Non-binary or genderqueer genders

How to cite:

© 2016 Taylor Francis

Version: Accepted Manuscript

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.3109/09540261.2015.1106446

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.

oro.open.ac.uk
Title: Non-binary or genderqueer genders

Christina Richards MSc1,2, Walter Pierre Bouman MA MSc FRCPsych1, Leighton Seal MBBS FRCP PhD2, Meg John Barker PhD3, Timo O. Nieder PhD ECPS4, Guy T’Sjoen MD PhD5

1 Nottingham Centre for Gender Dysphoria, 3 Oxford Street, Nottingham NG1 5BH, United Kingdom
2 Charing Cross Gender Identity Clinic, London, United Kingdom
3 Psychology in Social Sciences, The Open University, Walton Hall, Milton Keynes, MK76AA, United Kingdom.
4 Interdisciplinary Transgender Health Care Center Hamburg, Department for Sex Research and Forensic Psychiatry, University Medical Center Hamburg-Eppendorf (UKE), Germany
5 Center for Sexology and Gender, Department of Endocrinology, Ghent University, Belgium

Correspondence: Christina Richards, Nottingham Centre for Gender Dysphoria, Nottinghamshire Healthcare NHS Trust, 3 Oxford Street, Nottingham, NG1 5BH, United Kingdom. Tel. +44 115 876 0160. Fax: +44 115 9475609. Email: christina.richards@nottshc.nhs.uk
Non-binary or genderqueer genders (3635 of 4000 words, excluding abstract and references)

Abstract (198 of 200 words)

Some people have a gender which is neither male nor female and may identify as both male and female at one time, as different genders at different times, as no gender at all, or dispute the very idea of only two genders. The umbrella terms for such genders are genderqueer or non-binary genders. Such gender identities outside of the binary of female and male are increasingly being recognised in legal, medical and psychological systems and diagnostic classifications in line with the emerging presence and advocacy of these groups of people. Population-based studies show a small percentage - but sizable proportion in terms of raw numbers - of people who identify as non-binary. While such genders have been extant historically and globally, they remain marginalised and as such - while not being disorders or pathological in themselves - people with such genders remain at risk of victimisation and of minority or marginalisation stress as a result of discrimination.

This paper therefore reviews the limited literature on this field and considers ways in which (mental) health professionals may assist the people with genderqueer and non-binary gender identities and/or expressions they may see in their practice. Treatment options and associated risks are discussed.

Introduction

Gender is often considered to come in two forms – male (masculine) or female (feminine). Indeed, it is frequently elided with physical sex such that when a person is assigned a female sex at birth - through visual inspection of their external genitals - it is assumed that their gender too will be female; that they will likely be feminine (their gender role); and that they will most likely be sexually attracted to men when they reach sexual maturity. Of course, this series of inferences is correspondingly made with males - linking sex, to gender, to gender role, to sexuality. It is a trivial assertion, however, to say that these inferences are not invariably correct. For example, male people may be attracted to other male people; people assigned male at birth may have a female gender identity; and people assigned female may have a male gender identity but, for pragmatic reasons, have a female gender role, etc., (cf. Richards & Barker, 2013; 2015).

All these acknowledged variations nonetheless still presuppose a binary system of male and female, albeit that ‘male’ and ‘female’ here may be expressed in different ways as gender, sex, role, etc. Notwithstanding this, people with an intersex or Diversity/Disorder of Sexual Development (DSD) condition (APA, 2013a) will have physical sexual characteristics which sit fall outside of this binary
(Roen, 2015); although the majority of people with this range of conditions do still identify their gender within the binary - as men or as women (Harper, 2007; Richards & Barker, 2013).

In contrast to this, there are a significant number of people who do not have an [observable] intersex/DSD condition, but who nonetheless identify outside of the gender binary. Such non-binary gender identity or expression has been present over time and across different global cultures (Herdt, 1996).

In the current Western context, however, some people may identify as predominantly male, but with aspects of the ‘other’ gender and use the identity term male generally; or may identify as predominantly female, but with aspects of the ‘other’ gender and use the identity term female generally – but both groups of people may define additionally as genderqueer when necessary – for example in accepting environments or when neither a male nor female identity suits. Those people who incorporate aspects of both male and female, but who have a fixed identity, may identify as androgynous, mixed gender or sometimes pangender as the latter is a flexible term. In contrast, people who move between genders in a fluid way may identify as bigender, gender fluid or sometimes pangender again. Some people move between more than two genders and so identify as trigender, and sometimes pangender as it is a flexible term. Some people identify as a specific additional gender (either between female and male or otherwise additional to those genders) and so identify as third gender, other gender, and sometimes again as pangender. Then there are those people who disrupt the gender dichotomy though challenging its very ontology and/or veracity and so identify as genderqueer or genderfuck. And there are also people who have no gender and so identify as agender, gender neutral, non-gendered, genderless, neuter, or neutrois.

An example of this is present in Bockting (2008) who found in the course of a US-American online study a variety of identities amongst 1,229 transgender persons that were not reconcilable with a binary understanding of sex. These included “shemale, bigender, two-spirit, gender neutral, genderless, androgyne, ambiguous, intergendered, 3rd gender, pan-, poly- or omni-gendered, dynamically gendered, gender fluid, nonbiological intersexed, In-between and beyond” (Bockting, 2008 p. 214). In her qualitative study, Hines (2007) quotes such further non-binary identities as “gender terrorist, intersex by design, intentional mutation, hermaphrodyke, queer trannie boy” (Hines, 2007, p. 80). All of the above terms are often subsumed within the umbrella terms of non-binary or genderqueer identities. In this emerging field terms are likely to change, however, and, as usual, we should attend to people’s own preferred terms when undertaking clinical work.

In this area, it is also important to use people’s preferred pronouns (in addition to names and terms for gender). Some non-binary people use they/their/them/themselves or an explicitly developed term such as xe/xyr/xem/xyrself rather than he/his/him/himself or she/her/her/herself. With all these aspects, ask etiquette is appropriate (Richards & Barker, 2013) which simply involves
asking what terminology people prefer and how they experience their gender. This move towards a more accepting and accommodating approach towards non-binary and genderqueer people is mirrored in generally more favourable media reporting within the global North and West, especially in online and youth oriented media. Within mainstream media there is still a tendency towards a perhaps patronising ‘interest’ which situates non-binary and genderqueer people as Other to the assumed norm of the viewer – something which can be tiring for these minority groups (cf. Sue, 2010)

This paper then, consists of a necessarily extremely brief overview of the current psychiatric literature pertaining to such non-binary or genderqueer identities as these have formed the basis of the literature until now. It then considers how (mental) health professionals might assist these groups of people within clinical practice in a non-pathologising manner, which recognises the pressures and needs of this group of people at this time in history.

Prevalence of Non-Binary People

There are two population studies, which have aimed to estimate the prevalence of people who identify as non-binary. Kuyper & Wijzen (2014) examined self-reported gender identity and dysphoria in a large Dutch population sample (N=8,064, aged 15-70 years old), and found that 4.6% of people assigned male at birth and 3.2% of people assigned female at birth reported an ‘ambivalent gender identity’ (defined as equal identification with other sex as with sex assigned at birth) and 1.1% of people assigned male at birth and 0.8% of people assigned female at birth reported an ‘incongruent gender identity’ (defined as stronger identification with other sex as with sex assigned at birth). Recently, Van Caenegem et al. (2015) reported results based on two population-based surveys, one of 1,832 Flemish persons and one of 2,472 sexual minority individuals in Flanders, Belgium examining the prevalence of ‘gender incongruence’ (defined as identifying stronger with the other sex than with the sex assigned at birth) and ‘gender ambivalence’ (defined as identifying equally with the other sex as with the sex assigned at birth). Their findings showed that the prevalence of ‘gender ambivalence’ or non-binary gender was 1.8% in natal males and 4.1% in natal females.

In terms of trans populations more specifically, one UK study found that 5% of Lesbian, Gay, Bisexual, Trans and Questioning (LGBTQ) youth identified as neither male not female (METRO Youth Chances, 2014); a US study found that 13% of trans people surveyed were “a gender not listed here” (Harrison, Grant & Herman, 2012, p.14); and a Scottish study on trans mental health (McNeil, Bailey, Ellis, Morton, & Regan, 2012) found that over a quarter of survey participants identified as non-binary.

Turning to wider gender experience and expression, rather than specific identities, it seems that the figures are likely to be much higher. Joel, Tarrasch, Berman, Mukamel and Ziv (2013) surveyed people
in the general population in Israel and found that, out of 2225 participants, over 35% felt that they were to some extent the ‘other’ gender, ‘both’ genders, and/or neither gender.

These are clearly significant proportions of people, however comparatively few appear to be seeking treatment. For example, in Beek, et al (in press), out of 360 applicants for gender reassignment treatments only 4 explicitly stated that their non-binary identity was their motivation for treatment. This may, of course, be related to the number of non-binary people who feel able to be open about their identities in such settings.

**Human Rights and Legislation for Non-Binary People**

Many of the non-binary groups of people listed above will use their birth assigned gender as a matter of necessity in day-to-day business and bureaucracy due to the fact that many systems (including health systems) and social circles only recognise binary genders. This is changing, however. For example the European Union’s Council of Europe Parliamentary Assembly Resolution 2048 6.2.4 recommends that European Parliaments “Consider including a third gender option in identity documents for those who seek it” (Council of Europe, 2015). Similarly the United Nations’ (UN) General Assembly Report of the United Nations High Commissioner for Human Rights Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity (United Nations, 2015) advocates for fair treatment of LGBT people in all UN member states and notes that:

“The terms lesbian, gay and bisexual and transgender are used throughout the report, but often abbreviated to LGBT. These terms are used to refer to same-sex behaviour, identities or relationships and non-binary gender identities.” (United Nations, 2015 p.4; Italics not in original)

Thus the report includes non-binary people within its purview and consequently within international law. Notably, holders of New Zealand passports may already have their gender marked as Male (M), Female (F), or as neither male nor female (X). More broadly, organisations from Facebook to the United Kingdom’s Royal Mail are including non-binary genders as gender options for their customers. It follows therefore that health professionals should be attendant to this cultural shift in their work.

**Diagnostic Classification concerning Non-binary People**

This trend toward acceptance, as well as a greater understanding of the diversity of gender, has been reflected within the context of mental health care as in the last revision to the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual 5th edition (DSM-5 – APA, 2013a). The DSM-5
removed the DSM IV-TR (APA, 2000) diagnosis of Gender Identity Disorder which considered wishing to change one’s gender to be a disorder and only recognised the gender binary of male and female. The DSM-5 instead includes the diagnosis of Gender Dysphoria which explicitly recognises that having a different gender is not a disorder (APA, 2013b) and crucially includes the criteria:

“4. A strong desire to be of the other gender (or some alternative gender different from one’s assigned gender)
5. A strong desire to be treated as the other gender (or some alternative gender different from one’s assigned gender)
6. A strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one’s assigned gender)” (APA, 2013 p.452; Italics not in original)

Thus non-binary genders are recognised with the APA’s diagnostic taxonomy also. There are, of course, strong arguments for removing diagnoses pertaining to gender from the DSM entirely as there are no higher rates of psychopathology in this demographic (Cole, O’Boyle, Emory & Meyer III, 1997; Colizzi, Costa & Todarello, 2014; Haraldsen & Dahl, 2000; Hill, Rozanski, Carfagnini & Willoughby, 2005; Hoshiai et al, 2010; Kersting et al, 2003; Simon et al, 2011). Of course this does not include wider psychological distress, most commonly minority or marginalisation stress, which is stress caused by being in a group which is discriminated against and so may lead to psychopathology – it is the discrimination rather than the demographic membership of this specific group which is psychopathogenic.

Nonetheless, gender diagnoses have been retained predominantly for the purely pragmatic reason that some people who do not remain in the gender they were assigned at birth wish for physical interventions to alter their body such that it is congruent with their sense of self such that they have a more holistically congruent self. This might include such things as hormones, chest surgeries, and genital surgeries of various sorts to give people genitals a body more in keeping with their gender; or psychological and counselling assistance to assist with psychosocial transitions (cf. Richards, Bouman & Barker, forthcoming 2016). Consequently the World Health Organisation’s (WHO) forthcoming revision of the International Classification of Diseases and Related Health Problems-11 (ICD-11), which is expected to be published in 2017 will likely remove the diagnostic category Gender Identity Disorders from the Chapter 5–V (Mental and Behavioural Disorders) of the ICD-10 (WHO, 1992) (which again used a disorder and binary gender model). The recommendation from the Working Group on the Classification of Sexual Disorders and Sexual Health is to replace it with a diagnosis of Gender Incongruence, which does not include the assumption of disorder and again includes non-
binary or genderqueer identities. They further exerted that based on more reflective and contemporary scientific evidence and best practice there is merit in placing Gender Incongruence in an entirely separate ICD chapter that would contain no other entities (Drescher, Cohen-Kettenis, & Winter, 2012).

**Prevalence of studies in the literature**

A PubMed search was carried out on April 10th 2015 in an endeavour to undertake an examination of the extant peer-reviewed medical literature (see Table 1). Some items returned multiple false positive entries (i.e. trans because it is a homonym) in which case only the first 100 entries were reviewed and articles were excluded as necessary.

<table>
<thead>
<tr>
<th>Search term</th>
<th>Qualifying search term</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(None)</td>
</tr>
<tr>
<td>Genderqueer</td>
<td>5</td>
</tr>
<tr>
<td>Non-binary</td>
<td>54</td>
</tr>
<tr>
<td>Trans</td>
<td>264531</td>
</tr>
<tr>
<td>Transsexual</td>
<td>976</td>
</tr>
<tr>
<td>Disorder of Sexual Development</td>
<td>17871</td>
</tr>
<tr>
<td>Diversity of Sexual Development</td>
<td>705</td>
</tr>
<tr>
<td>Intersex</td>
<td>36855</td>
</tr>
</tbody>
</table>

Table 1. Number of PubMed results by term

As peer reviewed literature on genderqueer and non-binary identities is evidently extremely rare, that which was found was snowballed to further include literature, which electronic engines have not adequately catalogued. Further, the authors’ own very recent work was included, as well as the legal and prevalence items mentioned above. Lastly, some consideration was given to the grey and community literatures as these are a rich source of information on this emerging field which will not be listed on PubMed. Given the heterogeneity of this literature, both in source and type, it has been included in a bricolage above and below, rather than in a positivist fashion.
A Discussion of the literature

Non-binary people might appear to be a relatively recent and under-researched phenomenon, but it is likely that some people who previously would have identified as trans[sexual] – that is within the gender binary, but moving across it – may have identified outside of the binary if that discourse was available to them. However, it is very likely that they were not distinguished as such but were instead diagnosed as having a Gender Identity Disorder Not Otherwise Specified by gender teams at medical centres; and have only become increasingly visible in recent years (Hage & Karim, 2000, Nieder & Richter-Appelt, 2011). An analogy may be drawn with the number of lesbian and gay people who became able to identify their sexualities within contemporary Western societies as when the possibility to do so became more available, and the identities became more widely understood and accepted. This also applies, to a lesser extent, to bisexual people, as bisexuality remains relatively invisible (Barker, Richards, Jones, Bowes-Catton & Plowman, 2012). Further, some non-binary and genderqueer people may have been reticent to foreground their identities for fear that they would not receive the physical testaments they desired. Hopefully compassionate clinical practice is now assisting this group of people to feel comfortable presenting to get their true needs met.

People who are now making changes to a non-binary identity are also increasingly availing themselves of the possibilities afforded by the change in legal and bureaucratic system – for example by using the title Mx and making a change of name to reflect their gender more accurately (a non-gendered name, initials only, or including both masculine and feminine names, for example). Other strategies enabling genderqueer people to express their non-binary identifications appropriately in a day-to-day context include the following (for detailed information see Nieder, 2014):

- **Stretching**: Making the established identity categories of femininities or masculinities more flexible (cf. Connell, 2005),

- **Diversifying gender**: Which is based on the concept of a continuum whose graduations manifest themselves via the interaction of sex characteristics, subjective gender experiences, and expressions (cf. Monro, 2007),

- **Dissolution or negation of sex difference**: Which is pursued by the genderqueer movement in particular (cf. Bornstein & Bergman, 2010; Nestle, Howell, & Wilchins, 2002) with the goal of a “non-gendered social order” (Monro, 2010, p. 246),

- **Creating ambiguity**: To express gender in a way that defies a mono-sex assignment that is exclusive and fixed over the life course (Engel, 2002).
It is therefore beholden on (mental) health care providers to respect these different strategies and to integrate them into the work.

When working with people who are existing psychiatric patients, professionals may understandably be concerned that an ‘atypical’ gender is as a result of some psychopathology such as psychosis or emotionally unstable personality disorder. However, as with the pathologisation of homosexuality in the past, it is vital not to pathologise a non-pathological identity, or to see it as pathology when it is ‘comorbid’, in a way that we would not with a binary gender (or heterosexuality).

Certainly there is no evidence to suggest that non-binary genders are pathological. Indeed what evidence there is suggests quite the reverse. It is worth considering that there are no psychological fields in which males and females are discrete (Fine, 2010) and that the overlap is always greater than any difference (Maccoby & Jacklin, 1974). This is clearly adaptive as it enables both males and females to carry out the variety of task required of them, and consequently those people who are more ‘sex typed’ - that is further towards the ends of a notional gender spectrum - are disabled by their rigid adherence to their gender role (Bem and Lenney, 1976). Indeed, exposure to gender role stereotypes diminishes confidence and interest in ‘the other genders fields’ such as mathematics for females (Correll, 2004), as well as actual performance in them (McGlone & Aronson, 2006).

(Mental) health professionals then may best serve their patients by supporting them in their identities and expressions and affirmatively exploring identities if that is the presenting problem. Empirical research in this area would also be most welcome. In addition, psychiatrists, psychologists and others may usefully utilise their clinical skills as necessary to assist with psychosocial transitions associated with non-binary genders. This will include such things as addressing anxiety around coming out to others and being seen in public; consideration of intimate relationships and family; sexuality and reproductive options; and consideration of physical interventions aimed at the bodily and psychological comfort of the non-binary person.

Those non-binary people who are seeking approval for physical interventions should be compassionately assisted, perhaps referring to standards of care such as the World Professional Association for Transgender Health’s (WPATH) Standards of Care for the health of transsexual, transgender and gender nonconforming people (WPATH, 2011) or the Royal College of Psychiatrists’ CR181 Good practice guidelines for the assessment and treatment of gender dysphoria (Wylie et, 2014).

It is important to note here the differences and similarities between trans people who make gender changes within the binary and non-binary people who do not as this is important in planning appropriate support for individuals. A significant number of trans people decide not to undergo surgical interventions to address the incongruence between their physical and mental gender (Bockting,
This does not, in and of itself, define the individual as having a non-binary gender identity, and the support and health care needs of these individuals will differ from those with a non-binary gender identity.

When considering physical interventions then, the means for achieving overt masculinisation or feminisation is quite established (Gooren, 2011) but in order to guide genderqueer individuals in hormonal and/or surgical treatments, and to predict their effect short or long term, we have to creatively rely on principles of treatment in trans men or women, or – in the case of hormones - on data and treatment from related endocrine conditions such as hypogonadism; precocious puberty; polycystic ovarian syndrome; menopausal replacement therapy; infertility; DSD; and on principles of hormonal contraceptives.

Indeed, when relying on such information we much also note that the physical intervention needs of non-binary individuals are diverse; For example, as with trans people within the gender binary, some do not desire any such interventions. However, for a significant minority it is most important to remove obvious markers of masculinity or femininity (e.g. breasts or facial/body hair). Others wish to combine such markers, or may be taking a more conventional trans masculine or feminine treatment path whilst maintaining a non-binary identity. For example, Rankin & Beemyn (2012) found that some non-binary people who were assigned female at birth had chest surgery and/or took hormones. Others did not engage in these methods, but modified some visible markers of gender in other ways, including breast binding, having a traditionally male hairstyle, not shaving their body hair, bodybuilding, and/or packing their groin region to give a stereotypically male contour. Non-binary people who were assigned male at birth similarly had varying relationships to hormones/surgeries. They frequently did things such as wearing make-up, having long hair, removing body/facial hair, and/or wearing ‘feminine’ jewellery. Some people liked to destabilize conventional markers of gender by dressing androgynously, by combining ‘men’s’ and ‘women’s’ clothing, and/or by dressing in clothing associated with a different gender. Some made similar shifts in mannerisms such as gait, making eye contact, and sitting with legs together or apart.

It is clear that the endocrine possibilities or limitations for this specific group are, so far, not described in the medical literature and indeed it is likely that a proportion of this group are self-medicating with the attendant risks (Rotondi et al., 2013). Further, cosmetic interventions may be sufficient to achieve partial feminisation. Breast implants can be considered safe, as is laser epilation, even if the effect on skin is thought to be less successful in the absence of hormonal treatment. The role of the hormone-prescribing physician is therefore to liaise with the multidisciplinary team as necessary and to monitor the effects and mostly cardiovascular side effects of anti-androgens/oestrogens or testosterone
treatment, and to try to modify cardiac risk factors through advising diet, exercise, and smoking cessation, and to encourage routine surveillance of glycaemia, lipids, haematocrit and bone mineral density. A second important role is in counselling the individual about what hormonal therapy is able to achieve so that the individuals’ expectations of therapy can be aligned with what is possible with current hormonal treatments, and the impact of treatment on physical health discussed.

Given the lack of literature on this topic, referral to an endocrinologist may be useful. For people assigned male at birth, the endocrinologist can decide with the client on anti-androgen or oestrogen monotherapy, with variable dosage or intermittent use. Unfortunately, no data on small dosage anti-androgen therapy is available. Gonadotropin releasing hormone agonists or antagonists may be less desired for this group since absolute testosterone suppression would be achieved, however used in combination with androgen and oestrogen they could offer the possibility of tailoring the hormonal milieu of the individual without surgical interventions such as gonadectomy. Lower dosage oral anti-androgen treatment (finasteride, cyproterone acetate or spironolactone) can create moderate androgen deprivation, possibly leading to interruption of the process of androgenetic alopecia, somewhat less virilisation, and the development of the desired mild gynaecomastia. Erectile dysfunction that may occur can be treated with PDE-V inhibitors on demand. All hormonal interventions should, of course, be preceded by a discussion on the effect on fertility (Richards & Seal, 2014; T’Sjoen, Van Caenegem, Wierckx, 2013) although it is worth noting that interruption of hormonal treatment is likely to restore spermatogenesis over a period of 6 months. The occurrence of metabolic side-effects of high-dose anti-androgen therapy, such as used in prostate cancer or sex offenders, can be considered modest. If feminising hormone therapy is used long term, without the desire for genital surgery, probably no specific oncological concerns are needed for the testicular tissue and breast cancer is rarely reported (Gooren et al, 2013). Indeed, prostate cancer is rarely reported in trans women, but they do occur and continuous monitoring has to be considered in all those undergoing anti-androgen therapy (Gooren & Morgentaler, 2014).

For people assigned female at birth, partial virilisation can be achieved through different therapies, depending on the wish of the client. Interruption of menstrual bleeding can be achieved by use of continuous progestins or intrauterine devices. Prolonged intake of combined oral contraceptive pills will lead to amenorrhea, but clients have to be warned about the possibly of spotting or irregular and unpredictable menses as there will be a 30% increased estrogen intake. Use of dihydrotestosterone is often desired, but remains hardly described; as is low dose or intermitted treatment with testosterone. It has to be considered that exogenous testosterone is aromatised to estrogen, and if no surgical steps are taken, monitoring for breast, cervix, endometrium or ovarian cancer remain necessary. Hormone dependent cancers have been rarely reported in trans men and so may also be the case here. Fertility
seems preserved, as has been shown in popular literature, and virilisation does not disappear if testosterone is temporarily interrupted for this cause, but specific guidance remains undescribed.

**Conclusion**

Recent reports indicate that the overall number of individuals with gender dysphoria who attend clinical services for an assessment has increased substantially over the years in many North American and European countries (Aitken et al, 2015; De Vries et al, 2015). There is also a significant increase in people who self-diagnose as suffering from gender dysphoria (Kuyper & Wijsen, 2014).

Although the proportion of people who identify as non-binary within the aforementioned research remains unknown it is highly likely that an increasing amount of non-binary people will present to clinical services seeking treatment. In the absence of clinical guidelines and treatment protocols for this group, prospective outcome studies are vital and timely. In the mean time we urge careful compassionate assistance for this patient group.
Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Acknowledgements: The authors would like to thank their co-authors, colleagues and most of all their clients and the activists who have developed the field.
References


