
Importance of Support Groups for Intersex (Disorders of Sex Development) Patients, Families and the Medical Profession

M.L. Cull^a M. Simmonds^b

^aAdrenal Hyperplasia Network, Lichfield, ^bAndrogen Insensitivity Support Group, London, UK

Key Words

Awareness · Education · Emotions · Intersex · Secrecy · Self-management · Shame · Support · Taboo · Well-being

Abstract

Taboo still surrounds intersex/disorders of sex development, in spite of more openness in society regarding sex. Peer support is valuable in providing information and emotional support to those affected. Support groups also work with clinicians to promote better care, to assist with research studies and to increase clinical awareness and expertise by helping to stage symposia. They also foster greater public understanding via media involvement and training videos; and play an advocacy role, providing one voice to channel the concerns of a scattered population with these rare conditions.

Copyright © 2010 S. Karger AG, Basel

Introduction

A Babylonian tablet, dated approximately 700 BC, tells us that 'If a woman gives birth to an infant that has no well marked sex, calamity and affliction will seize upon the land; the master of the house shall have no happiness'.

Although Western societies are today increasingly open about sexuality and sex in their media, people's problems in this area are still buried deeply. Many of those affected, their families and their friends, find intersex issues unacceptable, taboo and difficult to talk about because they are cloaked in shame and secrecy. Support groups provide essential emotional peer support via others with the same and similar conditions, helping to dispel these taboos [Cull, 2006] to make living and coping with these conditions more bearable.

Peer Support

Meeting others with intersex conditions who are going through similar experiences is the key to coping with rare conditions. A support group is often referred to as a second family; somewhere a person can go in order to talk

with and listen to others, air concerns and worries, share breakthroughs and experiences, good and bad. As the old saying goes, 'a problem shared is a problem halved'. Such groups hold peer and family support meetings and educational conferences that provide an opportunity for members to talk, share, laugh and cry together in a safe environment and to become better informed. Parents can meet affected adults as well as talk to other parents. Children and adolescents can meet others in their age group and older who are 'in the same boat'. Groups can also provide extra emotional support for the social aspects of intersex conditions, such as infertility and relationship challenges, and for the life-threatening aspects of conditions, such as congenital adrenal hyperplasia, which present the double-edged sword of having to deal with both the intersex issues and the fact that even mild infections like colds and flu, as well as stress, can have serious health implications.

Promoting Improved Care

By bringing patients and professionals together, support groups play a role in improving treatment and the clinical experience for patients and in promoting research.

In 1997 UK groups helped clinicians to set up a one-stop multi-disciplinary clinic (the coincidentally but perhaps aptly named 'Middlesex Clinic' at University College Hospital London, www.uclh.nhs.uk/middlesexcentre). Such ventures benefit patients and at the same time encourage services to become more effective and user-friendly. Older patients' experiences and campaigning can also urge caution in those irreversible decisions [Simmonds, 2004] that may be made in childhood without the informed consent of patients because they are made by ill-informed, frightened parents and inexperienced professionals. Groups may also work with clinicians and psychologists to improve patient literature and educational material, so that patients can become better informed about their condition, cope with its effects and self-manage it better.

Meetings of the UK Androgen Insensitivity Syndrome Support Group (AISSG) include a session for professional speakers. Clinicians thus get to meet and talk to all ages of patients. Learning in a non-clinical environment is important, as more can be learnt of what really matters to patients, especially on quality of life issues. Many support groups also have medical advisors who work closely with the group to ensure quality aims and support.

Symposia

Symposia can also bring patients and professionals together (www.aissg.org/15_anounce.htm) on an equal footing in a non-hospital context, so that each can learn from the other. They also provide an opportunity to write joint papers in academic journals. Authoring and co-authoring papers [Cull, 2002; Creighton et al., 2004] on the experience of living with rare intersex conditions, on case histories and other research topics, helps draw attention to outdated academic texts and theories, and to improve patient and professional experiences of dealing with these conditions. Still on an educational theme, group members often give lectures and presentations to trainees, medical students, researchers, nurses, GPs, universities, colleges, hospitals, and even schools.

Research Collaboration

Research plays an increasingly important role, with support groups bringing together patients and researchers from various specialties including medical and psychological. They help filter out the more sensationalist or opportunist propositions and help researchers to target areas that are important to patients [Cull, 2005]. Support groups can also help patients to make informed choices on whether to take part in studies, by providing high quality information in an easily understandable format.

Information Provision

Support groups gather together the latest information, research and treatment options into a central repository for easy access by patients and others. Modern technology, such as websites and e-mail, plays a key role in helping groups to make available accurate information in an easily understandable format. They help to raise awareness and to educate, and they act as a point of contact for people looking for support and information. Telephone, e-mail and letter support are very important in getting the required backup from groups and peers, and in keeping in touch with others.

Increasing Awareness

In the case of the media, support groups provide accurate information to help educate and promote awareness of rare conditions that are so often stigmatised, misunderstood and sensationalised. Members often provide interviews and take part in training videos (www.wonder-dog.co.uk/gender.html) and radio/TV documentaries to raise awareness.

Groups bring together people from all over the world to create a strong presence for affected people who would otherwise not have a voice, to help make changes and improve quality of life. Key medical experts, encouraged by support groups, also bring together clinicians from all over the world at international conferences, where professionals and people with these conditions can learn of alternative approaches to treatments and care.

Conclusion

Support groups can put forward the realities of living with intersex conditions, what it is like to deal with the shame, secrecy, stigma, and loneliness to which misunderstanding can give rise. They highlight the humanity of people with intersex conditions, who have desires, needs and feelings like anyone else and are not the two-headed monsters or freaks of nature that society often portrays them as. Most of all, though, support groups provide much needed personal support and contact opportunities and an informal communication interface with the medical profession. Together with medical care, all these functions of support groups can help to bring about physical and emotional well-being.

References

- Creighton SM, Minto CL, Liao LM, Alderson J, Simmonds M: Meeting between experts: evaluation of the first UK forum for lay and professional experts in intersex. *Patient Educ Couns* 54:153–157 (2004).
- Cull ML: Treatment of intersex needs open discussion. *BMJ* 324:919 (2002).
- Cull ML: A support group's perspective. *BMJ* 330:341 (2005).
- Cull ML: Dispelling the taboo of intersex conditions: we're only human like you!, in Balen R, Crawshaw M (eds): *Sexuality and Fertility Issues in Ill Health and Disability: From Early Adolescence to Adulthood*, chapter 12 (Jessica Kingsley Publisher, London 2006).
- Simmonds M: Patients and parents in decision making and management, in Balen AH, Creighton SM, Davies MC, MacDougall J, Stanhope R (eds): *Paediatric and Adolescent Gynaecology: A Multidisciplinary Approach*, chapter 17, pp 205–228 (Cambridge University Press, Cambridge 2004).