

Towards compassionate science based medicine/care for gender questioning individuals.

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There has been a major rise in referrals for mainly young people to Gender identity services. This appears to be, at least in part, due to changes in culture and beliefs of young people, fueled not insignificantly by on line fora. Our major concern is for vulnerable young people and the potential for overall harm indicated by the case studies of actual harm and limited evidence base. In this talk I will outline some key issues and then propose an alternative approach based on an understanding of the evidence and standard practices in medicine.

I am here as a generalist doctor and researcher with expertise in developing person centred care for vulnerable groups. I also work in a young people's mental health team where I now regularly encounter gender questioning young people on various points of the pathway to medical intervention. These have included individuals disappointed about the limited effects of hormones on beard growth and body fat redistribution, feeling sexually inadequate after transition and seeking psychological support to tolerate not transitioning.

The current positions are as polarised as virtually any in medicine. It is important that all views consistent with the evidence should be aired even if not in keeping with current policy. We should be able to speak up. The different positions reflect debates in the public sphere. I suggest that the basis for such differences amongst practitioners rests on three areas of belief:

Firstly, our understanding of the body, the brain and the mind. While medicine normally sees our sexual biology as binary and fixed, gender theory - also known as queer theory - instead suggests that some one's belief about what gender they are is of paramount importance and should be supported by medical interventions, legal changes and increasingly education in schools. In health care in the UK a Memorandum of Understanding and other guidance is increasingly suggesting we should endorse an individual's belief that they are 'trans'. Such a position conflicts with the evidence that the subjective psychological experience of being 'trans' is changeable rather than fixed; that there is no objective way for a doctor to declare someone is 'trans'; and that we should provide compassionate support rather than endorse biologically unsound beliefs.

Secondly, our approach to decision making varies. There is a conflict between a purely consumerist approach to giving people whatever medicine they want in relation to such beliefs, and current normal practice of shared decision making. Uncertainties, harms and benefits of the options should be discussed along with the hopes of patients. Often, when harms are likely to be small, the patient's choice will be respected. But doctors are not expected to provide surgery and medicine on demand; rather we have a duty of care to weigh up potential harms and benefits before intervening. For example opioid prescribing for chronic pain is now an area where the expectation is for doctors not to prescribe in response to patient requests - though until recently such prescribing was just one of a litany of medical 'innovations' now shown to be harmful. The new consumerist model of so called 'informed consent' for so called 'gender affirming' treatment - including via private on line clinics - is therefore in conflict with standard medical practice. It does not appear that the

uncertain risks of treatments are fully shared with young people, and the use of language seeks to minimise the significance of treatment, such that double mastectomy is relabeled 'top surgery'.

Thirdly, doctors can interpret evidence differently. For the last 50 or more years a small group of dedicated doctors have forged the practice and evidence to support gender medicine. With relatively little resource (compared to cancer for example) they have generated a body of evidence which describes physical changes before and after intervention along with the surgical and medical techniques. This is in many ways impressive but unfortunately lacks the normal requirements of evidence to support the introduction - let alone provision at scale - of medical advances. Randomised trials are absent or small and follow up too short – such that in the review of evidence carried out by Professor Carl Heneghan from Oxford University's Centre for Evidence Based Medicine it was concluded that 'The current evidence does not support informed decision making and safe practice'.

A coming together of these three factors - over selling of the current evidence for benefit, an unscientific thinking about the body and gender and a consumerist approach to decision making - along with changing beliefs and cultures among young people appear to have led to an escalation in referrals as well as BOTH an increase in treatment provision AND also distressing waiting lists. Unfortunately the ambitions of the Tavistock GIDS service to be developmental and trauma informed appears to have been weakened by these factors. The case for change is generally accepted but while NHS England propose expansion to deal with demand we are concerned about the harms of applying a relatively poor evidence base to a new and expanding cohort of younger mainly female individuals with different psychological profiles – much more rapid onset and with autistic trait and past trauma.

And as well as poor evidence for benefit we also have very little on which to quantify the potential harms. But we do have a duty to hypothesise as to how harms could occur in transgender medicine and try to mitigate these. Individual case study evidence shows all the following possible/likely:

1. Physical side effects - short and long term
 2. Emotional problems – neglect of mental health issues, emotional development, disappointment about unfulfilled physical expectations
 3. Social - difficulties – family discord, lack of partners
- Detransition can incorporate all of above. The speakers following me have the experience and expertise to illustrate these in detail.

So what do we make of this and how do we move forward to ensure we have the best service in the world for gender questioning individuals? I believe that one reasonable position to take given the state of the evidence is that:

All medical and surgical interventions for those under 25, still very much in a developmental phase, should be halted, except under research conditions, with randomised controls, and with independent monitoring. Instead we should provide compassionate person centered psycho-social support.

Given that we need to be realistic - such a change is unlikely in near future - we should consider how to mitigate potential harms while advocating for such a stance:

1. Prevention - acknowledge that gender questioning and feeling trans are influenced by complex mix of cultural norms and personal predispositions (related e.g. to trauma and autism trait) - this means we should stop encouraging people to believe they are trans and stop school based education, and other socialisation (e.g. guides etc). More general work in schools should explain why many girls are socialized to feel uncomfortable or even disgust with their bodies because of problematic gendered roles and past trauma. Results can include cutting, anorexia or wondering if they are 'trans'.

2. Provision of accurate information – NHS and websites of medical authorities and also charities need to mention potential harms, uncertainties and not glamourise transition or sexual stereotypes.

3. Endorse a person centred and scientifically accurate approach to practitioner interactions: exploring links between complex cognitive, emotional and social issues; talking accurately - distinguishing between biologically male/female bodies and the experience of feeling 'trans' or not being sure; exploring decisions in terms of balance of benefits and harms; separate affirmation of an individual's experience from being equated to being recommended and having a right to medical intervention. This will require a rewrite of the Memorandum and provision of guidance applicable to private as well as NHS service services by the GMC.

4. Add to current proposed NHSE service specifications key provision with ongoing evaluation, for which there are gaps: additional conservative supportive strategies - individual or group based support for individuals come to terms with biological bodies while expressing whatever (non gendered) role they wish; increased psychological input for the 17-25 year olds who will need a developmental trauma informed services as aspired to in GIDS; neutrally framed support for those on waiting lists provided on basis that some individuals will desist; services for those who have desisted and detransitioned.

5. Take advantage of the current recommissioning of adult services and create an ongoing long term cohort research study with independent scrutiny for all those presenting as questioning and entering services - with outcomes measured and assertive follow up those lost dropping out of care. Ensure the GIDS and adult services as well as private provision is joined up as one database. Use such a cohort should fully investigate the cause of the rapid change in presentation and bio-psycho-social profile of younger individuals.