in practice.

Based on our analysis, we suggest that foregrounding one normative model for decision-making is no moral panacea. We conclude that the first steps toward good SDM in GAMC are acknowledging and discussing its inherent normative and moral dimensions.

The prior studies showed how stakeholders' and guidelines' normative convictions concerning SDM in GAMC often hang together with conceptual assumptions regarding GI/GD. This relation is also evident in the history of GAMC: paternalistic assessment and decision-making processes were often justified as the object of care was conceptualized as a (mental) disorder. Against the background of the recent depsychopathologization of GI/GD, **Chapter 6** examines how the object of GD is shaped in current clinical practice and what norms regarding GD and GAMC this reflects. To this end, we draw from material semiotics, which posits that material and immaterial objects, such as GD, are not static but enacted by human and non-human actors and practices. Objects become (ontologically) different and multiple depending on how a given constellation of actors and practices engage with them. In this Chapter, we aimed to clarify how GD is enacted in daily practice by looking at how HCPs and clinical guidelines "order" it, i.e., how they seek to get a grip on GD. We analyzed (1) 16 interviews with MHPs and relevant excerpts from (2) SoC7, and (3) the *Diagnostic and Statistical Manual for Mental Disorders*, version 5. Through a thematic analysis, we identified four ways in which HCPs and clinical texts "order" GD: (1) treating GD as gender (diversity), (2) isolating GD from (other) mental health conditions, (3) gauging the persistence of GD by "doing" the future, and (4) creating continuity in GD by narrating the past. We illustrate how HCPs and clinical texts move and slip between multiple modes of ordering GD that co-exist, depend on, and conflict with one another. We also draw attention to how these different modes of ordering GD orient toward specific notions of good (decision-making in) GAMC. Our findings provide an empirical foundation to inform normative debates concerning the latter.

PART C: Developing an ethics support tool

Chapter 7 describes the development process of "GenderJourney," an ethics support tool for the consultation room to foster (reflection on) good SDM in GAMC and support stakeholders in handling concomitant ethical challenges. The GenderJourney focuses on the client-clinician relationship and is less problem-driven and cognitive/analytical than other ethics support tools. Theoretically, we based this participatory project on a dialogical take on empirical ethics, which aims to draw normative conclusions based on dialogue with stakeholders in practice. We included trans* clients and MHPs throughout the study in four homogenous and two heterogenous co-creation workshops. During the workshops, we (1) established participants' needs; (2) reached a consensus on the aims, content, and design; (3) developed and tested different iterations; and (4) presented the final version of the tool. The GenderJourney consists of three parts: (A) elucidating the (development of the) client's care request and corresponding decision-making processes and moments; (B) fostering a dialogue between clients and HCPs about expected/preferred decisional roles and collaboration through active verbs (e.g., support, inform, question); (C) stimulating evaluation, and identifying and handling SDM-related ethical questions and challenges; We arrived at these steps as participants expressed that good SDM in GAMC is attuned within the dyad to the person and intervention at stake. Participants stressed the critical importance of good (i.e., open and honest) client-clinician communication and collaboration. They also expressed the need to discuss more explicitly (expectations and ideals concerning) *decisional roles* about *specific* decisions/interventions. Moreover, respondents indicated that ethical challenges relating to SDM should be made more explicit and explored. We conclude that an iterative and open dialogue on what good SDM entails for *these* stakeholders at *that* in *this* context is an integral part of fostering good SDM. We argue, furthermore, that concomitant ethical challenges and dissensus ought to be taken seriously and made more explicit as they indicate the values and norms at stake and thus provide critical input for this dialogue.

In the Discussion (**Chapter 8**) we reflect on our findings and discuss three central points of discussion regarding transgender care, shared decision-making and ethics support, respectively. We conclude these sections with implications for practice and research.

The first section focuses on transgender care in the light of shared decision-making. Here we take a closer look at the ways HCPs' (perceived) decision-making responsibilities are complicated by uncertainties concerning GI/GD, particularly the epistemic inaccessibility of GI/GD and the inherent unpredictability of the effects of "personally transformative" treatment. We argue that HCPs' experienced duty to do no harm to trans* people should be weighed against the possible harms this very endeavor entails for the client-clinician decision-making process and, consequently, (the possibility of) realizing good care. Relatedly, we question whether "regret" ought to be prevented at all costs. In other words: we question "the logic of prevention" and a consequentialist interpretation of decision-making in GAMC. The above does not imply, however, that HCPs have no role in preventing harm. This raises the normative question of what the responsibility of HCPs and trans* clients should be with regard to non-maleficence. We believe that a first step is to identify and jointly explore this question by making the possible harms explicit and deliberating on their implications for good SDM.

The second section focuses on SDM in light of GAMC. Here, we describe how our empirical findings and theoretical framework may inform the ambiguous normative underpinnings of SDM. We argue that good SDM cannot be determined by applying a set of a priori universal SDM-related values such as “self-determination” or “protection,” but should be established by stakeholders in practice, time and again. We argue that such a take on good SDM does more justice to stakeholders’ diverse and dynamic values and norms, but also the specific contextual characteristics of GAMC. We explain how this approach to SDM dovetails with pragmatic-hermeneutic clinical ethics. Philosophical pragmatism and hermeneutics hold that our understanding and appreciation of the world are inextricably linked to our perspectives and presuppositions, and that (moral) learning comes about in exchanging them with others. However, our empirical findings illustrate that the possibility and willingness of stakeholders to engage in such an exchange is not self-evident. As such, they raise questions about the feasibility of a hermeneutic dialogue and the democratic attitude assumed by pragmatism.

In the third section, we reflect on pragmatic-hermeneutic CES and CES tools based on our experiences with the development of GenderJourney. We stress the importance of CES as a means of establishing a constructive and investigative dialogue in the current context of polarization of normative positions concerning GAMC. The current debate on GAMC has the tendency to solidify normative presuppositions and narrow the scope for dialogue about what good SDM and GAMC entails, both in the consultation room and beyond. A pragmatic-hermeneutic approach to CES—through its focus on recognizing normative presuppositions and stimulating moral reflection—may be conducive to dialogue about good SDM and a more collaborative approach to concomitant ethical challenges. We also highlight some critical questions and challenges relating to the normativity of a hermeneutic-pragmatic approach to CES, namely: (1) How does it deal with the resistance and/or inability of some stakeholders to adopt a dialogical or democratic attitude? (2) To what extent does it do justice to the impact of power differentials on the possibility of accounting for both loud and dim voices in moral deliberation? (3) What should be its role vis-à-vis institutional and/or structural barriers to good SDM and, more broadly, good care?

In conclusion, this thesis shows that SDM in GAMC is characterized by ontological ambiguities, epistemic uncertainties and normative contestations. Our empirical findings and a pragmatic-hermeneutical approach to clinical ethics emphasize that good SDM in GAMC necessitates various renditions of, an openness toward, and dialogue about what good SDM may entail for *these* stakeholders concerning *this* intervention at *that* moment and in *this* context. Ongoing deliberation on what good SDM should entail is vital. Not only in the consultation room—where norms and values pertaining to decision-making are varied, dynamic, (ostensibly) contradictory, and often implicit—but also within institutions and society at large. This thesis offers insight and support to those in clinical practice and provides a basis for future research on SDM and CES in GAMC. Its findings could also be relevant for those in care practices that, like GAMC, are characterized by inherent moral and normative dimensions. Finally, this thesis is relevant to those developing, providing and researching CES and CES tools, both in and outside GAMC. We hope that the findings and tool presented in this thesis provide a foothold for informational frictions and ongoing, critical-constructive dialogues toward better SDM in GAMC and beyond.

Nederlandse samenvatting

Dit proefschrift heeft twee centrale doelstellingen. Ten eerste: inzicht verkrijgen in het morele en conceptuele landschap van genderbevestigende zorg (hierna: transgenderzorg) voor volwassenen, met de focus op gedeelde besluitvorming. Ten tweede: het co-creëren van een ethiek support *tool* om (a) (reflectie op) goede gedeelde besluitvorming te stimuleren en (b) zorgverleners en transgender (trans*)[41] cliënten te helpen in het omgaan met gerelateerde ethische uitdagingen. Daartoe behandelden we de volgende onderzoeksvragen:

- Welke ethische uitdagingen ervaren zorgverleners die transgenderzorg leveren in een multidisciplinair team in Nederland? (Hoofdstuk 2)
- Wat zijn de ethische uitdagingen en normen rondom gedeelde besluitvorming van volwassen trans* cliënten die transgenderzorg ontvingen in Nederland? (Hoofdstuk 3)
- Wat zijn de ethische uitdagingen en normen rondom gedeelde besluitvorming van zorgverleners die transgenderzorg leveren aan volwassen trans* cliënten in Nederland? (Hoofdstuk 4)
- Wat zijn de conceptuele en normatieve aannames met betrekking tot het besluitvormingsproces en de autonomie van de cliënt in twee zorgmodellen voor transgenderzorg, en welke centrale ethische uitdagingen zijn daarmee verbonden? (Hoofdstuk 5)
- Op welke wijze geven zorgverleners in transgenderzorg vorm aan Genderdysforie in de dagelijkse praktijk, en welke normatieve aannames over Genderdysforie klinken hierin door? (Hoofdstuk 6)
- Wat voor ethiek support tool kan (reflectie op) goede gedeelde besluitvorming in transgenderzorg bevorderen en betrokkenen helpen bij het omgaan met gerelateerde ethische uitdagingen? (Hoofdstuk 7)

Hoofdstuk 1 introduceert bovenstaande onderzoeksvragen tegen de achtergrond van de huidige ontwikkelingen in transgenderzorg, gedeelde besluitvorming daarbinnen, en de behoefte aan thema- en praktijkspecifieke ethiek support. Steeds vaker melden trans* personen zich voor transgenderzorg: medische interventies zoals vermannelijkende (de-feminiserende) en vervrouwelijkende (de-masculiniserende) hormonen en/of operaties. Deze zorg streeft ernaar de kwaliteit van leven van trans* personen te verbeteren door gepaste behandeling te bieden waarmee trans* personen hun ervaren gender kunnen bevestigen en uitdrukken. Dit kan bijdragen aan het verlichten van wat – ten tijde van schrijven – geclassificeerd wordt als “Genderincongruentie (GI)” of “Genderdysforie (GD)”. Sinds het einde van de jaren zeventig hebben clinici en andere betrokkenen gewerkt aan het ontwikkelen van zorgstandaarden en het vaststellen van ethische principes zoals fysieke gezondheid, mentaal welbevinden, zelfontplooiing en veiligheid. Dat neemt echter niet weg dat zowel zorgverleners als trans* cliënten ethische uitdagingen ervaren die verband houden met de vraag: wat is *goede* besluitvorming?

Diverse belanghebbenden pleiten voor meer *gedeelde* besluitvorming (samen beslissen) in transgenderzorg. Gedeelde besluitvorming benadrukt het belang van gepersonaliseerde zorg, gedeeld eigenaarschap betreffende het beslisproces en een gezamenlijke verantwoordelijkheid voor het kiezen (of uitstellen) van een behandeling. Gedeelde besluitvorming is wijdverspreid in de hedendaagse gezondheidszorg en wordt gezien als het ideale beslismodel, vooral als het gaat om zogenaamde “voorkeursgevoelige beslissingen”, oftewel beslissingen waarbij meer dan één redelijke behandelmogelijkheid voorhanden is. De toename van behandelopties en de diverse behoeften en waardes van trans* cliënten rondom hun medische transitie maken de transgenderzorg een voorkeursgevoelige zorgpraktijk bij uitstek. De groeiende aandacht voor gedeelde besluitvorming is dan ook niet verrassend. Echter, “gedeelde besluitvorming” is zowel conceptueel als normatief ambigu. Deze conceptuele en normatieve ambiguïteit roept de vragen op wat gedeelde besluitvorming eigenlijk is en hoe het afgestemd zou moeten worden op de specifieke kenmerken van de transgenderzorg.

Deze vragen over gedeelde besluitvorming werden – en worden – prangender in de context van toenemende verwijzingen en wachtlijsten voor transgenderzorg. De toename van aanmeldingen betekent dat meer mensen geconfronteerd (zullen) worden met dergelijke vragen. Daarbij wordt de huidige “poortwachtersrol” van *mental health professionals* (in Nederland: psychologen en psychiaters) in het besluitvormingsproces door sommigen gezien als één van de oorzaken van de huidige wachtlijstenproblematiek en derhalve betwist. Daarnaast doen vragen over gedeelde besluitvorming zich voor in een polariserend sociaal-maatschappelijk en academisch discours over genderdiversiteit in het algemeen en (besluitvorming in) transgenderzorg in het bijzonder: stemmen die pleiten voor radicale zelfbeschikking in of juist het volledig aan banden leggen of criminaliseren van transgenderzorg klinken steeds luider. Het bovenstaande maakt dat de vraag wat goede gedeelde besluitvorming in transgenderzorg inhoudt niet alleen betwist en onzeker maar ook bijzonder urgent is.

Ethiek support heeft als doel om te ondersteunen bij het omgaan met ethische kwesties in de klinische praktijk. Het probeert daarmee morele competenties, samenwerking en de kwaliteit van zorg te verbeteren. Ethiek support kan trans* cliënten en zorgverleners ondersteunen bij het herkennen van en omgaan met ethische uitdagingen over gedeelde besluitvorming, maar ook bij het vaststellen van wat goede gedeelde besluitvorming behelst. Ethiek support wordt steeds vaker aangeboden in transgenderzorg via ethiek consulten en Moreel Beraad, maar kan ook worden vormgegeven middels de co-creatie van thema- en praktijkspecifieke ethiek support tools. Het zou lonend kunnen

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[41] Transgender (trans*) is een parapluterm voor verschillende genderidentiteiten, rollen en uitdrukkingen die verschillen van (de normatieve verwachtingen van) het bij geboorte toegekende geslacht.

zijn om een dergelijke tool te ontwikkelen gericht op gedeelde besluitvorming in de specifieke context van de transgenderzorg. Dit proefschrift onderzoekt op welke manier zorgverleners en trans* personen in de transgenderzorg ondersteund zouden kunnen worden in het komen tot goede gedeelde besluitvorming en gerelateerde ethische uitdagingen. Het onderzoekt welk type ethiek support tool daar het beste bij past.

Een goed ontwikkelproces vereist een grondig begrip van de behoeftes van zorgverleners en trans* cliënten. Daarnaast is inzicht in het morele en conceptuele landschap van gedeelde besluitvorming in transgenderzorg onmisbaar. Welke ethische uitdagingen spelen er op de behandelvloer? Hoe verhouden deze uitdagingen zich tot zorgmodellen en klinische richtlijnen? Wat is de impact van de conceptuele en normatieve aannames van betrokkenen rondom GI/GD op de transgenderzorg? Onderzoek naar deze vragen is tot nu toe schaars maar essentieel; niet alleen voor de co-creatie van de beoogde tool, maar ook om een constructieve dialoog over wat goede gedeelde besluitvorming in transgenderzorg inhoudt te bevorderen. We richten ons op deze vragen in de eerste twee delen van dit proefschrift. Het eerste deel (A) beschrijft de ethische uitdagingen en normen van zorgverleners (Hoofdstukken 2 en 4) en trans* cliënten (Hoofdstuk 3). Het tweede deel (B) verheldert de conceptuele en normatieve aannames rondom het beslisproces en de autonomie van de cliënt in twee zorgmodellen (Hoofdstuk 5). Daarnaast onderzoekt het hoe het fenomeen GD wordt vormgegeven of "gedaan" in de klinische praktijk (Hoofdstuk 6). Geïnformeerd door de voorgaande hoofdstukken beschrijft het derde deel (C) de co-creatie van GenderJourney, een visuele ethiek support tool (Hoofdstuk 7). In lijn met een pragmatisch-hermeneutische kijk op ethiek support brengt dit proefschrift gedeelde besluitvorming ("theorie") in dialoog met transgenderzorg ("praktijk"), teneinde de besluitvorming te verbeteren.

Deel A: Het in kaart brengen van ethische uitdagingen en normen

Hoofdstuk 2 beschrijft een etnografische studie naar de ethische uitdagingen van zorgverleners die transgenderzorg leveren in een multidisciplinair team in Nederland. Gedurende zeven maanden observeerden we multidisciplinaire teamoverleggen en individuele consultaties. We analyseerden ook transcripten en rapporten van Moreel Beraad sessies. Middels een thematische analyse ontdekten we dat zorgverleners ethische uitdagingen ervoeren rondom (1) het bepalen van de omstandigheden waaronder trans* cliënten *niet* in aanmerking mogen komen voor behandeling; (2) het vormgeven van de inhoud van de zorg met beperkte wetenschappelijke evidentie, met name rondom "niet-traditionele" behandelverzoeken; (3) het omgaan met de multidisciplinaire aard en volgordelijkheid van de verschillende behandelingen; (4) het vaststellen van de striktheid van en mogelijke uitzonderingen op de klinische richtlijnen; (5) het beoordelen van de "aanwezigheid" en "authenticiteit" van GI/GD; en ten slotte (6) gedeelde besluitvorming. Ethische vragen rondom gedeelde besluitvorming bleken bijzonder prangend en urgent. Zorgverleners beschreven hoe zij balanceerden tussen een ervaren plicht tot niet-schaden enerzijds en recht willen doen aan de zelfbeschikking en wensen van cliënten anderzijds. In de praktijk leidde dit evenwichtsspel tot ethische vragen als: Moeten we een behandeling starten als een cliënt de gevolgen ervan niet overziet of onvoldoende draagkracht heeft en er risico is van schade en spijt? Wie moet beslissen of een "niet-traditioneel" behandelverzoek toelaatbaar is? Waar liggen de morele grenzen van de behandelmogelijkheden?

Hoofdstuk 3 en Hoofdstuk 4 beschrijven de ervaren ethische uitdagingen met betrekking tot gedeelde besluitvorming van respectievelijk trans* cliënten en zorgverleners. We namen 10 interviews af met volwassen trans* personen en 11 met zorgverleners. We analyseerden de transcripten middels thematische analyse. Verschillende (voornamelijk trans*) respondenten waren meer geneigd om te spreken over wat goede of juiste besluitvorming volgens hen (niet) behoort te zijn dan om ethische onzekerheid of twijfel daarover te uiten. We besloten daarom zowel ethische *uitdagingen* als ethische *normen* te identificeren. Daarnaast hebben we in onze analyse onderscheid gemaakt tussen *expliciet* uitgedrukte en *impliciete* ethische uitdagingen die we indirect afleidden uit de transcripten. Ook verhelderden we de specifieke *context* waarin deze ethische uitdagingen en normen zich voordoen.

Trans* cliënten uitten de volgende overkoepelende ethische normen en vragen: (1) Cliënten moeten de leiding hebben in het beslisproces, *maar wat moet dit behelzen?* (2) Schade moet worden voorkomen, *maar wie moet daar verantwoordelijkheid voor dragen?* (3) Het beslisproces dient afgestemd te worden op de cliënt, *maar hoe moet deze afstemming eruitzien?* We cursiveerden deze vragen omdat we zagen dat cliënten vaak uiteenlopende ethische normen verbonden aan vergelijkbare waarden, waarvan de praktische en ethische consequenties sterk uiteenliepen. Dit betekent dat ze steeds opnieuw interpretatie en deliberatie vereisen. Verder beschreven we de manier waarop de ethische uitdagingen en normen van cliënten verbonden zijn met de specifieke context van (machtsverschillen binnen) de cliënt-behandelaarrelatie. Ook werden ethische normen rondom het beslisproces door trans* personen vaak in verband gebracht met impliciete en expliciete noties over wat (hun) GI/GD (niet) ís: meer laissez-faire in het geval van "natuurlijke variatie" en meer paternalistisch in het geval van een "mentale stoornis". We vonden bovendien een sterk effect van tijd, deels samenhangend met het transitieproces op zich: de waarden van cliënten rondom hun behandeling alsook hun ideeën over goede besluitvorming veranderden vaak met de tijd.

De overkoepelende ethische uitdagingen van zorgverleners waren: (1) Hoe moeten we onze beslisrollen en -grenzen verdelen en definiëren? Wanneer moeten we bijvoorbeeld een behandeling uitstellen of onthouden? (2) Hoe moeten we als (multidisciplinair) team de besluitvorming vormgeven? Wat is mijn individuele verantwoordelijkheid rondom multidisciplinaire beslisprocessen? (3) Hoe moeten we met de factor "tijd" omgaan in de besluitvorming? Wat mag de impact zijn van mogelijke toekomstige gevolgen op het huidige beslisproces? De ethische uitdagingen van zorgverleners bleken zich voor te doen in een context van diverse onzekerheden met betrekking tot de richtlijnen, evidentie en uitkomsten van transgenderzorg, en de "grenzen" en "aanwezigheid" van GI/GD.

Overkoepelend beschreven we dat zorgverleners vaak impliciet verschillende beslismodellen hanteerden. Cliënten bleken eveneens verschillende behoeftes, angsten en dynamische opvattingen over het beslisproces te hebben, maar bespraken deze veelal niet met hun zorgverleners. Onze bevindingen illustreren hoe gedeelde besluitvorming in transgenderzorg het best kan worden begrepen als een dynamisch proces dat voortdurend – en vaak impliciet – wordt afgestemd tussen verschillende betrokkenen en verspreid is over diverse tijden en plaatsen. De diversiteit, complexiteit en het veranderlijke karakter van de ethische uitdagingen en normen van trans* cliënten en zorgverleners onderstrepen onzes inziens de noodzaak om de besluitvorming te diversifiëren en expliciet af te stemmen op de dyade (i.e., cliënt en zorgverlener), interventie, context en tijd. We concluderen dat voor goede gedeelde besluitvorming in transgenderzorg meer open dialoog en uitwisseling tussen client en zorgverlener noodzakelijk is, niet alleen over de inhoud van de te nemen beslissing, maar ook over de ethische overwegingen met betrekking tot het beslisproces en beslisrollen. De data benadrukken dat de context waarin de zorg geleverd wordt (zoals het gehanteerde zorgmodel) van grote invloed is op de wijze waarop dit gesprek gevoerd kan worden.

Deel B: Het ophelderen van conceptuele en normatieve aannames

Hoofdstuk 5 onderzoekt ethische uitdagingen rondom gedeelde besluitvorming in het licht van twee verschillende zorgmodellen die in de internationale transgenderzorg worden gebruikt: de *Standards of Care 7* (SoC7) en het *Informed Consent Model* (ICM). De SoC7 stelt dat mental health professionals gezien hun opleiding het best toegerust zijn om GI/GD te diagnosticeren en om te beoordelen of trans* cliënten in aanmerking komen voor GAMC, daar transgenderzorg vaak intensief en (gedeeltelijk) onomkeerbaar is. Het ICM daarentegen benadrukt de zelfbeschikking van cliënten en minimaliseert de rol van zorgverleners rondom de besluitvorming tot het verschaffen van informatie en verkrijgen van *informed consent* (geïnformeerde toestemming). Dit hoofdstuk heeft tot doel de conceptuele en normatieve aannames met betrekking tot besluitvorming en autonomie van de cliënt in deze zorgmodellen op te helderen om uiteindelijk ethische uitdagingen in de praktijk beter te begrijpen.

Onze conceptuele analyse laat zien hoe SoC7 zowel beoordelende als ondersteunende taken voor mental health professionals aanbeveelt die terug te voeren zijn op tegenstrijdige opvattingen over de besluitvorming en de autonomie van de cliënt. We beschrijven hoe dit aanleiding kan geven tot een rolconflict van de kant van zorgverleners en ook tot angst, wantrouwen en zelfverhulling aan de kant van cliënten. Deze dynamiek kan de cliënt-behandelaarrelatie verstoren, het beslisproces ondermijnen en uiteindelijk de realisatie van goede zorg in de weg staan.

Op het eerste gezicht lijkt het ICM dit ethische probleem te omzeilen. Onze analyse laat echter zien dat het komen tot gedeelde besluitvorming en het afstemmen op de individuele zorg- en beslisbehoeften van trans* cliënten in het ICM worden bemoeilijkt door een nauwe interpretatie van informed consent en autonomie. Onze analyse toont bovendien aan dat de conceptuele en normatieve invulling van informed consent in (de diverse lokale zorgmodellen die vallen onder de noemer van) het ICM vaak ambigu is. In de praktijk kan dit leiden tot vragen over wat als voldoende informed consent zou moeten worden beschouwd.

Op basis van onze analyse suggereren we dat het centraal stellen van één normatief besluitvormingsmodel geen moreel panacee is. We concluderen dat de eerste stappen naar goede gedeelde besluitvorming in transgenderzorg het erkennen en bespreken van de inherente normatieve en morele dimensies ervan zijn.

Uit de voorgaande studies bleek dat *normatieve* overtuigingen met betrekking tot gedeelde besluitvorming in transgenderzorg vaak samenhangen met achterliggende *conceptuele* aannames rondom wat GI/GD al dan niet ís en hoe men dat kan weten. Dit zien we ook terug in de geschiedenis. Zo werden paternalistische beoordelings- en beslisprocessen voor transgenderzorg vaak gerechtvaardigd doordat het object van zorg werd geconceptualiseerd als een (mentale) stoornis. Tegen de achtergrond van de recente depsychopathologisering van GI/GD, onderzoekt **Hoofdstuk 6** hoe het object GD wordt vormgegeven in de huidige klinische praktijk en welke normen aangaande GD en transgenderzorg hierin doorklinken. Om deze vraag te beantwoorden, gebruiken we de materiële semiotiek, een benadering die stelt dat objecten (zowel materieel als immaterieel, zoals GD) niet statisch zíjn, maar telkens opnieuw door menselijke en niet-menselijke actoren en praktijken worden gedáán. Afhankelijk van de constellatie van actoren en praktijken worden objecten, zoals GD, dan (ontologisch) anders, en multipel. Om hier zicht op te krijgen, hebben we in dit hoofdstuk gekeken naar de manieren waarop zorgverleners en klinische teksten GD "ordenen", dat wil zeggen: hoe ze grip pogen te krijgen op GD. Hiertoe hebben we gebruikgemaakt van (1) interviews met 16 psychologen/psychiaters en (2) relevante fragmenten uit de SoC7 en (3) de *Diagnostic and Statistical Manual for Mental Disorders*, versie 5. Door middel van een thematische analyse identificeerden we vier manieren waarop GD wordt geordend door zorgverleners en klinische teksten. Ze (1) behandelen GD als (gender)diversiteit, (2) isoleren GD van (andere) psychische aandoeningen, (3) peilen de persistentie van GD door de toekomst te "doen" en (4) creëren continuïteit in GD door het verleden tot een kloppend verhaal te maken. We laten zien hoe zorgverleners en klinische teksten bewegen tussen deze verschillende "ordeningsmethoden" die naast elkaar bestaan, van elkaar afhankelijk zijn en soms met elkaar conflicteren. We sluiten dit hoofdstuk af door toe te lichten hoe in deze ordeningsmethoden specifieke noties van goede (besluitvorming in) transgenderzorg besloten liggen.

Deel C: Het co-creëren van een ethiek support tool

Hoofdstuk 7 beschrijft het ontwikkelproces van de "GenderJourney", een praktijkgerichte ethiek support tool die tot doel heeft om (reflectie op) goede gedeelde besluitvorming te stimuleren en om ondersteuning te bieden rondom gerelateerde ethische uitdagingen. De GenderJourney richt zich op de cliënt-zorgverlener relatie en is daarmee minder probleemgestuurd en cognitief/analytisch dan andere ethiek support tools. Dit participatieve project was theoretisch geënt op een dialogische benadering van de empirische ethiek, een benadering die normatieve conclusies beoogt te trekken op basis van dialoog met betrokkenen in de praktijk. We betrokken trans* cliënten en zorgverleners bij de ontwikkeling middels vier homogene en twee heterogene co-creatie *workshops*. Tijdens de workshops hebben we (1) de behoeften van de deelnemers vastgesteld; (2) een consensus bereikt over de doelstellingen, inhoud en vormgeving; en (3) verschillende versies ontwikkeld en getest. Vervolgens (4) presenteerden we de definitieve versie van de tool. De GenderJourney bestaat uit drie delen: (A) het verhelderen van de (ontwikkeling van de) zorgvraag van de cliënt en de bijbehorende beslisprocessen- en momenten; (B) het bevorderen van een dialoog tussen trans* cliënten en zorgverleners over verwachte/ideale beslisrollen en samenwerking aan de hand van actieve werkwoorden (e.g., steunen, informeren, bevragen); (C) het herkennen van en omgaan met ethische uitdagingen in het beslisproces, en het bieden van mogelijkheden om hierover in dialoog te gaan. We kwamen tot deze onderdelen omdat de deelnemende cliënten en zorgverleners aangaven dat goede gedeelde besluitvorming steeds weer in de dyade afgestemd moet worden op de persoon en de interventie. Deelnemers benadrukten het cruciale belang van een goede (d.w.z. open en eerlijke) dialoog en samenwerking tussen cliënt en behandelaar. Ook werd de wens geuit om voorkeuren en idealen met betrekking tot beslisrollen *in relatie tot* specifieke beslissingen/interventies gerichter te bespreken. Bovendien vonden deelnemers dat ethische uitdagingen rondom gedeelde besluitvorming meer expliciet verkend dienen te worden. We concludeerden dat goede gedeelde besluitvorming al vroeg begint bij het faciliteren van een open dialoog tussen client en zorgverlener *over* gedeelde besluitvorming. We stellen dat bijkomende ethische uitdagingen serieus genomen moeten worden, omdat ze inzicht bieden in welke waarden en normen van belang zijn en daarmee wezenlijke input bieden voor deze dialoog.

In de Discussie (**Hoofdstuk 8**) reflecteren we op onze bevindingen en behandelen we drie centrale discussiepunten met betrekking tot achtereenvolgens transgenderzorg, gedeelde besluitvorming en ethiek support. We sluiten deze secties af met implicaties voor de praktijk en onderzoek.

De eerste sectie richt zich op transgenderzorg in het licht van gedeelde besluitvorming. Hier gaan we dieper in op de manieren waarop de (ervaren) verantwoordelijkheden van zorgverleners in de besluitvorming worden bemoeilijkt door onzekerheden rondom het fenomeen GI/GD: de epistemische ontoegankelijkheid van GI/GD en de inherente onvoorspelbaarheid van de effecten van een "persoonlijk transformatieve" behandeling. We pleiten ervoor dat de door zorgverleners ervaren (en soms door trans* personen veronderstelde) plicht om trans* personen geen schade te berokkenen, afgewogen moet worden tegen de mogelijke nadelen die dit streven met zich meebrengt: nadelen voor de cliënt-zorgverlener relatie, het beslisproces en daarmee goede zorg. In het verlengde hiervan trekken we de impliciete overtuiging dat "spijt" koste wat het kost voorkomen zou moeten worden in twijfel. Met andere woorden: we plaatsten vraagtegens bij "de logica van preventie" en een consequentialistische invulling van de besluitvorming. We benadrukken dat het voorgaande niet impliceert dat zorgverleners geen rol moeten hebben in het voorkomen van schade in gedeelde besluitvorming. Dit roept de normatieve vraag op wat de verantwoordelijkheid van zorgverleners (en cliënten) ten aanzien van mogelijke schade dan zou moeten zijn. Deze vraag kent geen eenduidig antwoord. Wat ons betreft is een eerste stap het benoemen en gezamenlijk verkennen van deze vraag door de mogelijke schade te expliciteren en te delibereren over de implicaties ervan voor goede gedeelde besluitvorming.

De tweede sectie gaat in op gedeelde besluitvorming in het licht van transgenderzorg. Hier beschrijven we hoe onze empirische bevindingen en ons theoretisch kader de dubbelzinnige normatieve fundering van gedeelde besluitvorming kunnen informeren. We beargumenteren dat goede gedeelde besluitvorming niet kan worden bepaald door a priori universele waarden zoals "zelfbeschikking" of "niet-schaden" toe te passen, maar keer op keer door betrokkenen in de specifieke praktijk moet worden afgestemd. We stellen dat een dergelijke invulling van goede gedeelde besluitvorming meer recht doet aan de diverse en dynamische waarden en normen van betrokkenen, maar ook de specifieke contextuele kenmerken van gedeelde besluitvorming in de transgenderzorg. Een dergelijke benadering van goede gedeelde besluitvorming sluit aan bij de pragmatisch-hermeneutische klinische ethiek. Deze denkrichtingen benadrukken dat ons begrip en onze waardering van de wereld onlosmakelijk verbonden zijn met onze perspectieven en vooronderstellingen en dat (moreel) leren tot stand komt door die uit te wisselen met anderen. Onze bevindingen tonen echter aan dat de mogelijkheid én welwillendheid hiertoe van betrokkenen in de praktijk niet evident is. Ze roepen daarmee vragen op aangaande haalbaarheid van de door de hermeneutiek voorgeschreven dialoog en de door het pragmatisme veronderstelde democratische houding.

In het derde deel reflecteren we op pragmatisch-hermeneutische ethiek support en ethiek support tools op basis van onze ervaringen met het ontwikkelen van de GenderJourney. We benadrukken het belang van ethiek support als een middel om tot een constructieve en onderzoekende dialoog te komen in de huidige context van polarisatie van normatieve posities met betrekking tot transgenderzorg. Het huidige debat over transgenderzorg maakt soms dat normatieve vooronderstellingen verharden en de bandbreedte voor dialoog over goede gedeelde besluitvorming en transgenderzorg versmalt, zowel in de spreekkamer als daarbuiten. Een pragmatisch-hermeneutische benadering van ethieksupport – door haar focus op het herkennen van normatieve vooronderstellingen en het stimuleren van morele reflectie en uitwisseling – kan bevorderlijk zijn voor dialoog en de gezamenlijke omgang met ethische uitdagingen. We belichten ook enkele kritische vragen met betrekking tot de impliciete normativiteit van deze pragmatisch-hermeneutische benadering van ethiek support, namelijk: (1) Hoe gaat ze om met de weerstand en/of uitdaging van sommige betrokkenen om een dialogische c.q. democratische houding aan te nemen? (2) In hoeverre doet ze recht aan de impact van machtsverschillen en biedt het de mogelijkheid om rekening te houden met zowel "luide" (geprivilegieerde) als "zachte" (gemarginaliseerde) stemmen? (3) Wat moet haar rol zijn als het gaat om institutionele en/of structurele belemmeringen tot goede gedeelde besluitvorming en – breder – zorg?

Concluderend laat dit proefschrift zien dat gedeelde besluitvorming in transgenderzorg gekenmerkt wordt door ontologische ambiguïteiten, epistemische onzekerheden en normatieve onenigheden. Onze empirische bevindingen en een pragmatisch-hermeneutische benadering van de klinische ethiek benadrukken dat goede gedeelde besluitvorming openheid en dialoog vereist naar wat dit inhoudt voor *deze* betrokkenen aangaande *deze* beslissing op *dit* moment en in *deze* context. Herhaaldelijke afstemming over wat goede gedeelde besluitvorming behelst is noodzakelijk om hier überhaupt toe te komen. Niet alleen in de spreekkamer – waar normen en waarden met betrekking tot besluitvorming gevarieerd, dynamisch, soms (ogenschijnlijk) tegenstrijdig en vaak impliciet zijn –, maar ook binnen instellingen en de samenleving als geheel. Het is een blijvend gesprek. Onze bevindingen en een dergelijke invulling van goede gedeelde besluitvorming kunnen relevant zijn voor andere zorgpraktijken, met name praktijken die net als de transgenderzorg getypeerd worden door inherente morele dimensies en contestaties. We stellen dat zorgverleners en cliënten in dergelijke praktijken aandacht moeten hebben voor de verwevenheid tussen gedeelde besluitvorming en zowel de inhoud als de context van beslissingen. De gezamenlijke ontwikkeling van de GenderJourney toont aan hoe (onderzoek naar) ethiek support kan helpen om deze verwevenheid te expliciteren en een kritisch-constructieve dialoog te voeren over morele dimensies en contestaties in de spreekkamer en daarbuiten. Andersom produceert deze dialoog inzichten voor de ethiek support door haar impliciete normativiteit te bevragen en aandacht te hebben voor de bredere context van de praktijken die ze poogt te ondersteunen.

List of publications

Publications labeled with an asterisk (*) are included as chapters of this thesis.

*de boer, W., Molewijk, A. C., Bremmer, M. A., Kreukels, B. P. C., Moyer, E. M., **Gerritse, K**. (n.d.). Doing and undoing transgender healthcare: the ordering of "Gender Dysphoria" in clinical practice. Submitted to *Sociology of Health and Illness.*

***Gerritse, K**., Martens, C., Bremmer, M. A., Kreukels, B. P. C., de Vries, A. L. C., Molewijk, A. C. (n.d.). GenderJourney: participatory development of an ethics support tool to foster dialogue and reflection on shared decision-making in gender-affirming medical care. Submitted to *Patient Education and Counseling.*

***Gerritse, K**., Martens, C., Bremmer, M. A., Kreukels, B. P. C., de Boer, F., Molewijk, A.C. (2023). "I should've been able to decide for myself, but I didn't want to be left alone." A qualitative interview study of clients' ethical challenges and norms regarding decision-making in gender-affirming medical care. *Journal of Homosexuality.* Advance online publication.

***Gerritse, K**., Martens, C., Bremmer, M. A., Kreukels, B. P. C., de Boer, F., Molewijk, A. C. (2022). Sharing decisions amid uncertainties: A qualitative interview study of healthcare professionals' ethical challenges and norms regarding decision-making in gender-affirming medical care. *BMC Medical Ethics. 23*, 139.

Gerritse, K., Bremmer, M. A., Van der Miesen, A. I. R., & de Vries, A. L. C. (2022). Uitdagingen in de besluitvorming van somatische transgenderzorg. *Tijdschrift voor Psychiatrie. 8*(64), 504-507.

***Gerritse, K**., Hartman, L. A., Bremmer, M. A., Kreukels, B. P. C., & Molewijk, A. C. (2021). Decision-making approaches in transgender healthcare: conceptual analysis and ethical implications. *Medicine, Health Care, and Philosophy. 24*, 687-699.

Gerritse, K., Labib, K., Martens, C., & Bremmer, M. A. (2020). Naar een meer expliciet kwetsbaarheidsbegrip voor transgender personen in (bio)medisch onderzoek. *Podium voor Bioethiek, 27*(4), 21-25.

***Gerritse, K**., Hartman, L. A., Antonides, M. F., Wensing-Kruger, A., de Vries, A. L. C., & Molewijk, A. C. (2018). Moral challenges in transgender care: a thematic analysis based on a focused ethnography. *Archives of Sexual Behavior*, *47*, 2319–2333.

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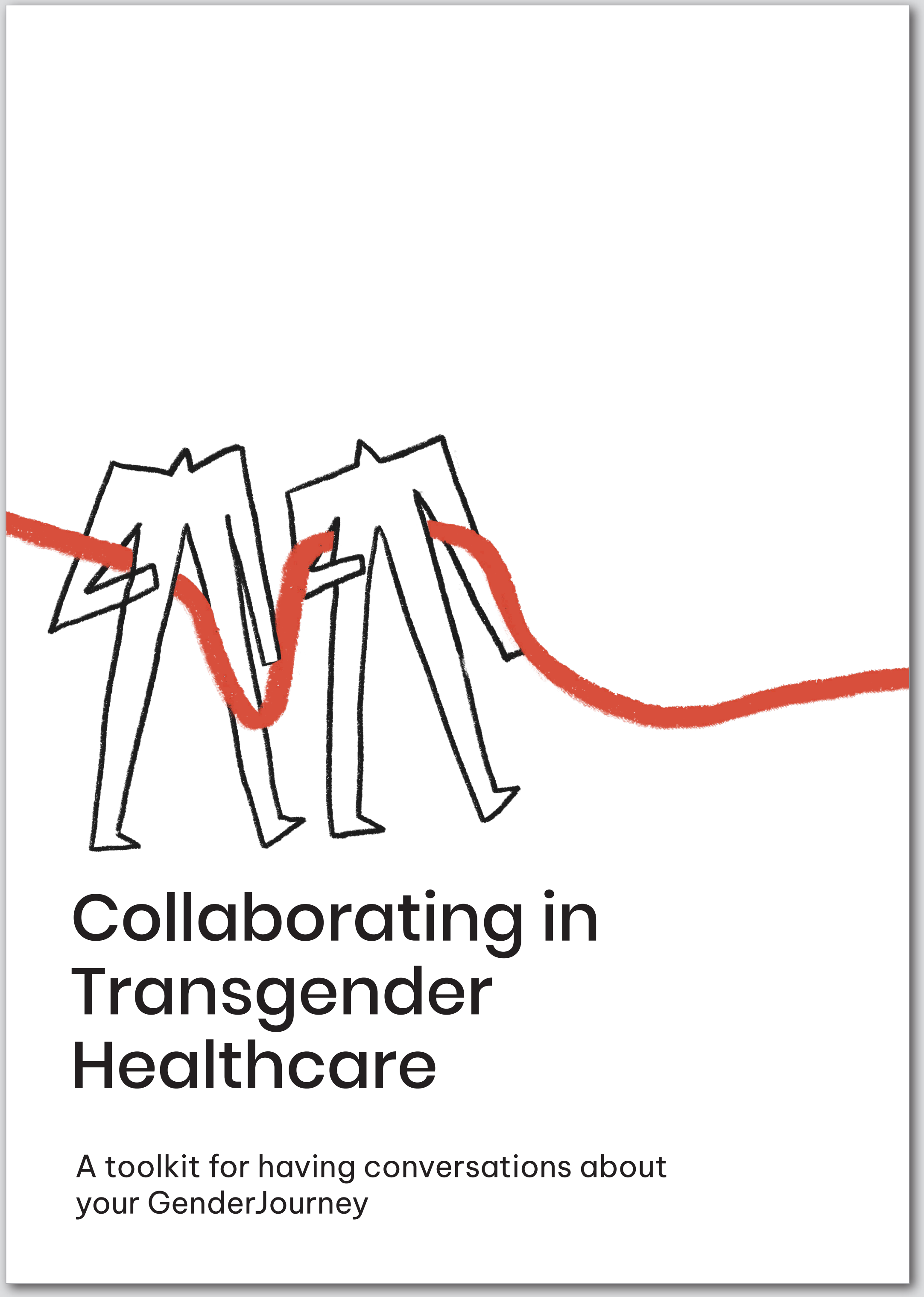
Lieve Gable, wat moet ik zeggen. Bij jou kom ik thuis, steeds opnieuw.

Supplementary materials

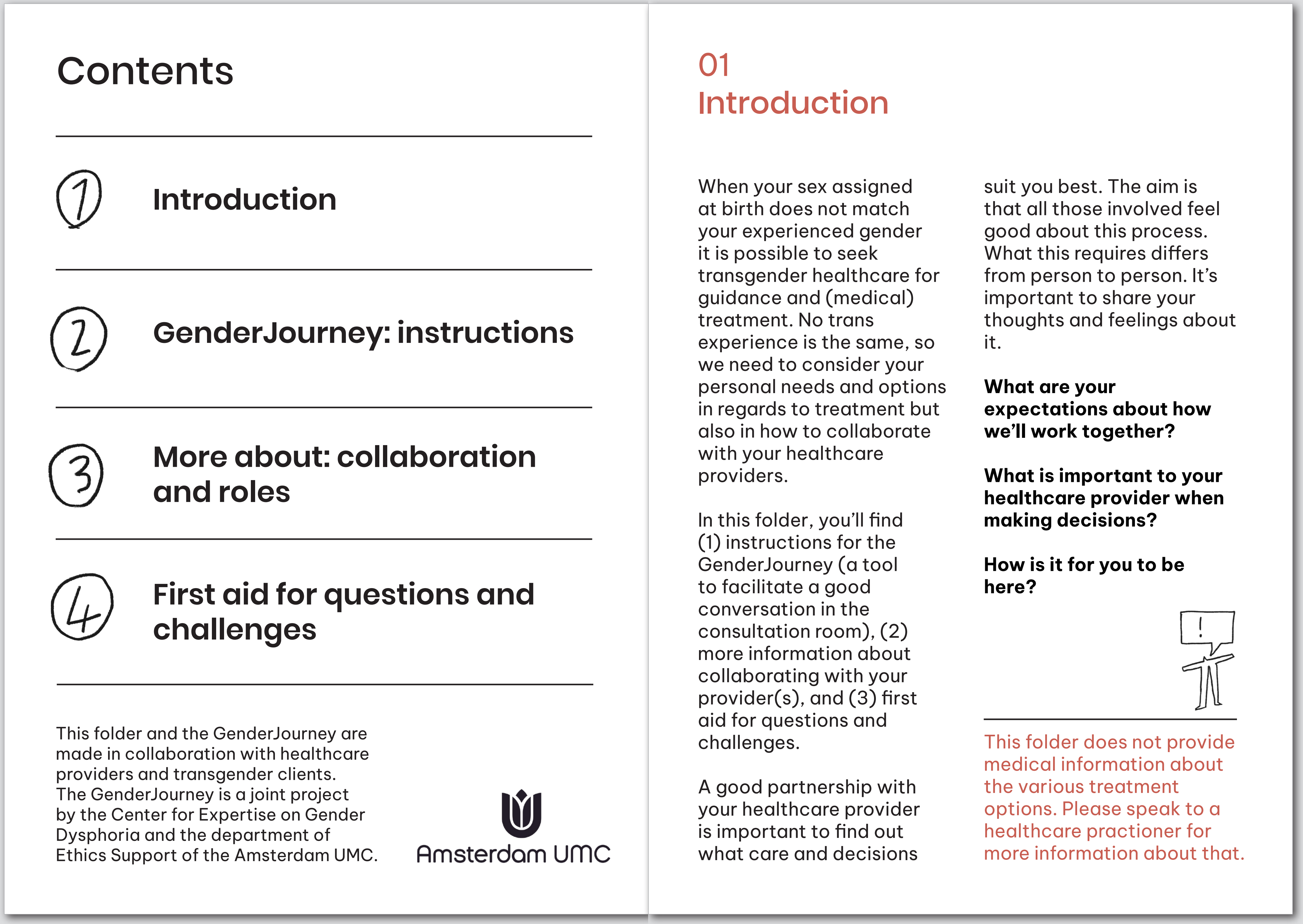
Brochure for TGD clients in English

GenderJourney map in English



Collaborating in Transgender Healthcare

A toolkit for having conversations about your GenderJourney



Contents

① Introduction

② GenderJourney: instructions

③ More about: collaboration and roles

④ First aid for questions and challenges

This folder and the GenderJourney are made in collaboration with healthcare providers and transgender clients. The GenderJourney is a joint project by the Center for Expertise on Gender Dysphoria and the department of Ethics Support of the Amsterdam UMC.

Amsterdam UMC

01
Introduction

When your sex assigned at birth does not match your experienced gender it is possible to seek transgender healthcare for guidance and (medical) treatment. No trans experience is the same, so we need to consider your personal needs and options in regards to treatment but also in how to collaborate with your healthcare providers.

In this folder, you'll find (1) instructions for the GenderJourney (a tool to facilitate a good conversation in the consultation room), (2) more information about collaborating with your provider(s), and (3) first aid for questions and challenges.

A good partnership with your healthcare provider is important to find out what care and decisions suit you best. The aim is that all those involved feel good about this process. What this requires differs from person to person. It's important to share your thoughts and feelings about it.

What are your expectations about how we'll work together?

What is important to your healthcare provider when making decisions?

How is it for you to be here?

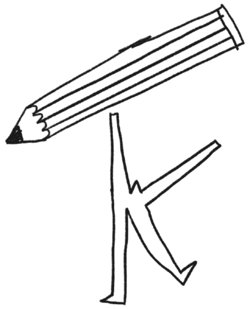
!

This folder does not provide medical information about the various treatment options. Please speak to a healthcare practioner for more information about that.

02

GenderJourney: instructions

The GenderJourney helps you get an overview of your (medical) transition. It also guides the conversation between you and your healthcare provider about what is important when making decisions together. For example, when you are about to **start** your trajectory, when you want to take the **next step**, or **a step back**. You can use the GenderJourney at different times, by yourself or together with your healthcare provider.



Three reasons to use the GenderJourney:

① **Plotting the course**: *clarifying your care request and ideas about the route and destination*

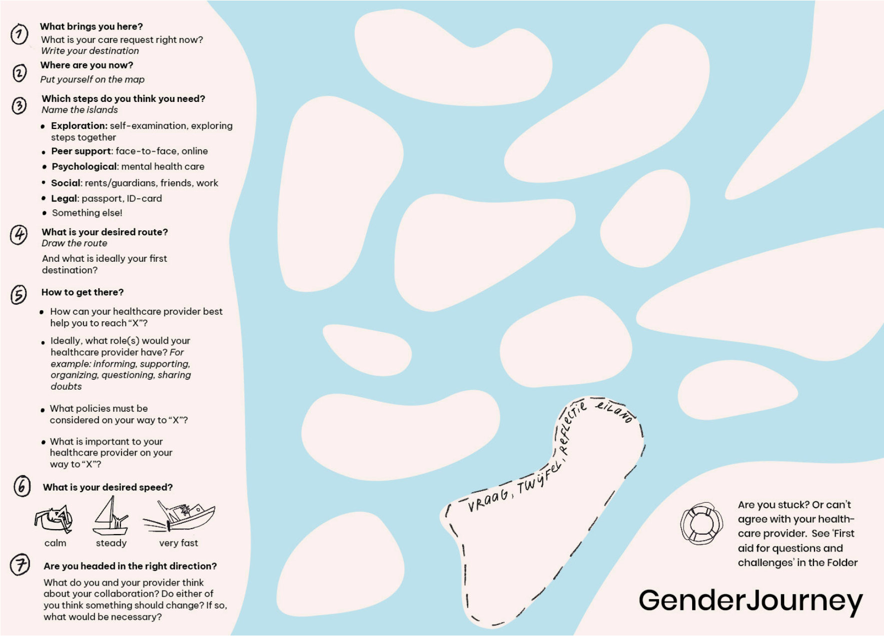
② **Defining roles**: *discussing expectations, roles and doubts about decision-making*

③ **Taking a step back**: *evaluating and dealing with potential challenges*

What do you need?

○ The GenderJourney printed in A3 or online

○ Pens, markers



① **What brings you here?**
What is your care request right now?
Write your destination

② **Where are you now?**
Put yourself on the map

③ **Which steps do you think you need?**
Name the islands

- **Exploration:** self-examination, exploring steps together
- **Peer support**: face-to-face, online
- **Psychological**: mental health care
- **Social**: rents/guardians, friends, work
- **Legal**: passport, ID-card
- Something else!

④ **What is your desired route?**
Draw the route

And what is ideally your first destination?

⑤ **How to get there?**

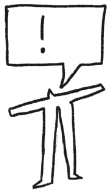
- How can your healthcare provider best help you to reach “X”?
- Ideally, what role(s) would your healthcare provider have? *For example: informing, supporting, organizing, questioning, sharing doubts*
- What policies must be considered on your way to “X”?
- What is important to your healthcare provider on your way to “X”?

⑥ **What is your desired speed?**

⑦ **Are you headed in the right direction?**
What do you and your provider think about your collaboration? Do either of you think something should change? If so, what would be necessary?

Are you stuck? Or can’t agree with your health-care provider. See ‘First aid for questions and challenges’ in the Folder

GenderJourney



The GenderJourney does not tell you what (medical) treatment is best for you or how you should decide with your healthcare provider. It can help you to discuss this and find out what is important to you.

02
GenderJourney: instructions

Plotting the course

① **What brings you here?**
Write or draw your care request (destination) on the map
Your GenderJourney is a process: there are many possible routes and destinations. What is your care request at this moment in time? For example, self-acceptance and feeling better in my body. It's OK if you don't know yet. Your request can also be to explore what it is you need.

② **Where are you now?**
Draw your vessel on the map
Have you already taken any steps? For example, coming out to friends

③ **Which steps do you think you need?**
Name the islands
There are many options, for instance: an exploration of your gender identity/expression, peer support, medical-surgical, psychological, social, and legal. Maybe you need something different. Perhaps you're in doubt, or you don't know yet. In that case, discussing your doubts or what you don't know could be the next step.

④ **What is your desired route at this moment? And your first or next destination?**
Draw and describe your ideal course and first or next destination, "X"
What does your healthcare provider think about your envisioned route and destination?

Dividing the roles

⑤ **How will you get there?**
On your way to "X," you and your healthcare provider can have different roles. For example, you can ask questions and tell your provider about your feelings, doubts, or treatment goals. Your provider may inform, support or critically question you.

How can your healthcare provider best help you to reach "X"? *Where would you place your healthcare provider on the map (for example, at the helm, ashore)?*

Ideally, what role(s) would your healthcare provider have? *Reflect on this with your healthcare provider*

What policies must be considered on your way to "X"? *Ask your healthcare provider. What do you and your provider think about these policies?*

What is important to your healthcare provider on your way to "X"? *Ask your healthcare provider*

⑥ **What is your desired speed?** *Encircle your desired speed on your way to "X."*

Some people hurry to get to their destination, while others like to take their time. What do you think is best for you?

Taking a step back

⑦ **Are you headed in the right direction?**
During your GenderJourney, it's helpful to check if you're headed in the right direction concerning your transition and collaboration. How do you and your provider feel about your journey and partnership? Are changes necessary? If so, which?

03

More about: collaboration and roles

Shared decision-making is a process

1. Talking about the options and their pros and cons

2. Exploring, together with your practitioner, what care is most fitting

3. Discussing your roles per phase or step

4. Making or deferring a decision

The proper care: essential and challenging

- There are many options (for example, guidance, hormones and/or surgeries), and over time, more will become available

- Your treatment wishes may change over time

- Often, there are multiple practitioners involved in your gender journey

- Medical steps usually hang together but may have different criteria (for example, regarding smoking or BMI)

- the effects of medical treatment are not completely predictable

Collaborating in transgender healthcare: other important issues

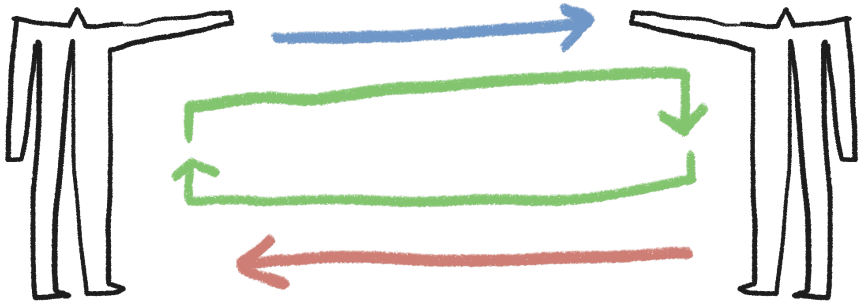
- How you and your provider want to work together may change over time or differ per treatment step

- For every medical treatment, there's a moment in which you and your provider discuss whether this step is fitting

- our provider has to follow guidelines and agreements. Over time, these might change.

- You can make non-medical decisions by yourself or with others.

How do we decide about X?



The provider decides what's best and takes the client's wishes and preferences into account

Shared decision-making: the client and provider discuss what's in the client's best interest and decide together

After the provider has informed the client about the treatment, the client decides

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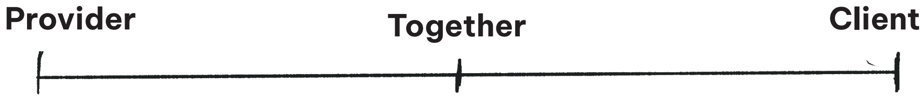
Where would you place an ✗?
And where would your provider place it? Why there?



04

First aid for questions or challenges

You and/or your healthcare provider may have questions about how you work and decide together. It’s important to talk these through. The following steps can guide the conversation. Hopefully, they’ll help to answer your question or deal with the challenge.

① **Starting point: What is the ethical challenge?**

What are you or your healthcare provider confronted with? Is there any doubt or uncertainty about the way you work together? Do you have different viewpoints on what is appropriate and which role fits the current moment?

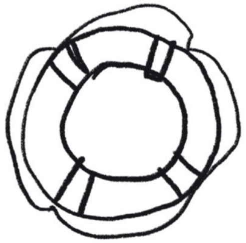
② **Do you recognize a theme?**

Ethical challenges regarding collaboration and decision-making often involve self-determination, protection, trust, honesty, responsibility, disagreement, dependency, or communication.

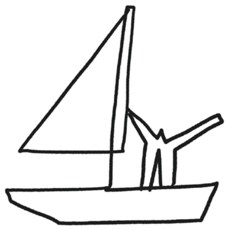
③ **Who is involved?**
What is important to you and your healthcare provider about the challenge? Can you both express your priorities and concerns?

④ **What happens next?**
According to you and your healthcare provider what should happen next?

For example:



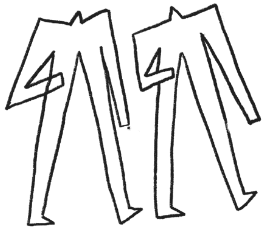
- **Self-determination:** I should decide, but I want to do that together with my healthcare provider
- **Responsibility:** Who should decide whether the risks are acceptable? The provider or the client?
- **Honesty:** Should I be honest with my healthcare provider when I doubt or disagree with something?
- **Disagreement:** How do we deal with disagreement (for example, about supportive therapy) and come to a decision?
- **Dependency:** To what extent may a client and/or healthcare provider go against the team’s advice?



04

First aid for questions or challenges

In case of a disagreement

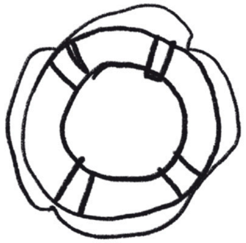


Do you disagree?

Do you agree about what's important, but do you disagree about what needs to happen? Or do you disagree about what should happen because your priorities are different? Do you understand what's essential to the other? Is it possible for both of your concerns to be met?

Weighing up the options

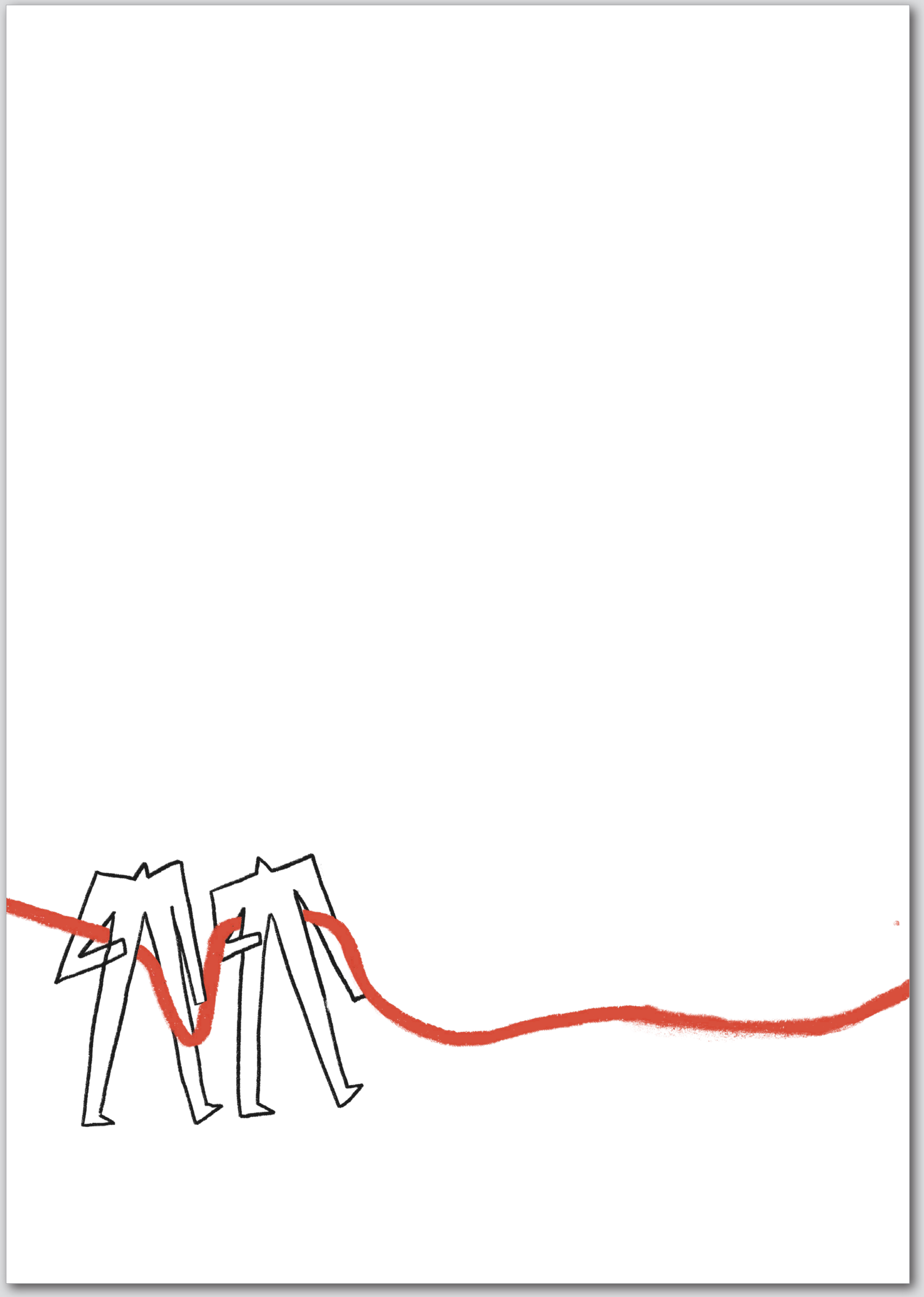
What is decisive to you and your healthcare provider concerning the question or challenge? What do you think needs to happen? In case not everything you and the other find important can be done: are there ways to do justice to the things that are receiving insufficient attention at the moment?



Do you still disagree? Are you stuck?

Sometimes there's no clear-cut answer to your question or solution to your challenge. You and your healthcare provider may still have different ideas about what's important concerning a decision or what your collaboration should look like.

Fortunately, there are options: exploring alternatives; including relatives, friends, or partners; writing down your thoughts and sharing these; requesting a Moral Case Deliberation, mediator, spiritual care worker, member of the client council, or independent healthcare professional; filing an official complaint; etc.



Samenwerken in Transgenderzorg: Hoe en Wat?

Een goed gesprek over je GenderJourney

Inhoudsopgave

① Inleiding

② GenderJourney: uitleg

③ Meer over: samenwerken en rollen

④ Eerste hulp bij vragen en uitdagingen

Deze folder en de GenderJourney zijn gemaakt samen met behandelaars en transgender cliënten in een project van de Genderpoli en de afdeling Ethiek Support van het Amsterdam UMC.

Amsterdam UMC

01
Inleiding

Als je geboortegeslacht niet past bij hoe je je voelt, kun je terecht in de genderzorg voor begeleiding en (medische) behandeling. Geen transgender persoon is hetzelfde. Daarom wordt er rekening gehouden met persoonlijke behoeftes en mogelijkheden. Rondom de behandeling, maar ook in de samenwerking met je behandelaars.

In deze folder vind je (1) uitleg over de GenderJourney (een tool voor een goed gesprek in de spreekkamer, (2) meer informatie over het samenwerken met je behandelaar(s) en (3) eerste hulp bij vragen en uitdagingen.

Een goede samenwerking is belangrijk om erachter te komen welke zorg en keuzes het beste bij jou passen. Het streven is dat iedereen zich daar goed over voelt.

Wat daarvoor nodig is, verschilt per persoon. Het is belangrijk om het hier met elkaar over te hebben.

Wat zijn je verwachtingen over hoe we gaan samenwerken?

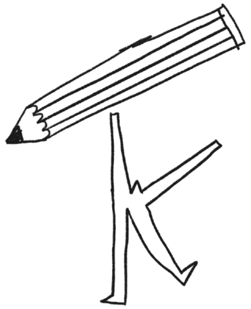
Hoe denken je behandelaars hierover?

Hoe zit je hier?

Deze folder geeft geen inhoudelijke informatie over de verschillende behandelingen. Daarvoor kun je terecht bij je behandelaars.

02
GenderJourney: uitleg

De GenderJourney helpt om overzicht te krijgen in jouw genderreis en het hierover te hebben met je behandelaar(s), zoals je psycholoog. Bijvoorbeeld aan het *begin* van je traject, als je een *volgende stap* wilt zetten, of een *pas op de plaats* wilt maken. Je kunt de GenderJourney dus op verschillende momenten gebruiken, alleen én samen met je behandelaars.



De GenderJourney heeft drie doelen → Waarom en wanneer gebruik je de GenderJourney?:

① De koers uitzetten: *je hulpvraag en ideeën over de route duidelijk maken*

② De rollen verdelen: *de samenwerking, rollen en twijfels bespreken*

③ Een stap terugnemen: *evalueren en omgaan met vragen en uitdagingen*

Benodigdheden:

De GenderJourney, uitgeprint op A3-formaat of op internet

Stiften, pennen of pionnen

① **Wat brengt je hier?**
Wat is je hulpvraag **op dit moment**?

② **Waar sta je nu?**
Zet jezelf op de kaart

③ **Welke stappen denk je nodig te hebben?**
- **Verkennen**: zelfonderzoek, samen stappen uitzoeken
- **Onderling contact**: transvisie
- **Medisch**: hormonen, operaties
- **Psychologisch**: behandeling in de GGZ
- **Sociaal**: ouders, vrienden, werk
- **Juridisch**: paspoort
- iets heel anders

④ **Wat is op dit moment je gewenste route?**
Wat is je eerste bestemming?

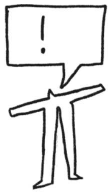
⑤ **Hoe kom je daar?**
- Hoe kan je behandelaar jou het beste helpen?
- Wat is voor jou de ideale rol van je behandelaar? *Bijvoorbeeld: informeren, steunen, organiseren, vragen stellen, twijfels delen, kritisch bevragen.*
- Wat kan je behandelaar wel en niet voor je doen?
- Wat is voor je behandelaar belangrijk? En waarom?

⑥ **Wat is je gewenste snelheid?**
rustig
met vaart
heel snel

⑦ **Ga je de goede kant op?**
Wat vinden jij en je behandelaar van de samenwerking? Denk jij of je behandelaar dat het anders zou moeten? Wat is daarvoor nodig?

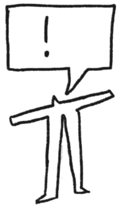
Zit je vast? Of niet op één lijn met je behandelaar? Zie 'Eerste hulp bij vragen en uitdagingen' In de folder!

GenderJourney



De Genderjourney vertelt niet welke behandeling het beste bij jou past of hoe je met je behandelaars keuzes moet maken over behandelingen. Wel kan de GenderJourney helpen om hierover na te denken en over in gesprek te gaan.

02
GenderJourney: instructies



Wat je belangrijk vindt in je genderreis en in de samenwerking kan over de tijd veranderen of per stap verschillen. Hoe jij en je behandelaars tot een keuze komen over hormonen kan anders zijn dan over operaties. Het is dus goed om hierover met je behandelaars in gesprek te blijven!

De koers uitzetten

① **Wat brengt je hier?**
Je genderreis is een proces: je komt ergens vandaan en gaat ergens naartoe. Onderweg kan er van alles gebeuren. Wat is je hulpvraag op dit moment? Bijvoorbeeld, zelfacceptatie en me beter voelen in mijn lief. Het is OK als je dit nog niet weet op dit moment. Je hulpvraag kan ook zijn om dit (samen) te exploreren

② **Waar sta je nu?**
Waar kom je vandaan?
Heb je al stappen gezet?
Bijvoorbeeld, coming-out naar vrienden

③ **Welke stappen denk je nu nodig te hebben?**
Benoem de eilanden.Er zijn verschillende mogelijkheden: medisch, psychologisch, sociaal, juridisch. Misschien heb je wel iets heel anders nodig. Het kan ook zijn dat je twijfelt of meer zelfonderzoek wilt doen. Dat is OK!

④ **Wat is op dit moment je gewenste route? En je eerste of volgende bestemming?**
Teken en beschrijf je ideale route en eerste bestemming “X”
Wat denkt je zorgverlener over je voorgestelde route en eerste of volgende bestemming?

De rollen verdelen

⑤ **Hoe kom je daar?**
Op weg naar “X” kunnen jij en je behandelaar verschillende rollen aannemen. Jij kan bijvoorbeeld vragen stellen en je behandelaar vertellen over je gevoelens, twijfels en behandeldoelen. Je behandelaar kan je bijvoorbeeld informeren, ondersteunen of kritisch bevragen.

- **Hoe kan je behandelaar je het beste helpen op weg naar “X”?** *Waar zou je je behandelaar plaatsen op de kaart (bijvoorbeeld, aan wal of juist aan het roer)?*
- **Wat voor rol(len) heeft je behandelaar in een ideale situatie?** *Heb het hierover met je behandelaar*
- **Wat zijn de regels en richtlijnen op weg naar “X”?** *Vraag het je behandelaar. Hoe denken jullie hierover?*

⑥ **Wat is je gewenste snelheid?**
Sommige mensen hebben haast, terwijl anderen liever hun tijd nemen. Hoe zit dit bij jou?

⑦ **Ga je de goede kant op?**
Als je onderweg bent, is het goed om af en toe te kijken of je de goede kant op gaat. Wat vinden jij en je behandelaar van de samenwerking? Moet er iets veranderen? Wil je een volgende stap zetten of de route veranderen?

03

Meer over: samenwerken en rollen

Samen beslissen is een proces

1. Het bespreken van de opties en hun voor- en nadelen

2. Met je behandelaar uitzoeken welke zorg het beste past bij wat voor jou belangrijk en mogelijk is

3. Bespreken wat jullie rollen per fase of stap zijn

4. Een keuze maken of uitstellen

De juiste zorg: Belangrijk én uitdagend

Er zijn veel opties (bijv. begeleiding, hormonen en/of chirurgie) en over de tijd zullen er nog meer beschikbaar komen

Je behandelwensen kunnen over de tijd veranderen

Er zijn vaak meerdere behandelaar(s) betrokken bij je genderreis

Medische behandelstappen hangen soms met elkaar samen en kunnen verschillende criteria (bijv. roken en/of BMI) hebben

De effecten van een behandeling zijn niet precies te voorspellen

Samenwerken in de genderzorg: Andere belangrijke zaken

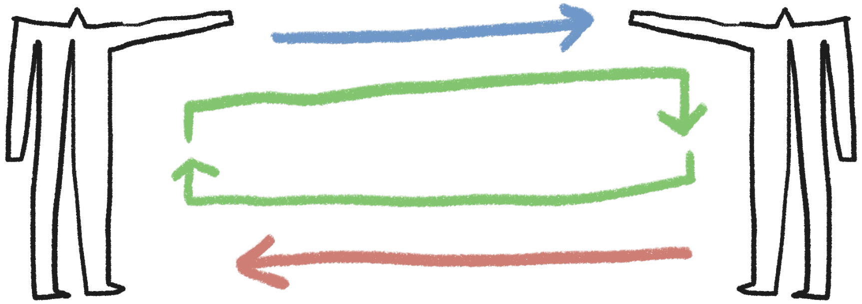
De manier waarop je met je behandelaars wilt samenwerken kan over de tijd veranderen of per stap verschillen

Voor elke medische behandelstap is er een moment waarop je samen met je behandelaars bespreekt of deze stap bij jou past

Je behandelaars moeten zich houden aan richtlijnen en werkafspraken. Die kunnen door nieuwe inzichten veranderen

Niet-medische keuzes kun je ook zelf of met anderen maken

Hoe maken we EEN keuze over stap x?



De behandelaar beslist wat het beste is om te doen en neemt hierin de wensen en voorkeuren van de cliënt mee

Samen beslissen: cliënt en behandelaar onderzoeken wat het beste past bij de cliënt en nemen vervolgens samen de keuze

Nadat de behandelaar de cliënt heeft geïnformeerd over de behandeling, belist de cliënt zelf

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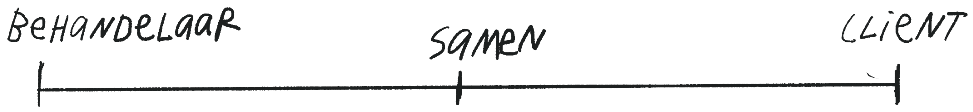
Waar zou jij ✗ zetten? En je behandelaar? Waarom daar?



04

Eerste Hulp bij vragen of uitdagingen

Het kan zo zijn, dat jij en/of je behandelaars vragen hebben over het samenwerken, of dat jullie anders denken over wat een goede samenwerking is. Het is belangrijk om het daar op tijd over te hebben. Onderstaande stappen kunnen helpen om hierover in gesprek te gaan: al pratende kan de vraag beantwoord worden of kunnen jullie een goede manier vinden om met de uitdaging om te gaan.

1 **Startpunt: Wat is de vraag of uitdaging?**

Waar loop jij of lopen jullie tegenaan? Is er sprake van twijfel, onzekerheid, een meningsverschil of iets anders?

2 **Herken jij of herkennen jullie een thema?**

Vragen en uitdagingen rondom het samenwerken hebben vaak te maken met: eigen regie, beschermen, vertrouwen, eerlijkheid, verantwoordelijkheid, onenigheid, onduidelijkheid, communicatie

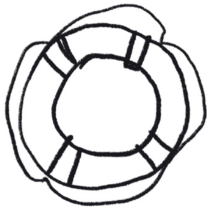
3 **Wie zijn er betrokken?**

En wat is er voor hen belangrijk rondom de vraag of uitdaging?

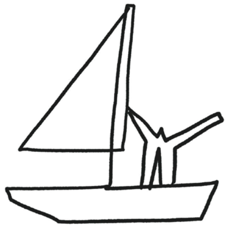
4 **Wat moet er gebeuren?**

Wat moet er volgens jou en andere betrokkene(n) gebeuren, omdat jullie dat belangrijk vinden?

Bijvoorbeeld:

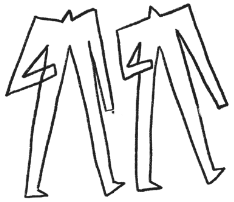


- **Eigen regie:** Ik moet zelf kunnen beslissen, maar wel samen met mijn behandelaar
- **Verantwoordelijkheid:** Wie mag beslissen of bepaalde risico's acceptabel zijn? De behandelaars of cliënt?
- **Eerlijkheid:** Mag ik eerlijk zijn tegen mijn behandelaar dat ik twijfel of het ergens niet mee eens ben?
- **Onenigheid:** Als cliënt en behandelaar het niet eens zijn over diagnostiek en behandeling in de ggz, hoe gaan we daar dan op een goede manier mee om?
- **Afhankelijkheid:** In hoeverre mag een cliënt en/of behandelaar tegen het advies van het team ingaan?



04
Eerste Hulp bij vragen of uitdagingen

Bij een meningsverschil:

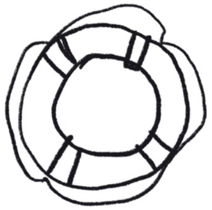


Zijn jullie het niet met elkaar eens?

Vinden jullie iets anders belangrijk? Of zijn jullie het erover eens wat er belangrijk is, maar niet over wat er moet gebeuren? Begrijp je wat de ander belangrijk vindt?

Wikken en wegen

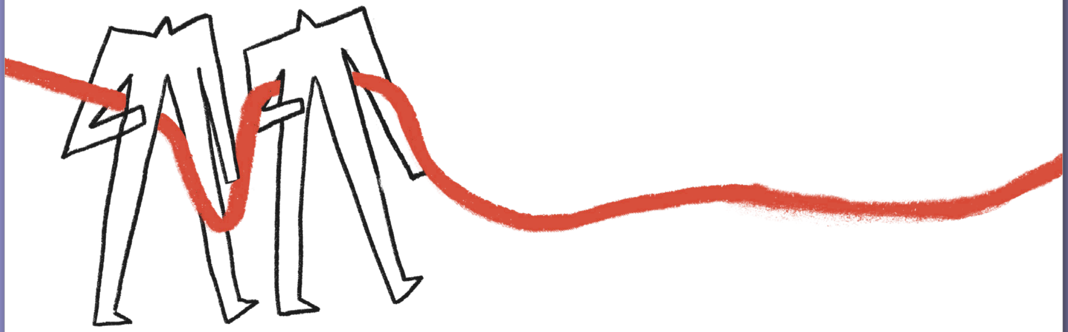
Wat is voor jou en de ander doorslaggevend in de vraag of uitdaging? Wat vinden jullie dat er moet gebeuren? Als niet alles gedaan kan worden, wat jullie belangrijk vinden: is het mogelijk om hier (deels) aan tegemoet te komen?



Komen jullie er niet uit?

Soms is er geen duidelijk antwoord op de vraag of oplossing voor de uitdaging. Het kan zijn dat jij en je behandelaar(s) nog steeds een ander idee hebben over wat belangrijk is. Of hoe de samenwerking eruit moet zien.

Gelukkig zijn er andere opties: alternatieven verder verkennen; betrekken van naasten, familie of begeleiding; gedachten delen en opschrijven; moreel beraad aanvragen, mediator, geestelijk verzorger, cliëntenvertegenwoordiger of onafhankelijke behandelaar betrekken; klacht indienen, etc.



1 **What brings you here?**
What is your care request right now?
Write your destination

2 **Where are you now?**
Put yourself on the map

3 **Which steps do you think you need?**
Name the islands

- **Exploration:** self-examination, exploring steps together
- **Medical**: hormones, surgery
- **Peer support**: face-to-face, online
- **Psychological**: mental health care
- **Social**: Parents/guardians, friends, work
- **Legal**: passport, ID-card
- Something else

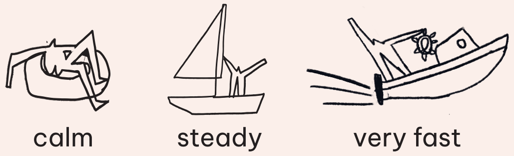
4 **What is your desired route?**
Draw the route

And what is ideally your first destination?

5 **How to get there?**

- How can your healthcare provider best help you to reach “X”?
- Ideally, what role(s) would your healthcare provider have? *For example: informing, supporting, organizing, questioning, sharing doubts*
- What policies must be considered on your way to “X”?
- What is important to your healthcare provider on your way to “X”?

6 **What is your desired speed?**



7 **Are you headed in the right direction?**
What do you and your provider think about your collaboration? Do either of you think something should change? If so, what would be necessary?

Are you stuck? Or can’t agree with your healthcare provider? See ‘First aid for questions and challenges’ in the Folder

GenderJourney

① **Wat brengt je hier?**
Wat is je hulpvraag op dit moment?
Zet op de kaart

② **Waar sta je nu?**
Teken je vaartuig

③ **Welke stappen denk je nodig te hebben?**
Benoem de eilanden

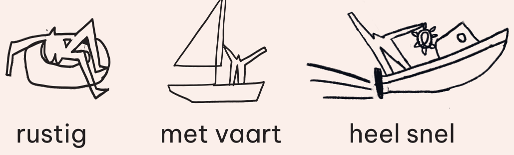
- **Verkennen**: zelfonderzoek, samen stappen uitzoeken
- **Onderling contact**: transvisie
- **Medisch**: hormonen, operaties
- **Psychologisch**: behandeling in de GGZ
- **Sociaal**: ouders, vrienden, werk
- **Juridisch**: paspoort
- iets heel anders

④ **Wat is op dit moment je gewenste route?**
Teken de route
Wat is je eerste bestemming?

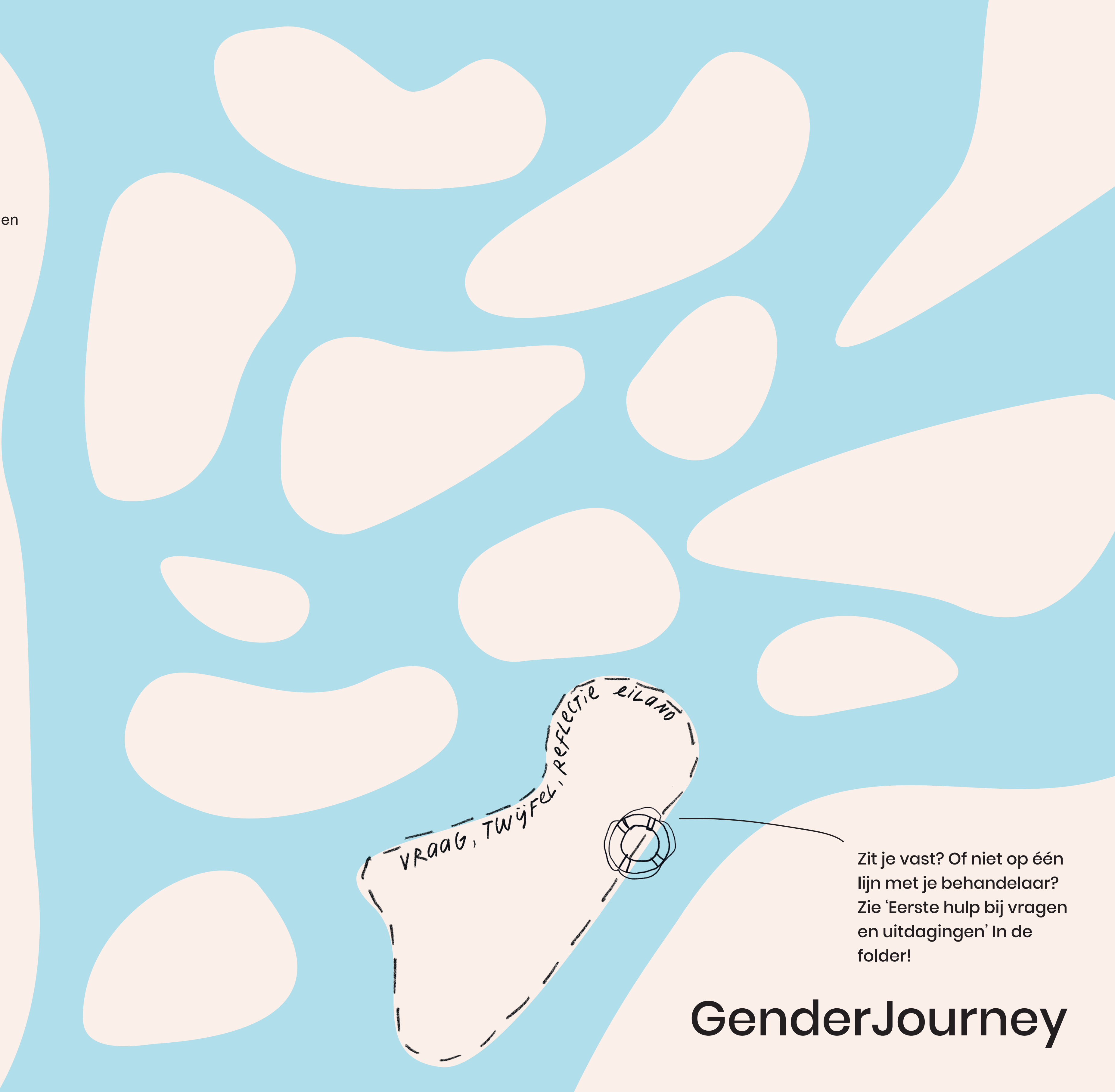
⑤ **Hoe kom je daar?**

- Hoe kan je behandelaar jou het beste helpen om “X” te bereiken?
- Wat is voor jou de ideale rol van je behandelaar? *Bijvoorbeeld: informeren, steunen, organiseren, vragen stellen, twijfels delen, kritisch bevragen.*
- Wat kan je behandelaar wel en niet voor je doen?
- Wat is voor je behandelaar belangrijk op weg naar “X”? En waarom?

⑥ **Wat is je gewenste snelheid?**



⑦ **Ga je de goede kant op?**
Wat vinden jij en je behandelaar van de samenwerking? Denk jij of je behandelaar dat het anders zou moeten? Wat is daarvoor nodig?



Zit je vast? Of niet op één lijn met je behandelaar? Zie ‘Eerste hulp bij vragen en uitdagingen’ In de folder!

GenderJourney

Colofon

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Worldwide, an increasing number of transgender individuals turn to gender identity clinics for gender-affirming medical care: interventions to affirm and express their experienced gender.

A central ethical challenge faced by those receiving and providing such care is: How should we go about making and sharing decisions? In other words: what does good shared decision-making entail?

This thesis has two central aims. First, to gain insight into the moral and conceptual landscape of shared decision-making in this specific care practice. Second, to co-create an ethics support tool that fosters (a joint reflection on) good shared decision-making and aids stakeholders in practice in recognizing and handling related ethical challenges.

Amid polarization, we sought to bring together and encourage deliberation among healthcare professionals and clients through a participatory design, qualitative methods and ethics.

This thesis highlights that shared decision-making in gender-affirming medical care is characterized by ontological ambiguities, epistemic uncertainties and normative contestations. We hope the findings and tool presented in this thesis provide a foothold for ongoing, critical-constructive dialogues toward better shared decision-making in transgender healthcare and beyond.