



UCL Institute for Women's Health

Working psychologically with women diagnosed with androgen insensitivity syndrome (AIS)

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GrApSIA XIII Congress
Bilbao, 30th November, 2013



Changing nomenclature

‘Intersex’

Birth conditions associated with the presence of male-typical and female-typical internal and/or external genitalia as a result of disruptions to regular sex differentiation and development

‘Disorder of sex development’

“Congenital conditions in which development of chromosomal, gonadal or anatomical sex is atypical” (Hughes et al., 2006)

Recommended clinical protocol

- Multi-disciplinary team
- Full disclosure
- Conservative approach to medically non-essential treatment, until the patient can give consent
- Psychological support
- Evidence-based practice
- Collaborative approach

Middlesex Clinic UK

- National centre of referral
- Adolescent and adult women (AIS and other diagnoses)
 - Transfer from paediatric services (i.e. condition identified during childhood)
 - Condition identified in adolescence or adulthood
 - Socially and ethnically diverse
 - With or without history of history of genital surgery
- Patient-driven development of MDT service from 1990s, predating international and UK care documents, and involving: endocrinology, genetics, gynaecology, nursing, psychology, radiography, urology...
- *INTER*-disciplinary framework and integrated care made possible by the high value placed upon Psychology by progressive medical and nurse practitioners
- Has trained clinicians of different disciplines throughout UK and other parts of the world



Psychological concerns in AIS

- Anxiety relating to self-disclosure about AIS
- Social and sexual relationships
- Vaginal reconstruction
- Anticipatory and experienced sexual difficulties
- Decision making about surgery
- Parenthood

Aims of this presentation

Present 2 areas of work

- Self-disclosure
- Vaginal reconstruction

Offer a model for understanding how these 2 aspects may be related

Once a dark secret

Anonymous, BMJ 1994

“The next six years were spent in periods of deep depression with frequent desires for suicide. My consultant did what he could but there were several events which increased my despair.”

- “I was admitted to hospital for adhesions and a nurse asked me if I had previously had a penis.”
- “I was seen by a psychiatrist at his office in a maternity hospital with a heavily pregnant doctor participating.”
- “I was seen by a psychosexual counsellor who tried to take me apart and reconstruct my psyche, a process which nearly caused a mental breakdown.”

Middlesex Communication Study

Liao, Green, Creighton, Crouch, Conway, BJOG 2010

- 126 eligible within study period invited to participate
- 122 agreed; 4 declined
- 16/122 questionnaires not subsequently returned
- 6/122 were not correctly completed and/or had large amounts of missing information
- 100 formed usable sample (100/126, 80%)
- 30/100 AIS; 26/100 CAH; 18/100 MRKH

Satisfaction with receiving component parts of medical information

<i>Information:-</i>	<i>No. for whom applicable</i>	<i>More or less appropriately informed</i>	<i>Wish informed sooner / differently</i>	<i>Wish never informed</i>
<i>Primary amenorrhea</i>	69	64%	36%	0%
<i>Infertility</i>	81	63%	37%	0%
<i>Absent uterus</i>	63	56%	43%	1%
<i>Absent ovaries</i>	57	51%	47%	2%
<i>Lifelong oestrogen</i>	58	62%	36%	2%
<i>Vaginal anomalies</i>	73	51%	48%	1%
<i>Clitoral anomalies</i>	36	44%	53%	3%
<i>Genital surgery</i>	55	47%	49%	4%
<i>Testes</i>	44	25%	73%	2%
<i>Y chromosome</i>	54	33%	65%	2%

Percentages of younger and older patients' beliefs about parental knowledge of condition

	Age <27	Age 27 or older
<i>Parents knew and said hardly anything</i>	21%	59%
<i>Parents knew some things and told what little they knew</i>	30%	33%
<i>Parents knew more than what they told me</i>	9%	9%
<i>Parents knew a lot and shared it all with me</i>	41%	0%

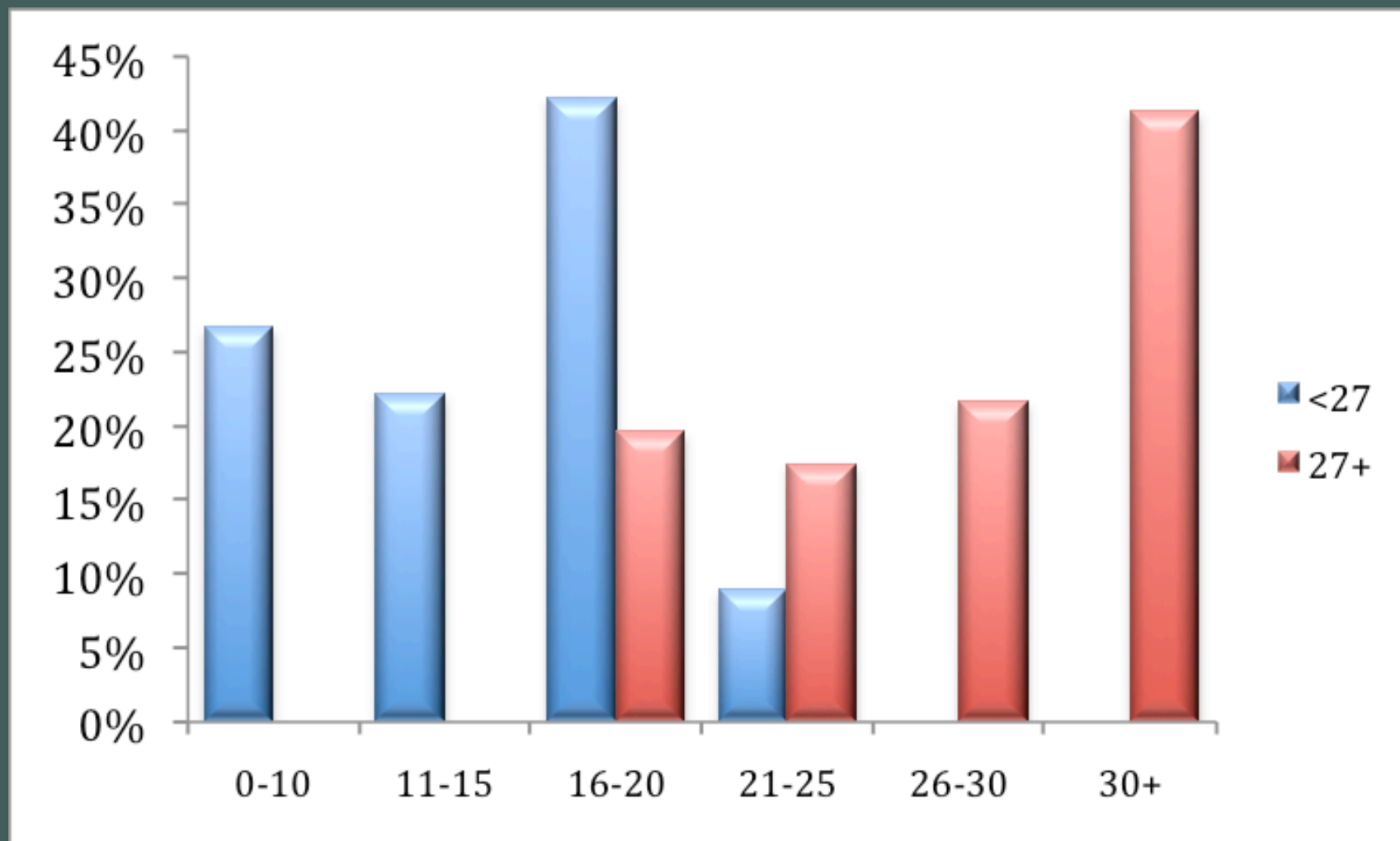
Percentage of participants reported having stumbled information by chance

	Age <27 years	Age 27 years or older
Never	41%	30%
Yes through mass media	41%	44%
Yes through health professionals	21%	33%
Yes through family members	16%	7%

% younger and older participants having discovered component parts of diagnostic information by age 15

DSD information:-	< 27 years	27 years or older	p value
Primary amenorrhea	58%	25%	0.007
Infertility	50%	25%	0.022
Absent uterus	60%	17%	0.001
Absent ovaries	65%	17%	0.001
Lifelong oestrogen	71%	17%	0.001
Vaginal anomalies	66%	21%	0.001
Clitoral anomalies	79%	36%	0.02
Genital surgery	67%	40%	0.58
Testes	77%	4%	0.001
XY karyotype	68%	3%	0.001

Difference in age of discovery of full diagnosis for younger and older service users (n=100)




Disclosure / discussion about condition to close others

<i>Discussed with:</i>	<i>almost/ everything</i>	<i>something</i>	<i>next to/ nothing</i>
<i>Partner</i>	71%	13%	16%
<i>Ex-partner(s)</i>	34%	37%	29%
<i>Father</i>	55%	23%	21%
<i>Mother</i>	74%	19%	7%
<i>Sibling with same condition</i>	63%	0%	37%
<i>Sibling without same condition</i>	47%	30%	27%
<i>One or two friends</i>	40%	42%	18%
<i>Several friends</i>	16%	31%	52%

Proportions of participants who have disclosed about applicable aspects of condition to the one most knowledgeable person outside professional and support forums

<i>Aspects of conditions</i>	<i>Have disclosed to the one person who knows the most</i>
<i>Primary amenorrhea</i>	91%
<i>Infertility</i>	91%
<i>Absent uterus</i>	87%
<i>Absent ovaries</i>	88%
<i>Lifelong oestrogen</i>	86%
<i>Vaginal anomalies</i>	82%
<i>Clitoral anomalies</i>	75%
<i>Genital surgery</i>	71%
<i>Testes</i>	75%
<i>Y chromosome</i>	85%



Talking about AIS and other differences in sex development remains a key challenge

“Is living a ‘normal’ life with a secret more harmful than living a life without secrets but with a reasonable chance for stigma or shame?”

Cohen-Kettenis 2010, p328

Vaginal reconstruction

Can be highly invasive, e.g. Hensle et al., 2006 - bowel vaginoplasties
1980-2004

- 36/57 MRKH & CAIS
- Sigmoid colon, ileum & cecum
- 2/36 home dilation + oestrogen suppositories
- 20/36 require pads for mucus production
- 34/36 home douching
- No pre-treatment measure available for comparison but:
 - High rate of reported orgasms, any sexual satisfaction and any sexual desire
 - 33% (any) sexual arousal
 - 33% (any) sexual confidence

Anatomy does not equal sex

“I felt...like [] I hadn’t learned all the social sort of skills that were needed to [] you know to-to establish a relationship and that maybe that was the main problem, and having a vagina wouldn’t really help... there’s more going on than just vaginal length.”

Boyle, Smith & Liao, 2005

And sex does not equal vaginal penetration

“Sexual dysfunction or heterosexual dysfunction?” *Boyle, 1993*

“Full genital performance during heterosexual intercourse is the essence of sexual functioning, which excludes and demotes nongenital possibilities for pleasure and expression. Involvement or non-involvement of the nongenital body parts becomes incidental, of interest only as it impacts on genital responses identified in the nosology.” *Tiefer, 1995:53*

Person-centred psycho-sexual input

Aim for good enough relating via:-

- Increasing control over social and sexual situations
- Increasing awareness of variations in male and female sexualities
- De-centralising genital intercourse
- Self permission to explore a range of sexual activities – alone or partnered
- Challenging the sexual imperative? Self permission not to pursue sexual activities – as appropriate to clients (and partners)

Non-surgical vaginal reconstruction

Rationale

- Less invasive
- Fewer risks
- Not irreversible
- Options for most women not operated on are: dilation with surgery or dilation without surgery
- Opportunities for psychological and psychosexual input

Obstacles

- Compliance with post-vaginoplasty dilation is poor and patient satisfaction low (Minto Liao, Conway et al., 2003)
- Significant barriers to self management (Liao et al., 2006)

Dilation as 1st line approach to vaginal agenesis: A multi-disciplinary development

Liao et al., JOG 2006

- Psychology-led protocol development
- Drew on motivational and behavioural interventions to enhance 'self management' in other chronic disease contexts
- Informed by critical sexological perspectives
- Designed to develop the role of the nurse specialist
- Opportunities for psycho-sexual education and counselling
- Multiple outcomes and patient satisfaction assessed

Dilation as 1st line approach to vaginal agenesis: A multi-disciplinary care delivery

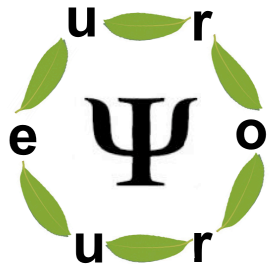
Ismail-Pratt et al. Hum Reprod 2007

- 1st prospective evaluation
- 21/26 completed programme (17 sexually active; 4 maintenance therapy) (MRKH & CAIS)
- Changes in vaginal perceptions correspond with changes in vaginal dimensions
- Significant reduction in sexual anxiety and depression
- 3/26 suspended temporarily
- 2/26 referred to surgery (Vecchiatti)

Managing atypical sex anatomy: Biomedical paradigm



If treatment is not enough, there's other things to try, e.g. psychology...

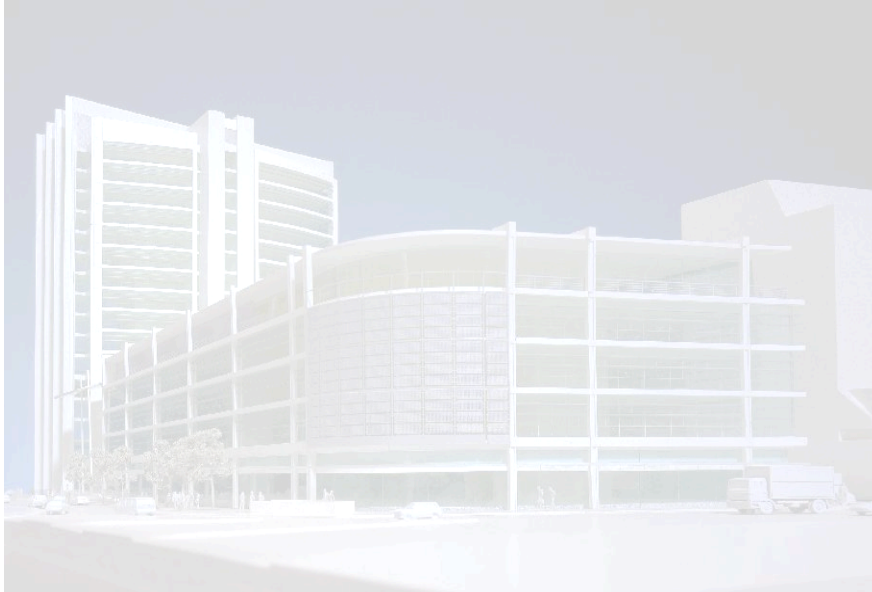


EuroPSI

European Network for
Psychosocial Studies in
Intersex/DSD

www.europsi.org

a new multi-disciplinary
professional network with user
group leads -
to be launched in early 2014



The greatest impact on psychological well-being will come from successful systemic interventions to improve public understanding. This means health professionals must be **advocates** for their patients in future – staying in the safety of the consulting room. laboratory and operating theatre won't be enough.