Introduction

During the final few decades of the 20th century, the concepts of gender and sexuality, and their association with power relationships, began to be questioned. Members of the disciplines of psychology, sociology, anthropology and linguistics began to explore previously unquestioned 'truths' and 'facts' about the nature of sex, gender and identity. It was thought most organisms were divided into two sexes: male and female. It was an undeniable biological fact. The English language only recognised the binary sexes and genders: male and female: this also was an undeniable social and linguistic fact. However, in recent years, critical analysis of these 'facts' and 'truths' is revealing the binaries may not be as real and as finite as first thought. Eventually, after it was suggested the concept of gender was a social construct, it was generally accepted that, yes a person's gender identity was influenced by social conditioning. Yet, according to Bing and Bergvall, 'the claim that not only gender but the category of sex itself is also … socially constructed is usually greeted with disbelief and scepticism' (Bing and Bergvall 2000, p.5). Consequently, it was not biology, which was trapped within a structure of finite boundaries, but the interpretation of the evidence and the subsequent discourses generated, which locked people into the binary classifications of male and female. It is through a critical linguistic analysis of these discourses that the assumptions underpinning such socially constructed classifications are revealed. Therefore, rather than revealing finite measurable boundaries, everything exists within an infinite, multidimensional spectrum of possibilities.

There has always been clear evidence of variation from the sex and gender binaries, or what could be referred to as a spectrum between the two binary opposites. However, these were dismissed and marginalised by being explained away as simply aberrations and products of 'dis-ease' and 'dis-order', which required medical intervention to cure and thus 'normalise'. Bing and Bergvall asked why, if the binaries were so immovable, factual and thus not problematic, 'it is curious that so much energy is expended to reinforce them and to render invisible large numbers of people, including homosexuals, bisexuals, transvestites, eunuchs, cross-dressers, hermaphrodites, intersexed individuals, and others who assume social and sexual roles different from those that their cultures legitimise' (Bing and Bergvall 2000, p.5)?•

The voices of the 'data', the 'evidence', or the 'objects' of research, once silenced by the scientific processes of interpretation have, in recent years, begun to be heard: but, sadly, not listened to. Many individuals who suffer dis-ease or dis-ability, or breach the binaries, subsequently feel isolated, alienated and marginalised by the dominant scientific discourses. A lucky few have found commonality of experience, and thus community, through the medium of the internet: web information resources and discussion forums. Turner describes the internet as 'a highly interactive medium that allows for quick

• Not only are researchers met with scepticism when it is suggested that the categories of sex and concepts of gender may not be as finite and fixed as is believed but, from personal experience, to also question such concepts and facts and attempts to apply these questions to the technical and popular Klinefelter discourses generates significant vitriolic attacks from members of the on-line Klinefelter community.

revision, …[and] speeds up the process by which emerging minority groups can articulate their collective identities', thus allowing people to reclaim their personal histories 'from the medical establishment and clarify their goals as a group' (Turner 1999, p.463).

During the 1990's, individuals, or parents of children with the chromosomal based condition known as either Klinefelter Syndrome or XXY, created on-line web-based support services and information resources. One of the first Klinefelter Syndrome/XXY support groups to have utilised this new medium of communication and information dissemination, was an American support group *Klinefelter Syndrome and Associates* (KSA). First established in 1989, the KSA is a non-profit organisation, which claims to provide support and information to XXY individuals and their families. The *New Zealand Klinefelter Association* (NZKA) was also established by the parents of sex chromosome variant children and adults born with at least one additional 'sex' chromosome.[*] First registered in 1995 as a Charitable Trust, the initial purpose of the Association was to:

> *provide updated readable information for the men and parent's of boys with additional X and Y chromosomes, to help provide assistance in gaining the specialist help the boys and men might require and to provide support. We also provide updated information to their doctors and the general public* (NZSCS 2000a, p.1).

Five years later, the NZKA Board changed the organisation's name to the *New Zealand Sex Chromosome Society* (NZSCS) because, over the years, the Association had embraced other sex chromosome conditions such as Turners and Fragile X. The Klinefelter community initially established these web pages for the purpose of distilling complex scientific literature into easily understood or popular narratives, while providing communication services for the discussion of issues relevant to the Klinefelter/XXY communities. They have achieved this, either by lobbying medical facilities and specialists into publishing popular information booklets and articles, or non-medical members have published their own articles based on their interpretation of the scientific literature.

Later personal accounts of members, or what could be referred to as stories of their lived experiences, began to appear either on the web-pages, or discussion lists affiliated with the various Klinefelter/XXY organisations. Yet, it soon became apparent the lived experiences of many of the members differed somewhat from (and even contradicted) the discourses published on the web-sites and their original sources: academic medical literature. However, unlike the influences the lived experiences of other intersex people have had on members of their respective organisations, something else entirely was occurring within the Klinefelter community: that being an apparent retreat back into outdated gender based discourses and perceptions of binary sex, even to the point of expelling a great deal of energy in the attempt to include XXY within the binary classification of XY. One means of seeking to achieve this outcome is through the administration of therapies for the purpose of modifying the body and mind of XXY individuals.

[*] When referring to the additional chromosomes, I will refer to them as 'sex' chromosomes for convenience sake in order to distinguish them from other chromosomes.

The following paper is an examination of the discourses generated, firstly by medical researchers into Klinefelter/XXY Syndrome, and secondly the subsequent interpretations of such discourses by non-medically trained members of Klinefelter organisations in the on-line and web page mediums. The paper is not intended to be an in-depth analysis of the medical condition and recommended therapies, nor does the author make any claims of expertise in the medical discipline. Rather, it is an attempt to undertake a very general socio-linguistic survey of the medical and popular discourses, in order to examine the representation of Klinefelter Syndrome/ XXY, and briefly link the discourses to issues such as the representation of sex, gender, sexuality and identity. An in depth analysis of these issues has not been attempted due to word-length limitations.

The data, the evidence, the 'proof', the 'facts', or the 'truth' are one thing, (and highly questionable at that) but it is the representation of these elements which matter: it is how XXY individuals are represented in the literature, which influences the perception of these individuals and subsequently how they are socially conditioned and medically treated. Thus the paper is an exploration, from various perspectives not generally applied to such discourses, but which seeks to demonstrate that discourses possess many layers, some of which are subtle, but yet effectively subliminal and therefore have significant impact on the lives of the people such discourses claim to represent and empower.

1 Background

During the early 1940's, Dr H. F. Klinefelter (1984) first identified a physiological disorder in men that usually resulted in undersized testicles, eunuchoidism and sterility. His studies culminated in the publication, in 1942, of a paper in which he claimed the disorder was caused by a still unknown endocrinal disease that inhibited the production of testosterone, resulting in subsequent problems such low levels of testosterone would produce. In 1959, Jacobs and Strong established a link between the supposed endocrinal disease to the presence of an extra X sex chromosome: thus resulting in the karyotype 47,XXY (Klinefelter 1984, p.6). Subsequent studies, undertaken by Klinefelter and other researchers, confirmed that over 80% of men with Klinefelter Syndrome also possessed an extra X chromosome, or variations of X and Y chromosomes from the common 46,XY. Smyth and Bremner claims, Klinefelter Syndrome is characterised by the presence of at least one extra X chromosome, which is a 'fundamental etiological factor of Klinefelter Syndrome' (Smyth and Bremner 1998, p.1310). Nevertheless, not all individuals who present characteristics associated with Klinefelter Syndrome present an additional sex chromosome. Furthermore, not all individuals with additional sex chromosomes will necessarily develop the physical characteristics associated with Klinefelter Syndrome.

Smyth and Bremner (1998) report approximately 1 in 500 births present the sex chromosome variation of 47,XXY, and such patients are also characterised by an increased tendency towards psychiatric, endocrinal and fertility disorders. They claim, unlike Downs Syndrome where the extra chromosome is derived from the mother, 'the maternal and paternal errors … were almost equally responsible for causing the 47,XXY karyotype….' (Smyth and Bremner 1998, p.1310). DNA analysis of parents and offspring indicate 44% of newborn XXYs obtained their extra X chromosome from their father and 56% from their mother (Harvey, Jacobs, Hassold & Pettay 1991, p.292).

XXY is caused by the presence of an extra chromosome, either in the egg or the sperm, or as a result in an error of cell division during the first few days following conception. Significant visible or tangible physiological changes do not occur, however, until the onset of puberty which, Stewart (1990, p.137) claims, usually commences around the same time as XY boys. However, puberty is often only partial and, while an increase in size of the testes occurs in XY individuals, the testes of XXY individuals usually remain shrunken due to the low level of natural testosterone. Bucar (1999, p.2) claims the low levels of natural testosterone in XXYs allow the production of two other hormones FSH and LH, which are higher than that produced by XY boys. These higher levels of FSH and LH, Bucar explains, 'are responsible for the development of female characteristics', such as breast development and 'other feminine characteristics' (Bucar 1999, p.2). Other physiological consequences of low levels of testosterone in XXY people include, what Smyth and Bremner calls 'obvious features of eunuchoidism': abnormally long legs, arm span greater than height, sparse or absent facial hair, decreased muscle mass and feminine fatty distribution including breast development (Smyth and Bremner 1998, p.1310).

It is very difficult to determine the extent of influence the extra X chromosome has on the psychological, psychosexual or personality development of the infant: signs

such as mood and behavioural differences are the only indicators, but these are open to many interpretations. Tangible evidence of differences usually only emerges later in life. Yet, because the lived experiences of XXY individuals are usually not considered valid data, evidence of possible intangible variations (for example sex, gender identity, or sexual orientation) are ignored in favour of maintaining binary systems of thought.

Consequently, it is evident that medical professionals are only interested in the visible and tangible evidence of difference and the physical presentation of the individual is deemed valid, while intangible factors, being difficult to measure, are ignored or explained away. As will be explored later, this approach has led to the assertion the extra X chromosome is unimportant and can be ignored, while the subsequent visible endocrinal symptoms become the focus of medical therapies.

Possibly, one explanation for the focus on the endocrinal symptoms is that, while medical science has not developed gene and chromosome therapy and thus cannot cure the extra X chromosome and make XXYs into XYs, the endocrinal symptoms can be treated and manipulated by drug therapy and surgery. The ease of such medical interventions has led to the belief that, if the physical appearance of the XXY individual can be modified, then the extra X chromosome can be rendered invalid. Consequently, a whole set of culturally generated set of myths have emerged: all of which are contained and cultivated within the medical and scientific disciplines. Ultimately, these perceptions and interpretations are derived from the subtle social and religious belief systems of the researchers themselves.

It must be strongly emphasised that, since its discovery by Klinefelter, surprisingly very little research has been undertaken into the condition: especially the effect the extra X chromosome has on XXY individuals. As a consequence of this lack of research, the clinical data presented in this paper is not based on reliable information and is often contradictory. Smyth and Bremner (1998, p.1311) claim the early studies need to be approached with caution, because the research was often flawed and data collection methods, at best, dubious. While Valentine (1966, p.144) claimed that, prior to the onset of puberty, visible physiological evidence of the extra X chromosome was not apparent, later research by Ratcliffe (1982, p.703 - 704), suggested the size of new-born XXYs were smaller than average and presented an appearance almost identical to the body size of female controls. Furthermore, even though small testes were noticeable in infants from around the age of three years, only a small minority of cases had a smaller penis than average.

The earliest screenings for the presence of extra X chromosomes in individuals were conducted in penal and psychiatric institutions: the findings of which resulted in researchers, such as Valentine (1966, p.148), claiming the incidence of criminal behaviour was higher in individuals with chromosomal variations, from the XY controls. Subsequent large-scale screenings of the general population have disproved much of this early data, even though, as Smyth & Bremner (1998, p.1311) claim, learning difficulties associated with XXY individuals may account for some degree of delinquent behaviour.

As indicated by the academic medical literature, most researchers appear to be very apprehensive about providing conclusive definitions of, (what they determine as) evidence of the lack of masculine physical and psychological characteristics in XXYs.

However, most recommend the same solutions to the problem: hormone therapy and sometimes surgery. Most of the medical literature, which advocates the administration of testosterone therapy, focuses primarily on the physiological benefits of the hormone on XXYs who, it is claimed, suffer from 'low levels of testosterone', or 'androgen deficiency', compared to that of normal XYs (Smyth & Bremner 1998, p.1313).

The medical discourse commonly refers to testosterone therapy as 'Hormone Replacement Therapy' (HRT), which suggests the endocrinologist is merely replacing or topping up levels that have declined for unexplained reasons. However, this terminology is misleading, because most XXY individuals produce their own natural levels of testosterone, which vary from individual to individual: thus the therapy serves to increase the natural amount of testosterone to levels found in the 'average' XY. The focus of the therapy, therefore, is to induce physical and psychological modifications in the body and mind of XXY individuals, in order for them to aspire to some kind of socially constructed ideal, or myth, of what it is to be male.

Researchers (and pharmaceutical companies) claim that testosterone therapy induces increased facial and pubic hair; a masculine distribution of body fat; more goal directed thinking; improved self esteem, less fatigue; increase libido; bone density and strength (Smyth and Bremner 1998). Nielsen, Pelsen & Soresen (1988) examined 30 Klinefelter patients who were either on a HRT program, or had ceased the therapy. According to their data, '77% had a good effect'; 7% had a moderate effect, and 17% were not responsive to the therapy. They conclude the 'frequency of socially well-adjusted individuals [were] higher amongst males who had continued testosterone treatment (86%) than those who had discontinued (76%)' (Nielsen, Pelsen & Soresen 1988, p.263).· Nielsen, Pelsen & Soresen (1988) did not provide a definition of their term 'socially well adjusted': yet their interpretation of 'good effect' seems to have been determined by the development of characteristics they believed were essential for the male sex.

A close reading of Nielsen, Pelsen & Soresen's article implies that, when the testosterone therapy works, a disproportionate amount of attention is focused upon the drug and the individuals receiving the 'good effects'. In stark contrast however, for those individuals who either ceased therapy, or the drug had little effect, the article either briefly mentions this outcome, or, more often, subtly suggests the fault lies with the individual: thus marginalising the people who were not responsive to the therapy. Consequently, it appears that, while a great deal of attention is paid to the beneficial effects of testosterone therapy, very little research has been undertaken to establish the reasons for any ineffective or harmful outcomes. An invariable consequence of this approach, is that some people in the online Klinefelter/XXY community assume the therapies are always beneficial and do not produce any harmful effects.

2 Discourse Mediums

· This journal article was reproduced in the *Klinefelter Syndrome and Associates Newsletter*, made available to subscribing members of the organisation. The editor wrote 'we found this article on testosterone therapy to be of exceptional value and we recommend it to you' (KS&A Newsletter 1992, p.1).

Dickens (1982, p.233), state physicians have a legal and ethical duty to provide as much information as required to the parents of children diagnosed with an XXY karyotype, in order to assist them in making choices regarding the management of their child. Yet, up until very recently, the methods of educating parents and XXY individuals was the responsibility of treating physicians and skilled counsellors, whose source of information, naturally, was derived from the medical and scientific disciplines. Halliday and Martin warn, however, that scientific discourse is elitist, as it 'sets apart those who understand it and shields them [the members of the medical community] from those who do not' (Halliday & Martin 1993, p.21).[•] Such discourse is constructed of technical terms and possesses its own form of grammar, which Halliday and Martin (1993) explain, alienates people who are not part of the scientific disciplines and who, therefore, find such discourses incomprehensible.

The major drawback of scientific discourses is that the people who are the object of the discourse (i.e. XXY individuals) cannot relate to how their experience is constructed within the medical literature. Not able to identify with such academic narratives, a growing number of people directly affected by Klinefelter Syndrome and/or XXY began to explore means of accessing information from the technical discourse they believed was essential, while omitting information they found irrelevant to their immediate needs. One of the most successful mediums to achieve this aim was the establishment of support groups, in this case for people directly affected by Klinefelter Syndrome and/or possess additional sex chromosomes.

Klinefelter Syndrome/XXY support services are to be found in many countries. They range from small and intimate groups, founded by a few people who serve the needs of local communities, to large nation-wide organisations coordinated by management committees and supported by professional advisory boards. Organisations, such as *Klinefelter Syndrome and Associates*, and the *New Zealand Klinefelter Associatio,* established web-pages providing on-line information resources derived either directly from scientific journals or, most often, authored by non-medically trained members of the KS/XXY organisation, who had attempted to translate scientific and technical jargon into plain non-technical English.

Yet, it appears the fundamental underlying assumptions underpinning scientific medical discourses are directly translated into the popular medical literature, authored by the non-medically trained contributors to the web-pages. Consequently, the very same problems of alienation and 'detached' interpretations of XXY people's lived experiences are perpetuated and reinforced in the popular non-technical discourse. The major problem appears to be, in the case of Klinefelter Syndrome and/or XXY, is the perpetuation of cultural assumptions related to the representation of sex and gender, and may also be due to personal fears generated by such assumptions.

[•] According to British law, physicians do not have to disclose details of medical techniques, nor the pharmacological operation of drug therapy: rather they are only required to provide information on the 'goals and general nature of the treatment or drug' (Dickens 1982, p.238). He explains that physicians can resort to the 'therapeutic privilege' of non-disclosure in relation to procedures such as the administration of testosterone using intermuscular injections, in order to avoid having to account for their actions if they believe that the patient or parents may not comprehend the technical details of such therapies.

According to Bock (1993), a medical specialist who published a popular booklet on Klinefelter Syndrome, a major concern of many parents of XXY children was that they may grow up to be homosexual. Bock attempts to reassure his readers that such a fear was groundless, because there was very little medical evidence to support such claims. Nielsen, in a booklet written specifically for parents of Klinefelter/XXY children, states: 'the chromosome constitution has, however, nothing to do with homosexuality, and Klinefelter males have no increased tendency to homosexuality', and furthermore, 'Klinefelter males identify themselves as males and are as much real males as males with normal chromosomes' (Nielsen 2000, p.7). Such statements are based on the opinion of the authors because, according to other researchers, such as Dr Meyer-Muhlburg, 'there has never been a modern, large-scale, scientific study of XXY sexuality' (Mulkern 2000, p.4). To date, only informal, or anecdotal evidence suggests the incidence of non-heterosexuality or non-male identity is greater within the XXY population compared to that of XYs.

Bucar undertook an informal on-line survey in which Klinefelter and/or XXY individuals and a small percentage of XY/XXY mosaics responded to questions, which included Sexual Orientation and Gender Identification[↕]:

Sexual Orientation		**Sex or Gender Identification**	
Heterosexual	39.7%	Male	84.8%
Homosexual	33.0%	Intersex	9.5%
Bisexual	21.7%	Female	4.8%
Transsexual	6.0%	Unsure	3.2%

(Bucar 2000, p.1)

Nevertheless, the lack of clinical, or formal research, into these issues does not appear to stop medical authors, who write for a non-medically trained audience, to give the false impression that everything is known about the actions of genes, chromosomes and their possible relationship to the sex and gender identification of XXY individuals. Consequently, when an author states 'there is little evidence', he or she actually means that very little research has been conducted into these issues. Somers claims that, in relation to the issues surrounding sex and gender determination, 'no one looks deep enough, except for a few … because it threatens the status quo and highlights their [the medical researchers] fears of difference' (Somers 2000, p.1). The direct outcome of the lack of medical evidence is that medical specialists, such as Bock and Nielsen, fall back onto assumptions derived from cultural and, apparently, religious belief systems related to the binary perceptions of sexuality, sex and gender identities.

Self-contradiction is one consequence of medical specialists attempting to base their evidence on cultural and religious based assumptions, as well as their personal fear

[↕] The cells of some individuals contain XXY chromosomes, while other cells contain the standard XY: such a presentation is referred to as a chromosomal mosaic.

issues and prejudices. Nevertheless, even though often blatant, physicians appear entirely unaware of such contradictions.

For hundreds of years, scientists relied on their visual senses in their quest to establish order in the natural world: consequently, animals and plants were classified according to their external appearance. It appeared there were two binary sexes, each possessing unique characteristics: penises and scrotums for males and vaginas for females. Plants often had comparable structures. The subsequent discovery of chromosomes, genes and DNA, initially confirmed the visual evidence that the binary systems were accurate. However, it soon became apparent that nature breached not only the binary system of the classification of male and female, but also what often appeared to be one thing to the scientist's naked eye, was entirely something else under an electron microscope. As a consequence of the new technologies and research methodologies, developed during the latter half of the twentieth century, members of the scientific disciplines were forced to reclassify species of animals and plants: because, while they may have appeared visually similar, according to their chromosomes and DNA, some animals and plants belonged to a different genus or species from that which they had originally been assigned.

The tradition of accepting the evidence of the naked eye as proof is so ingrained in the scientific disciplines that, even though animals and plants are being reclassified according to their genes, the representation of the species of Homo sapiens continues to be determined simply by visual appearance based on the binary classification of male = big enough penis, and female = small enough clitoris.[•] Following the confirmation that indeed the sex chromosome combination XY was found in males and XX in females, it soon became apparent these combinations were not as finite as initially believed: rather a range of combinations exist which breach, and thus extend beyond the binary classifications. Yet, rather than accepting the new evidence of unbounded variations, scientists chose to ignore their own scientific research methods and classification systems. Instead, they continued to rely exclusively on their visual senses to determine sex and gender.

It is interesting to note that, prior to the discovery Klinefelter Syndrome was usually, (but not exclusively) caused by an extra X chromosome, the affected individuals were often called 'pseudo males'. Yet, on discovering the variation from the XY, which should have confirmed the classification of 'intersex', the term was soundly rejected by the medical researchers. Nevertheless, Ford (1973) perceived XXY not as males with an extra X chromosome, but as females with a Y chromosome. He claimed, 'Klinefelter's behave as males and often pass as such, although their breasts are enlarged ... Indeed it now seems likely that about one 'man' in 1,000 is a transformed woman of this kind' (Ford 1973, p.43). Ford's interpretation appears as equally plausible as the more common view that XXYs are males with an extra X chromosome. Yet, why we assume that XXYs are males with an extra X chromosome is based on the tradition that if it looks male then it must be male.

[•] The sex of intersex infants is often determined by the size of their genitals: if the penis is too small, sex reassignment surgery is performed in order to turn the individual into a girl. However most infants born with ambiguous genitalia have female genitals constructed simply because 'its easier [for the surgeon] to dig a hole than build a pole' (Maurer 1997, p.1).

The ignoring of the chromosomal evidence in favour of 'clinical observation', or the visual binary classification of male and female, was established very early after the discovery of chromosomes. In their book titled *Intersexual Disorders*, Dewhurst and Gordon clarified the meaning of the terminologies they used:

> *The patients with an XX arrangement of sex chromosomes and ovaries but whose sex is clinically in doubt will be referred to as female intersexes. Similarly XY patients with testes, or with rudimentary testicular tissue will be described as male intersexes… No phrase implying the intersexual state will be used for patients who have a sex chromosome abnormality alone: it must be accompanied by clinical evidence of intersex. They will be referred to collectively as sex chromosome abnormalities….* (Dewhurst and Gordon 1969, p.16).

Subsequently, since its discovery, scientific discourse has rigorously avoided applying the term 'intersex' to individuals born with additional 'sex' chromosomes, such as XXY. The *Intersex Society of North America* (1995, p.1) defined Intersex as a generic medical term, applied to individuals who are either born with ambiguous genitalia, or their primary and/or secondary sexual characteristics are at variance with their chromosomal sex, or the number of sex chromosomes vary from the common binary of 46,XX or 46,XY. Haynes defines the term intersex as individuals 'sharing physiological characteristics of male and female with contradictory body shape and chromosome pattern' (Haynes 2000, p.3). It is very interesting to note that Dewhurst and Gordon employ the term 'abnormal' rather than assigning those with chromosomal variations into the classification of 'intersex'.

Terms such as 'aberration', 'abnormality' and 'disorder' are most commonly used to refer to the presence of extra sex chromosomes. These choices of terms may suggest that, as the scientific community cannot conceive of the spectrum between the binaries, they perceive chromosomal variations inflict some kind of 'dis-order' onto the traditional binary classifications: something which the medical community cannot reconcile. Therefore, in their quest to preserve the visual binary classifications, XXY and other chromosomal variations are usually isolated from the classification of intersex.

Evidence of the attempts to preserve the traditional binary visual classifications and reinforce the binaries via language, are to be found in the interpretation of XXY data by researchers and their subsequent discourses. During a conference in the United States Mulkern (2000, p.4) reported that even though Dr Meyer-Bahlburg claims very little is known about the action and influence of the genes, he emphatically rejected any suggestion XXY individuals were intersexed:

> *XXYs are not intersexed, defined as a condition where the phenotype expression [physical appearance] of primary sexual characteristics is at variance with one's genetic sex…. But old myths/misunderstandings live on….* (Mulkern 2000, p.4).

It seems, therefore, Meyer-Bahlburg's definition efficiently discounts XXY as an intersex condition. Nevertheless, analysed more closely, his definition is illogical and inconsistent in itself, for it assumes that XXY is not an intersex condition even before it is associated with a 'phenotype expression'. Rather Meyer-Bahlburg seems to be suggesting

that XXY actually exists within the binary of XY: thus, somehow, the extra sex chromosome has disappeared from the equation. It also appears Meyer-Bahlburg is perpetuating the idea that one's physical appearance, and especially one's genitals, determines one's sex and gender. Yet he himself admits he is at a loss to explain the increased incidence of transsexualism amongst XXYs compared to the XY population (Mulkern 2000, p.4). Possibly, Meyer-Bahlburg's self contradiction is caused by his inability to accept that one's chromosomes may play a role in one's sex and gender identification. He is, therefore, drawing upon the comfortable binary myths, derived from a discourse historically controlled by a patriarchal culture (Bing and Bergvall (2000, p.6).

Why, if XXYs are not intersex, does the literature highly recommend XXY individuals undergo similar hormonal and surgical therapies to those administered to people with intersex conditions? An alarming outcome of the apparent shifting of the goal-posts, and thus isolating XXYs from the classification of intersex, could be that when laws are introduced to protect intersexed infants and children from intrusive medical procedures (i.e. until they are old enough to provide personal informed consent), such legal protections will not be extended to XXY individuals, because it has been determined that 'they do not have an intersex condition'. As will be discussed directly, the drive to isolate XXY from the term intersex has become a major focus in the medical discourses, specifically targeting the non-medically trained XXYs and their families.

3 Popular Web-page Resources

Dickens (1982, p.240), argues both the XXY adolescent and his parents should be able to comprehend the information provided: thus enabling them to participate in the decision making process. If the parents and affected individual continue to decline treatment, the endocrinologist should respect such refusals. It would seem such decision making abilities would be entirely dependent on the quality of the information provided to the people having to make the decisions, and the extent to which such comprehensive resources empower (or actually disempower) XXY individuals. The Klinefelter support services, such as those found on-line and the popular medical literature produced by medical professionals for a non-medical reader, claim this is their mission: to provide clear, balanced and concise information, in order for these people to make informed decisions. But do they?

It appears, on the surface, authors in these web-pages echo the concern of ethicists, such as Dickens, who argue XXY individuals must be informed of their condition in such a way as to ensure 'their innate difficulties in maturing should not be aggravated by reducing their sense of themselves as masculine …' (Dickens 1982, p.234).* Certainly, on a conscious level, such authors do attempt to ensure the self-esteem of an XXY individual is nurtured. Yet, by undertaking a closer reading of these discourses, it becomes evident the authors seek to persuade parents and XXY individuals, that they must aspire to some culturally generated stereo-typical model of what it is to be male: or suffer dire consequences. Possibly, this contradiction between intent and action may be due to the researchers and authors operating from unconscious assumptions related to the culturally generated notions of binary sex and gender. The language employed in these texts reflects these assumptions: thus communicating, subtly, a very different message to that which they claim to be promoting.

Bock states it is crucial to emphasise, when informing XXY individuals of their infertility, that they are not in 'any way less masculine than other males [their] age' (Bock 1993, p.4). However, Bock's language indicates that, unless these individuals aspire to some undefined ideal of masculinity, they are in fact presented as being somehow un-masculine and thus unworthy. Repeating the scientific discourse to his non-medical audience, Bock (1993, p.5) explains XXY children are often passive, undemanding, unlikely to take leadership roles, make few friends, are co-operative and eager to please. Such qualities, he emphasises, persist into adulthood. Yet, read in the context of his discourse, it appears, from Bock's perspective, these qualities are actually impediments to masculinity and maleness, and are therefore undesirable and need addressing. He refers to Dr Robinson, who claimed XXY boys 'don't necessarily make good foot-ball players or good basket-ball players [and] these kids are not very good competitors in general' (Bock 1993, p.8). Hence the message conveyed to parents of XXY individuals, or the person themselves, is the emphasis and re-emphasis the individual possesses characteristics that prevent them from measuring up to XY males; the innate qualities of XXYs are undesirable, and they lack the qualities essential for a

* This presupposes though that all XXYs identify as being fully male. Thus to promote only this one option would be detrimental to the sense of self of non-male identifying XXYs.

valid male. Yet Bock's language suggests all XY males possess an overabundance of the qualities he believes are essential for a valid all-round sports minded, competitive male.

Bock (1993, p.4) discusses the 'problem' of how open parents should be, both to their XXY child and people in general, about their child's condition. He recommends the child should not be told about his condition until adolescence. If told earlier, Bock argues, he may not be able to cope with the information. Yet, if informed as a child, he may tell his friends which, according to Bock, may result in 'a malicious … child [telling] all the neighbourhood children [about the] freak because he has an extra chromosome' (Bock 1993, p.4). Furthermore, Bock suggests, 'the child should be told that some people may misunderstand this information and that he should exercise discretion in sharing it with others' (Bock 1993, p.4).[*] Such language, instead of nurturing and protecting a child's self esteem and the positive outlook of the parents, is actually disempowering, as it promotes a message the condition is something shameful.

The elements of shame Bock associates with the 'inappropriate' disclosure of a chromosomal 'abnormality' mirror the experiences of people diagnosed with an intersex condition. Alexander (1997, p.3) explains that, by forbidding intersexed children from discussing their condition with their peers, an atmosphere of secrecy and silence is created which, in the long run, is far more harmful to the child than the condition itself.

The *Klinefelter Syndrome and Associates* web-page promotes a similar message to that which Bock is communicating to XXYs and parents of XXY children. It states that:

> *Boys with Klinefelter Syndrome may have less confidence in their maleness than other boys. They may be more immature, shy, dependant … They may be somewhat passive and apathetic, they may lack initiative, be very sensitive, and have a fragile self-esteem (KS&A 2000, p.2).*

Read in the context of the web-page, the tone of language presents these characteristics as something shameful, less than appropriate for a male, and thus requiring some kind of intervention in order to rectify. Haynes claims 'there is a basic presumption in this passage that the 'normal' state of someone with this chromosomal configuration is male', and suggests the 'whole passage demands reconstruction from the perspective of a person with 47,XXY chromosome', who may not feel they are entirely male (Haynes 2000, p.4). Consequently, Haynes believes, it would be a natural reaction for someone who does not identify as male to feel 'less confidence in their maleness': especially when they are being forced into this role by social and medical pressures.

The *New Zealand Sex Chromosome Society* also claims that undiagnosed or untreated XXY children are 'considered quiet, prefer quiet games … and also there is a total lack of defiance reaction' (NZSCS 2000b, p.1). Furthermore, the web-page includes a quote from a medical article by Bradman and Briet (1984) in which it is claimed the 'symptoms of problems and psychiatric illness include apathy, lack of initiative, poor mental ability, shyness, and having few friends' (NZSCS 2000b, p.1). The *Klinefelter Syndrome and Associates* web-page argues the undesirable characteristics of shyness,

[*] Realistically, the concept of chromosomes would be beyond children, and as XXY children appear physically the same as other children, few if any of their peers would really react against the information.

quietness and reticence 'appear to be helped by [the administration of] testosterone therapy' (KS&A 2000, p.2). Consequently, characteristics associated with a quiet and/or reserved XY or XX child suddenly become problematic psychiatric conditions in a XXY child. Such 'inflicted' children, therefore, require medical intervention to ensure they develop the characteristics treating physicians deem is appropriate behaviours and qualities of a XY male. Exposure to messages such as these may be primarily responsible for the low self-esteem amongst XXY individuals, rather than any innate genetic issue.

4 Klinefelter Syndrome Versus XXY

In recent years, the Klinefelter organisations, which operate on-line information resources, have popularised a debate occurring in the medical discipline regarding the differentiation between the chromosomal variance XXY and its relationship to Klinefelter Syndrome. However, simply by referring to the medical discussions, the on-line non-medical authors have themselves become entangled in the same webs of scientific inconsistencies and semantic gymnastics as is evident in peer-reviewed medical literature. Bock, (1993, p.2) claims, within the medical community, the term 'Klinefelter Syndrome' had lost favour, as it appeared that many people born with an XXY karyotype did not necessarily develop the symptoms described by Harry Klinefelter. Consequently, Bock explains, most researchers now 'prefer to describe men and boys having the extra chromosome as 'XXY males'' (Bock 1993, p.2). The symptoms of Klinefelter Syndrome, Bock (1993, p.2) advises, can be treated with surgery and testosterone therapy from puberty 'to promote strength and facial hair growth as well as bring about a more masculine body type' (Bock 1993, p.2).

The *New Zealand Sex Chromosome Society* (NZSCS) (previously known as the *New Zealand Klinefelter Association* (NZKA)) emphasises, most emphatically and repeatedly, that characteristics associated with Klinefelter Syndrome 'including the 'pear shaped' body in the sort of fashion a woman might have', is caused, not by the extra X chromosome, but by a 'lack of testosterone' (NZSCS 2000c, p.1). Hope states emphasises:

> *one MAJOR point really needs to be STRESSED; most males who are born XXY do not develop 'Klinefelter Syndrome'. The 'Syndrome' only develops in males who do not have sufficient testosterone to masculanise their bodies at and during puberty. ALL XXY boys prenatally diagnosed do NOT have the disease 'Klinefelter Syndrome'.* (Hope 1999, p.1*)*

The logic of this argument suggests that, as there are no visible manifestations of the extra X chromosome, and many XXY individuals never develop the endocrinal characteristics associated with Klinefelter Syndrome, XXY therefore is not Klinefelter Syndrome.[•] Such a separation of the two conditions seems reasonable and is historically supported by H. Klinefelter's initial diagnosis of the Syndrome as an endocrinal condition. The NZKA claims Klinefelter Syndrome is simply a form of hypogonadism,

[•] However the claims made by Klinefelter support organisations, such as the NZSCS, are in contradiction to other studies, such as Smyth and Bremner's article (1998, p.131) which indicate that many of the symptoms associated with Klinefelter Syndrome occur prior to the onset of puberty: rather they are caused by the presence of the extra X chromosome.

which 'can be found in anyone who has an under supply of sex hormone' (IFAS 2000, p.2). To further support their argument, they mention that it appears some XXYs are actually females who have an extra Y chromosome and thus, naturally, do not suffer from hypogonadism and therefore do not have Klinefelter Syndrome. Consequently, following this logical train, the NZKA maintains the sex chromosome variation does not necessarily lead to the visible endocrinal condition called Klinefelter Syndrome. However, having established this premise, they then undertake a huge leap and state that as XXY is not Klinefelter Syndrome, therefore XXY is not an intersex condition. Again, like Meyer-Bahlburg, this assumes that XXY is actually contained within the binary of XY or XX.

Tucker (IFAS 2000) clarifies the position of the NZKA by stating that anyone with Klinefelter Syndrome cannot be intersex, simply because only males can have Klinefelter Syndrome. He explains that:

> *those males born XXY, XXYY, XXXY, XXXXY and mosaic forms of these, can go on to develop the disease Klinefelter Syndrome, but many of them won't. They will simply have or preferably, BE, whatever karyotype they have* (IFAS 2000, p.2).

Therefore, according to the NZKA, not all XXY individuals will develop Klinefelter Syndrome, for the Syndrome is simply a form of male hypogonadism, caused by a lack of testosterone: thus XXY is not an intersex condition. Consequently, it appears that a chromosomal variation has been completely transformed into an endocrinal condition that can be cured or, at the very least, concealed and thus rendered invisible, while the extra sex chromosome seems to have mysteriously disappeared!

It is reasonable to state that XXY and Klinefelter Syndrome can be two distinct conditions, because not all XXYindividuals develop the physical characteristics associated with the endocrinal condition and, conversely, not all individuals presenting the characteristics of Klinefelter Syndrome have additional sex chromosomes. Sadly though, this position is also being employed as a smoke screen to conceal the actual influences of the extra X chromosome on the physiological, psychological and psychosexual aspects of an XXY individual. Simply by masking the visible effects of Klinefelter Syndrome, via the administration of testosterone therapy or ,occasionally, surgery, the medical profession can 'prove' that if no variance from the 'normal' XY can be visibly detected, then the XXY individual has been successfully transformed into an XY male. Thus the researchers can ignore the potential influences of the extra X chromosome: for what cannot be seen therefore does not necessarily need to exist!

Bock typically illustrates the view of many of the popular medical resources when he states that, to prevent the symptoms associated with Klinefelter Syndrome from developing, the XXY be administered testosterone therapy in order to 'increase strength and bring on a more muscular, masculine appearance', and improve relationships with other people (Bock 1993, p.8). Another booklet written by a medical specialist, J. Nielsen (2000) specifically for XXY individuals and their parents, states, repeatedly, the only option for an XXY individual is testosterone therapy. While Nielsen advocates the providing of 'fully detailed information' to parents and individuals as early as possible, the manner in which he presents this information is extremely biased. The result of this

biased language is the promotion of testosterone therapy as a miracle universal cure, enabling all XXY individuals to live 'a normal sexual life and married life as other males' (Nielsen 2000, pp.9-10).

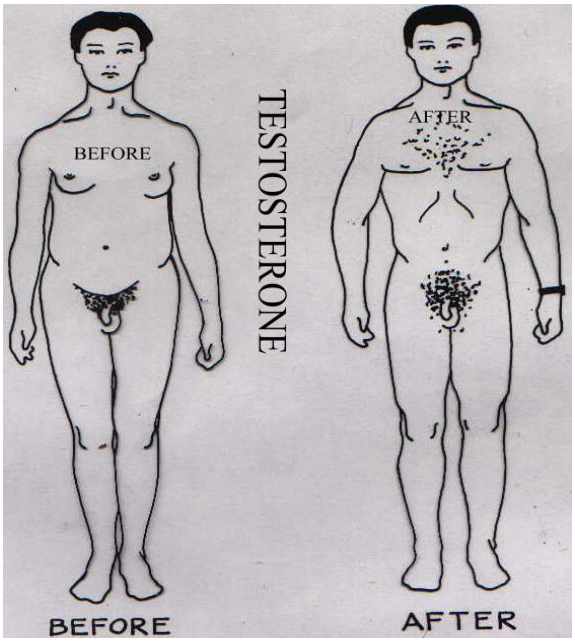
Nielsen also suggests testosterone therapy will reduce the undesirable qualities of non-assertiveness, quietness and passivity, because the hormone will 'induce a normalising effect', and believes the participation of all XXY individuals in 'different types of sport is of great importance' (Nielsen 2000, p.4). Nielsen does not adequately define the term 'normalising': from his discourse though, it appears his personal definition is the hormone will produce the physical and psychological characteristics of some undefined stereo-typical ideal of what it is to be a valid male. Consequently, the 'ideal male' is constantly and implicitly referred to, but is never explicitly detailed: only assumed.

The NZSCS web-page echoes Nielsen's views, by claiming it is essential for XXY individuals to be administered testosterone from puberty, or else they are 'more likely to develop feminine proportions [and] refusing to take testosterone, or refusing to allow your son to have testosterone treatment could … be detrimental to your or his health' (NZSCS 2000d, p.1-2). The author further argues the therapy assists in the development of behavioural characteristics considered desirable in males:

> *The boys become more aggressive, less irritable, more outgoing, self-confident, and ambitious. Libido and sexual activity is also increased [and creates] the masculine features associated with men…* (NZSCS 2000e, p.1).

Yet a study by Mazur and Booth (1997, pp.1-2), into the effects of increasing the natural levels of testosterone in men, indicate that 'the desirable characteristics of assertion and aggression', are viewed by the researchers as leading to anti-social behaviours, rebelling against authority and law breaking. Thus one wonders if the anti-social behaviours, commonly associated with XY males, are somehow elevated to desirable qualities in testosterone enhanced XXY individuals: for this would mean they would have been elevated to the status of the stereo-typical XY male ideal.

Under the title *Why all XY's and Variants Need Testosterone at Puberty*, the NZSCS provided an illustration (NZSCS 2000d, p. 2) depicting the effects of testosterone therapy on an XXY individual. It would appear, from the illustration below, one can only be a 'real man' if one has commenced a testosterone therapy program. The 'Before' illustration depicts all the 'undesirable' characteristics associated with a stereotypical feminine physique. Obvious is the soft rounded physique, including breast development and sparse body hair. Yet subtly and subliminally, but just as influential to the observer, is the styled hair, legs closed in a fashion often associated with femininity (restricted personal space) and the narrow jaw and'feminine' facial expression of a submissive or weak and sad person.



Compare that to the 'After' illustration, which clearly represents the stereotypical male ideal with his obvious body hair and strong muscular build. Less obvious, but equally persuasive, is the butch crew-cut hair; the strong, stern and confident facial expression; his square jaw; legs apart (his personal space is greater than the passive female) and his chunky male watch: yes you too can have a manly chunky watch if you take testosterone therapy!

One can only wonder why the illustrator made such a blatant attempt to ensure the 'After' illustration depicted what he determined to be a 'real man'. Could it have been to manipulate the observer, (probably an untreated XXY or the parent of an XXY child) into identifying with the 'Before' and thus yearning to aspire to the 'After' illustration? The illustration could also instil fear into a young XXY who does not feel fully male, but who is being pressured by social expectations into undergoing therapy.

From the early 1980's, researchers into XXY and Klinefelter Syndrome became interested in the personality and psychosexual development of affected individuals. Yet close analysis of the medical literature reveals more about the cultural assumptions and attitudes of the researchers, than of the XXY individuals. Smyth and Bremner claim XXY adolescents 'consider themselves more sensitive, introspective, apprehensive and insecure' and often display less interest in girls (Smyth & Bremner 1998, p.1312). Zastowny, Lehman and Dickerson argue the psychopathological disorders of XXY individuals are typified by 'passivity, low social drive, immaturity, paranoid tendencies, apathy and poor capacity' (Zastowny, Lehman & Dickerson 1987, p.156). Bancroft, Axworthy & Ratcliffe (1982, p.169) describes XXY boys as timid and lacking in aggression. Their discourse, therefore, suggests aggression is a desirable trait, which XXY individuals must aspire to: or their masculinity will be questioned. They admit though, at the time of publishing their research, the exact causes of these traits remained unknown. I would suggest that, possibly, while some of the symptoms described may be influenced by genetic and endocrinal factors, primarily they may be the result of

environmental influences, such as peer, parental and medical attitudes and assumptions, related to socially constructed binary gender and sex roles.

The terminologies employed in the Klinefelter/XXY discourses to describe desirable and undesirable XXY behaviours are derived from out-dated linguistic studies, which reflect sensibilities and attitudes no longer appropriate to gender, sex and sexuality issues. It seems, therefore, that while the rest of the world is moving on from stereo-typed binary gender ideologies, the Klinefelter discourses are taking huge strides backward. In a study undertaken by Williams and Bennet in 1975, and reproduced in Poynton's text *Language and Gender* (1985), the authors listed adjectives commonly associated with women and men. Listed adjacent to the adjectives were evaluative classifications of 'positive = +', 'negative = -' or 'neutral = 0'

It would seem, from the tables below, the language found in the Klinefelter medical and popular discourses attempts to present XXY individuals, who are not under a testosterone 'replacement' therapy program, as somewhat female or feminine, and employ adjectives commonly associated with males to promote the use of testosterone to cure the 'undesirable' qualities. Bing and Bergvall argue linguistic research into the relationship between language and gender indicates language 'not only reflects power relationships, but helps maintain them' (Bing and Bergvall 2000, p.5). They also suggest the use of such gender specific words serve to police the binary boundaries: 'thus assertive women may be nudged back into their approved roles by being labelled aggressive bitches, and nurturing men may be reminded of their deviance by being labelled wimp, sissy, fag…' (Bing and Bergvall 2000, p.3).

A selection of adjectives associated with females:

affected	-	feminine	0	sensitive	0
affectionate	+	soft-hearted	0	complaining	-
gentle	+	dependant	0	high-strung	0
submissive	0	dreamy	0	meek	0
emotional	0	mild	0	weak	-
excitable	0	whiny	-		

(Poynton 1985, p.60)

A selection of adjectives associated with males:

adventurous	+	realistic	+	aggressive	0
dominant	0	robust	0	ambitious	+
self-confident	0	assertive	0	forceful	0
stable	+	independent	+	steady	0
confident	+	strong	0	courageous	+
loud	-	tough	0	cruel	0
masculine	0	unemotional	0	rational	0

(Poynton 1985, p.60)

5 Sex, Gender and Identity

Evidence of applying dubious socially constructed concepts of male and female behaviour patterns, as the basis of research methodologies, are to be found in several studies into Klinefelter Syndrome and XXY variants. Bancroft, Axworthy and Ratcliffe (1982, p.170) attempted to identify the degree of masculinity or femininity in XXY individuals by establishing the 'boys principle interests and hobbies to rate these for the extent that they are typically boy or girl activities'. They also asked highly personal questions about the sexual activity and orientation of their subjects and seem to have expected accurate and honest results. Ratcliffe employed the *Cattell High School Personality Questionnaire* and the *Bem Sex Role Inventory* in order to discover that 'boys [who] rated themselves as more tender-minded', were apprehensive and insecure and less interested in girls (Ratcliffe 1982, p.106). Even though the XXY subjects achieved a lower score for masculinity, they also rated a lower score for femininity. Therefore, Ratcliffe claims there was 'no evidence of increased homosexuality' (Ratcliffe 1982, p.106).[*] Bancroft, Axworthy & Ratcliffe (1982, p.174) also noted that, even though their tests reflected a lower score for masculinity, neither did the data reflect a higher femininity score.

Bancroft, Axworthy and Ratcliffe utilised the *Draw a Person Test*, which they argued was a method of 'identifying people with a disturbance of gender identity' (Bancroft, Axworthy & Ratcliffe 1982, p. 171). According to the test, a child who identifies as male will first draw a male or what they state is a male. The XY controls all identified their first drawing as a male, yet of the XXY individuals, several could not identify the gender of their drawing. The researchers concluded that 'in general, the modest evidence of gender identity disturbance in the XXY boys may be understood as a lack of aggressive, assertive aspects of masculinity, with very little evidence of any feminine characteristics' (Bancroft, Axworthy & Ratcliffe 1982, p.174). Their language suggests qualities such as 'assertion' and 'aggression' are desirable traits in boys and such traits are not associated with girls. Even though Bancroft, Axworthy & Ratcliffe's *Bem Sex Role Inventory* acknowledged the existence of an androgynous scale between the binaries and admitted 'other explanations for these findings should be considered', it is apparent neither they nor Ratcliffe, in his individual study, ever undertook any investigations to try to solve this puzzle (Bancroft, Axworthy & Ratcliffe 1982, p.174).

Could this suggest that, even though the researches acknowledged the possible existence of a region between the finite binaries, the concept of the binaries is so ingrained as a cultural assumption, the researchers have remained reluctant to explore this avenue? Furthermore, they admitted they could not account for the findings that did not fit comfortably into their binary male/female, heterosexual/homosexual or passive/aggressive models or hypothesis. It is interesting to note that Bancroft, Axworthy and Ratcliffe's XY controls also achieved low scores for aggression and assertiveness, while also reporting incidents of behavioural problems. Yet, if this was the case, why did they emphasise that XXY individuals were lacking in some manner compared to the XY controls? Could it be that XXY individuals must aspire to some unachievable ideal of

[*] This link suggests the researcher believes all homosexuals are feminine!

what it is to be a valid male, as is the case where it appears that women need to be twice as good as men before they can be considered equal?

While there has been some interest in the gender identity of XXY individuals, few studies have been published and, of those, the authors seem reluctant to attribute gender identity variance to the influence of the extra X chromosome. Bancroft, Axworthy and Ratcliffe (1982, p.176) suggest the psychosexual development of XXY individuals are delayed, which they believe is due to the lack of testosterone. Yet they also suggest social factors, such as teasing and alienation from one's peers, may play a role.

Zastowny, Lehman and Dickerson (1987), and Seifert and Windgassen (1995), have published studies on two cases involving XXY individuals who displayed characteristics of gender dysphoria or transsexuality. Zastowny, Lehman and Dickerson's patient Mr H, was a 19-year-old XXY, who was admitted to hospital following a suicide attempt which, they claim, was caused by his confusion over his sexuality and gender. According to Zastowny, Lehman and Dickerson (1987, p.157), Mr H's XXY status was not immediately diagnosed, because he did not display the physical characteristics often associated with Klinefelter Syndrome. Accordingly, the initial diagnosis was that he suffered from a psychosexual disorder. During the initial interviews, Mr H expressed the desire to have a sex change because, 'he felt like a woman' (Zastowny, Lehman & Dickerson 1987, p.157).

Following the confirmation of Mr H's XXY status, the initial diagnosis of a gender disorder was discounted as, Zastowny, Lehman and Dickerson (1987, p.159) explain, gender dysphoria was defined as a psychological condition and not associated with chromosomal abnormalities. RXXY, who had been admitted to a transsexual therapy program, until she received the results of a karyotype test, experienced a similar rejection of her gender identity. On discovering her XXY status, the treating doctor stated 'your gender identity issues are not real issues after all, it just stems from you being confused due to being in-between, so we can make you into a perfectly happy boy' (RXXY 2000, p.1). The attitude of the physicians would suggest the prevailing medical view is that gender is determined by psychological factors and not chromosomal, and if a chromosomal variance is discovered, transsexual therapy is no longer appropriate. Could it be that it is preferable to associate gender dysphoria with intangible personal psychological issues, and thus preserve the integrity of binary systems of thought, rather than attribute gender fluidity to tangible chromosomes, which may threaten the binary classifications of sex and gender?

Rather than attempting to establish some relationship between Mr H's XXY status and his feelings of 'being like a woman', Zastowny, Lehman and Dickerson sought explanations in Mr H's family environment. Apparently Mr H had been treated as a female member of the family by being assigned 'female duties' and participated in 'female activities'. Therefore, Zastowny, Lehman and Dickerson (1987, p.157) claim, 'this "push pull" along the lines of sexual roles and behaviour [and] family expectations … may have sown the seeds for the patients later sexual identity disturbance...' Seifert and Windgassen also attributed their XXY patient's transsexualism to family dynamics, but concede his problems may have been magnified due to: 'somatic and psychosexual disorders characterising Klinefelter Syndrome' (Seifert and Windgassen 1995, p.312). They also blame their patient's decision to live as a woman as an act of spite towards his

physicians, who were trying to counsel him to accept testosterone therapy: as is 'proper' for a person diagnosed with Klinefelter Syndrome.

Smyth and Bremner believe it is crucial XXY individuals are diagnosed as early as possible, so the parents can be counselled on the appropriate treatment for their child. They state:

> *This information can help parents consider testosterone replacement therapy early in puberty and increase their awareness of learning disabilities and gender identification issues that may present themselves during childhood or adolescence* (Smyth and Bremner 1998, p.1313).

Smyth and Bremner also assert that testosterone therapy 'advances the development of secondary sexual characteristics and alters gender identification and subsequent behaviour' (Smyth and Bremner 1998, p. 1312). Their recommendations echo Zastowny, Lehman and Dickerson's stance that Mr H's gender confusion could have been prevented if there had been earlier medical intervention: 'there is some evidence that aggressive treatment of Klinefelter patients with exogenous testosterone at the time of puberty may reduce subsequent psychopathology...' (1987, p.161).

Smyth and Bremner's (1998), and Zastowny, Lehman and Dickerson's (1987) concerns over the gender identification of XXY infants and children is based on the theories of Dr John Money, which Brown explains, 'are based on the belief that gender identity is established in the first two years of a person's life' (Brown 1995, p.37). Money's guidelines recommend that, in order to ensure the 'establishment of an unambiguous, or normal, social and gender identity', surgical or hormonal therapies must be utilised to maintain a normal gender identity (Brown 1995, p.37). Meyer-Bahlburg believes 'the clinical management of such patients must minimise the risk of ambiguous rearing and of the development of gender-incongruent physical appearance' (Meyer-Bahlburg 1982, p.697). Smyth and Bremner's, and Meyer-Bahlburg's recommendations suggest they are convinced the purpose of testosterone therapy is to modify the body and mind of an XXY child, so that 'he' can fit into the culturally defined paradigm of what it is to be male. But what of the rights of the XXY individual?

5 Lived Experiences

Halliday and Martin are of the opinion that people, outside of the scientific disciplines, do not understand scientific discourse is not meant to reflect or describe human experience: rather 'it is a language … in which theories are constructed' and possess features 'which make theoretical discourses possible' (Halliday and Martin 1993, p.8). Therefore, both the medical and popular non-technical discourses represent XXY individuals as theoretical constructs. Treating a person merely as a theoretical construct has resulted in scientific discourses silencing the lived experience of the people who are the 'objects' of the discourse, while at the same time preserving culturally constructed myths related to the nature of sex and gender. Furthermore, the popular discourses, produced by members of the Klinefelter/XXY support groups, choose to ignore the lived experiences and perceptions of members of their own community to such an extent that any expression of variance from the medical discourses is effectively marginalised.[•] Nonetheless, a close reading of some of the published literature and personal accounts published on the internet provides a window into the lived experiences of XXY individuals. Such accounts demonstrate that variance from the culturally desired stereo-typical XY male representation is not uncommon.

Mr H, in Zastowny, Lehman and Dickerson's 1987 study, reported the feelings of being a woman began around the age of nine. By the age of 17, he had assumed a homosexual lifestyle: yet he felt out of place in the gay scene and was rejected by his homosexual peers. Similar feelings of alienation from males was expressed by BXXY in a private correspondence, where he states he was 'always conscious of being 'out of step' with other men, and never really identified with them' (BXXY 2000, p.1). Seifert and Windgassen's patient also expressed feelings of sexual and gender fluidity during his childhood and adolescence, and reported he 'felt he was between two chairs' (Seifert and Windgassen 1995, p.313). Eventually, according to Seifert and Windgassen (1995, p.314), their patient refused testosterone therapy. Instead, 'he' requested oestrogen therapy after fully adopting a female identity.

Language is the biggest hurdle for XXYs attempting to establish both a sex and gender identity. Traditionally, there are only two choices: the binaries of male and female sex and gender. Not only are researches, such as Smyth and Bremner (1998), Bancroft, Axworthy and Ratcliffe (1982), Seifert and Windgassen (1995) and Zastowny, Lehman and Dickerson (1987) trapped in the binary language, their patients also usually describe themselves as being transsexual: transitioning from being male to female, or from one end of the sex and gender spectrums to the other. It appears, therefore, from an analysis of medical and popular discourses, that a space between the binaries is not recognised: even by people who identify as intersexed! Such non-recognition may be accounted by the lived experience of many XXY individuals being beyond the language of the binaries.

[•] Hambley's web-page (2000) is one of the few examples where the author has attempted to include accounts of the experiences of a range of XXYs who did not fit into the presented XXY male model, as described in his main web-page. However, the very act of providing a separate page titled 'XXY Perspectives' and by including the disclaimer, 'the opinions of these various writers are their own and may not reflect the whole of the XXY community; nor is there any endorsement to their views by either this site or its author', continues to marginalise the experiences of these non stereo-typical XXYs (Hambley 2000, p.1).

Thus the English language, which includes scientific terminologies or 'jargon', does not possess the flexibility to describe the space between the binary opposites. Accordingly, the English language cannot validate experiences and perceptions existing somewhere 'in-between'. Bing and Bergvall have recognised this innate flaw in language and state that 'because language is discrete and biased towards dichotomy and clear boundaries, the scale values and unclear boundaries of reality are sometimes difficult to accept …[and, therefore,] we must continually remind ourselves that reality and language can conflict' (Bing and Bergvall 2000, p.1).

Nevertheless, evidence of this inability to express one's lived experience—because the English language is based on the binaries—is slowly emerging from non-conventional sources, such as internet discussion lists and intersex web-pages. Increasingly, accounts of people's lived experience include statements that, while they did not identify as being fully male, they also did not feel fully female: thus they expressed a perception of existing somewhere in-between. Initially, LXXY was unaware her underlying condition was considered an intersex condition. She continues to identify as transsexual, even though she feels alienated from the mainstream XY transsexual community. However, on discovering her XXY karyotype was considered an intersex condition by some organisations, she reported her life seemed to make more sense: 'but at the same time it makes it more difficult' (LXXY 2000, p.1). A person diagnosed with an XXXY karyotype wrote: 'I feel in the middle somewhere. It's natural for me. I've always been a bridge, a go-between, understanding both sides of any given coin but living somewhere on the middle edge' (Weirich 2000, p.11).

Somers, years before h/is XXY diagnosis, or the development of visible physical characteristics associated with Klinefelter Syndrome, possessed feelings 'more female than male, yet neither one nor the other ...' (Somers 1999, p.1) BXXY questioned his sex and gender identities, when he asked the question 'am I both "male and female", maybe I'm something else… I am still trying to find my place as an XXY on the spectrum...' (BXXY 2000, p.1). Somers has adopted the terms 'Intersex' and 'Androgynous' to describe h/is identity and states: 'I am not afraid of being who I am…' (Somers 2000, p.1). H/e explains even though XXY individuals visually appear 'more or less male … we are genetically different and biologically different too [because] the chromosomal difference cannot be denied' (Somers 2000, p.1). Ironically though, Somers argues, in one respect h/e is a transsexual, because 'I used to have lovely breasts [but] had a bi-lateral mastectomy when I was almost 17': a course of action h/e felt h/e had to submit to, as h/e feared the abuse of h/is peers. Somers, therefore, concludes: 'I have been modified to look more male than female, though I am neither' (Somers 2000, p.2).

MXXY wrote on an XXY discussion list:

> *For me, I accept my male and female physiological, psychological and psychosexual characteristics. I have aspects of my psyche, which are undeniably male, but simultaneously aspects usually identified as being female characteristics. Consequently, I fully acknowledge I am a complex blend or soup of male and female, which ironically counts each other out in many occasions. I continue to integrate my male and female facets, while trying to avoid perceiving myself and my characteristics within the language of the binaries. I am neutral in behaviour and manner: neither*

> *feminine nor effeminate, but also not masculine or manly*. (MXXY 2000, p.2).

In response to MXXY's comments, HXXY wrote he could not add anything to this description, because it 'fits me perfectly … I too have accepted myself as being a combination of both male and female, but not entirely one or the other' (HXXY 2000, p.2). HXXY also experienced a gender identity crisis, until he discovered the existence of intersex: 'I'd always thought of myself as male but with many thoughts and feelings society identifies as feminine' (HXXY 2000).

Haynes suggests the 'flaw in the clinical description of Klinefelter is not so much an inaccuracy, as generalisation from a few instances to everybody, a severe form of stereotype, which does not allow for gender differences and variety' (Haynes 2000, p.5). Few Klinefelter/XXY web-pages recognise that not all XXY individuals identify as exclusively of the male sex and/or gender. Consequently the specific needs of, for example, XXY transsexuals and XXY intersexed people are usually neglected, or even denied. On the rare occasions when variants from the stereo-typical 'norm' are discussed, their life experiences are trivialised. Their self-perception is dismissed as a life-style choice. After all, both the medical peer-reviewed discourse and on-line web-resources almost invariably state that all XXYs are born male, are male and will always be male.

CONCLUSION:

Historically, whenever a culture is on the brink of stepping into a new paradigm, members of that culture react quite predictably. As the old paradigm begins to disintegrate, people attempt to reinvigorate or reinforce the paradigm in order to try and preserve what is known and therefore safe and secure, while resisting the forces of change for fear of facing the unknown. During the final century of the old millennium, at a time when biologists were discovering the binaries did not exist in nature, and members of other disciplines (such as feminist researchers and linguists) were arguing binaries were product of language and culture, members of the medical disciplines sought to reinforce the binaries by identifying and focusing on differences. Consequently, as Bing and Bergvall claim, 'the boundaries between the sexes needed to be reinforced; intersex individuals ceased to be acknowledged and became redefined as a medical problem' (Bing and Bergvall 2000, p.6).

A graphic example of the retreat back into traditional and secure belief systems, as well as gender specific discourses, can be identified within the Klinefelter/XXY academic peer reviewed and non-technical popular discourses. While science had proven the sex chromosomes do not exist as a binary dichotomy, but rather are the polarised extremes of a spectrum of possibilities and potentials, the medical profession seeks to force 'variant' individuals into a socially constructed stereo-typical model of an XY male. An entire industry of medical specialists and therapists have developed, over the last few decades, therapies devoted to the 'normalisation' of XXY individuals: in an attempt to minimise difference and maximise sameness.

Scientific discourse, Halliday and Martin state, has not remained confined to the scientific disciplines: rather it 'has been taken over as the dominant mode of interpreting human existence' (Halliday and Martin 1993, p.11). Consequently, instead of listening to the many and varied lived experiences of their XXY brethren, the non-medically trained interpreters of the scientific discourses perpetuate the scientific assumptions, interpretations and theories, which protect and perpetuate the binary belief systems. It appears, from the discourses, the evidence of lived experience is not real, unless it has been subjected to the rigours of scientific research and interpretation. Yet, if the lived experiences of individuals do not correlate with existing theories and models, then the chances of research being undertaken to investigate such evidence is very low: simply because the 'other' lived experiences are marginalised, trivialised and invariably silenced.

Fidler warns that a researcher's personal socially generated assumptions often intrude into their data analysis, resulting in them interpreting their data in order for it to reaffirm their preconceived assumptions. Or, in other words, the researcher will 'find what they want to find or cause what they want to find', in order to protect their preconceived assumptions (Fidler 1998, p.4). Such unconscious pitfalls in the scientific research methodologies are to be found in the Klinefelter/XXY discourses because, since the discovery of variations such as XXY, researchers have resisted accepting evidence demonstrating the new data challenges the traditional concepts of the sex binaries and, therefore, the perceptions of sex, gender and identity. Instead, medical researchers have shifted the goal posts by reclassifying and reconceptualising data, resulting in the creation

of a very muddy field of discourse containing many holes of contradictions and paradoxes.

Changes in the perception, representation and thus treatment of individuals diagnosed with an XXY karyotype, will only occur when society develops new words to describe the lived experiences of people whose biology, life-experiences and self-perception exist outside of traditional binary sex and gender systems of thought. Bing and Bergvall suggest: 'if we are to abandon traditional dichotomies and binary questions, we must ask new questions and discover new metaphors, which help us think about sex, gender and language' (Bing and Bergvall 2000, p.14).

There are no winners in the Klinefelter Syndrome and XXY medical and popular discourses. XXY individuals who identify as male, vainly aspire to reach the unachievable goal of being transformed, by testosterone 'replacement' therapy, into the socially constructed, stereo-typical 'ideal male' represented in the discourses. Nor are the pleas of the XXY individuals, who identify other than fully male, listened to. Invariably, the specific needs of people, whose biology and self-perceptions exist in the mysterious and unexplored space between the binaries, are ignored. Non-exclusively male identifying XXY people are, (and continue to be) actively marginalised: their lived experiences are either dismissed or trivialised by the medical profession and research community, as well as within society in general. Hormone (Testosterone) Replacement Therapy remains the sole option for XXYs, for it has attained the status of a religion within the on-line Klinefelter/XXY community and the cry 'XXY is not an intersex condition' has become its mantra.

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