ACTA PÆDIATRICA
NURTURING THE CHILD

Acta Pædiatrica ISSN 0803-5253

VIEWPOINT ARTICLE

Partnering with parents to disclose Klinefelter syndrome to their child

Isabelle Tremblay (isatremblay2002@yahoo.ca or isabelle.tremblay.hsj@ssss.gouv.qc.ca)[1,2], Guy Van Vliet[2,3], Monique Gonthier[2,4], Annie Janvier[2,4,5]

1.Department of Psychology, Sainte-Justine Hospital, Quebec, Canada
2.Research Center, Sainte-Justine Hospital, Quebec, Canada
3.Endocrinology Service, Sainte-Justine Hospital, Quebec, Canada
4.Department of Pediatrics, University of Montreal, Quebec, Canada
5.Bureau de l'Éthique Clinique, University of Montreal, Quebec, Canada




Keywords
Disclosure, Family-centred care, Klinefelter syndrome, Parental perspectives, Sex chromosome aneuploidies, Truth telling, XXY syndrome

Correspondence
Isabelle Tremblay, PhD, Department of psychology, Sainte-Justine Hospital, 3175 Cote-Sainte-Catherine, Montreal, Québec H3T 1C5, Canada.
Tel: +1-514-345-4931 ext. 2913 |
Fax: +1-514-345-4809 |
Email: isatremblay2002@yahoo.ca or isabelle.tremblay.hsj@ssss.gouv.qc.ca

Received
22 May 2015; revised 3 December 2015; accepted 7 December 2015.

DOI:10.1111/apa.13301

ABSTRACT

In paediatrics, a diagnosis of Klinefelter syndrome can occur after prenatal testing or because of symptoms such as learning difficulties or incomplete puberty. After the diagnosis, parents have to decide when and how to speak about this condition to their child. Parents and healthcare professionals (HCPs) may have different perceptions related to disclosure of this diagnosis. Due to the absence of clear guidelines, parents and HCPs may feel uncomfortable discussing the condition and may hide the truth in a prolonged fashion.

Conclusion: For patients with a prenatal diagnosis, we recommend a gradual and personalised disclosure process starting between the ages of 5 and 13 years. For older patients, a personalised approach should also be the goal. Various communication strategies and recommendations regarding disclosure of Klinefelter syndrome are proposed.

CASE PRESENTATION

David is an 11-year-old boy with Klinefelter syndrome diagnosed prenatally. His parents decided not to tell him about his condition in order to avoid stigmatisation or compromise his identity development. They asked all healthcare professionals (HCPs) involved in the care of their son not to mention the diagnosis in front of David. During early childhood, David's development was normal with the exception of language delay. Dyslexia and attention deficit disorder were diagnosed later. David is shy, sensitive and anxious. A psychological evaluation revealed that he suffers from generalised anxiety disorder and symptoms of depression. The geneticist, psychologist and paediatrician never spoke to him about his condition, but are increasingly uncomfortable about not doing so. During his last visit with his primary paediatrician, David reports that he knows something is wrong with him. He asks his paediatrician 'Why am I different from others in my class, what is wrong with me? Please, tell me the truth!' What should his paediatrician do? Should he tell David the truth or respect the parents' preferences?

Abbreviation
HCP, Healthcare professional.

INTRODUCTION

Klinefelter syndrome is a frequent chromosomal anomaly with an estimated prevalence between 1/500 and 1/1000 males (1). This syndrome is characterised by an extra X chromosome in males (47, XXY karyotype). An increasing proportion of diagnoses are made in a prenatal fashion (2,3). This proportion is bound to increase with noninvasive genetic testing (4). In around 25% of cases, the diagnosis is made postnatally during childhood or adulthood (3,5). When Klinefelter syndrome is diagnosed postnatally, the

karyotype is usually ordered for developmental disorders, hypogonadism or infertility (3). Finally, many individuals living with this condition remain undiagnosed (3).

The phenotype initially described by Klinefelter et al. and later shown to be associated with a 47, XXY chromosome constitution is highly heterogeneous (2,5). Physical manifestations may include tall stature, gynaecomastia, infertility, decreased facial or pubic hair and hypogonadism (2,5). Klinefelter syndrome is also associated with an increased prevalence of speech delay, learning disorders such as dyslexia and deficits in executive functions (6). Individuals living with Klinefelter syndrome are more likely to exhibit problems with attention, concentration and memory (7,8). They are also frequently described as shy, sensitive and showing poor affirmation abilities (9). Finally, this condition is associated with an increased prevalence of mood, anxiety disorders and psychotic disorders (8–10).

Given its relatively benign and nonspecific manifestations, this common condition is largely underdiagnosed. On the other hand, in recent years, it is increasingly discovered during prenatal testing (11). Parents then have to decide when and how to disclose this information to their son. Healthcare professionals (HCPs) are important partners in this endeavour. Some parents decide to disclose the diagnosis as soon as their child asks questions related to his health. Other parents prefer to disclose information related to the syndrome gradually or wait for the 'right time' in their child's life. Lastly, some parents, like David's, may indefinitely postpone the disclosure of the diagnosis. They generally do so in order to protect their child, as they often worry that disclosure might have a negative impact on self-esteem (12) or expose their child to stigmatisation, discrimination and bullying (13).

Many diagnosed children recognise their particularities and ask questions about their differences (14). Parents may disagree with HCPs about when and how to disclose this information. Considering that there are no official recommendations or guidelines, it may be more difficult for some providers to partner with parents and speak about these issues. For the remainder of this article, we will analyse how the disclosure of this diagnosis fits into the life trajectory of children and their families, using an ethical perspective and a family perspective, as well using evidence in the psychological development of children. Finally, strategies for disclosing this diagnosis during childhood or early adolescence will be identified.

PARENTAL PERSPECTIVES ON DISCLOSURE

Due to their age-related cognitive limitations, healthy children are unable to make their own healthcare decisions and parents are generally the decision-makers (15,16). Respect for parental autonomy means recognising their ability to make decisions in the best interests of their child (16,17). When parents of children with a genetic condition such as Klinefelter syndrome have to decide whether, when and how to disclose this diagnosis, several factors may determine which option they think is optimal. Some parents may decide to disclose the diagnosis to their child in order to explain why he has specific problems, such as language delay or a learning disorder (18). Revealing a diagnosis often decreases uncertainty and anxiety for the child, particularly when he recognises that something is not right (14). Furthermore, disclosing the diagnosis may also increase the level of the involvement of the child in his own care and interventions (18). Lastly, some parents expect that disclosing the diagnosis might open discussions with their child about the condition instead of keeping it secret (18,19).

On the other hand, several reasons might explain why some parents decide to withhold the diagnosis from their children. Some parents may have different opinions about when the child is developmentally ready to learn about his diagnosis (19), waiting for the 'right time' for their child to receive this information (19,20). Some parents may worry that their son may decrease his efforts, considering the genetic condition as an obstacle impossible to overcome (genetic determinism) (18). Many parents want to avoid stigmatisation during childhood, compromise identity development and possible disruption of their relationship with him (15). For instance, it is sometimes suggested that males with sex chromosome aneuploidies such as Klinefelter syndrome as well as 47, XYY syndrome are more likely to develop criminal behaviours. Even if this affirmation is not supported by scientific literature, some parents may worry that disclosing the diagnosis to their child and to other people may cause him prejudice. Others may also prefer not talking about the diagnosis because they are unsure whether and what their child will understand, and they do not want to harm him (15,17,19,20). Finally, several studies have shown that many parents prefer nondisclosure because they are uncertain about how to initiate the conversation, how to explain the diagnosis, to discuss infertility, to talk about hormonal replacement therapy and to answer their child's questions (18,21,22).

In summary, parents are expected to make decisions in the best interest of their child. In choosing between disclosure and nondisclosure of a diagnosis, parents are trying to help their child and protect him from harm. David's parents believe that nondisclosure is superior to disclosure at the present time. Respect for parental autonomy means accepting their decision even though their son asks for answers to his particularities. On the other hand, a child's autonomy and right to know should also be taken into consideration.

CHILD'S RIGHT TO KNOW

Decisions made by parents should respect the principles of beneficence (duty to make decisions in the best interest of the child) and nonmaleficence (duty not to harm) (16). Sometimes, respect of beneficence and nonmaleficence may conflict with the principle of autonomy (16,17). For instance, David's desire to know the truth regarding his condition conflicts with the desire of the parents to keep it secret.

For children with genetic conditions such as Turner syndrome, discussions about the diagnosis and treatment are recommended as soon as the child is able to understand or

Table 1 Recommendations for healthcare professionals regarding disclosure of a diagnosis of Klinefelter syndrome to a child

Recommendations for healthcare professionals	
Before disclosure	• Before speaking to parents, review up-to-date information on Klinefelter syndrome. • When the diagnosis is disclosed to parents (or shortly after), discuss with them how they plan to inform their family and later on, their child. Inform parents that a healthy disclosure is part of the child's health care and that HCPs are there to help if needed. This will be different for a prenatal diagnosis, where parents have ample time to prepare, compared to a diagnosis in childhood or adolescence. • Ask parents to explain, in their own words, what is Klinefelter syndrome. If necessary, clarify or add more information. • Psychological support may be relevant. When parents are familiar with the diagnosis and accept it, they are better equipped to support their child. • Offer additional information that may best suit the parents such as written information on the condition and websites. Meeting with other families, blogs and/or forums may also be useful. • Inform parents that disclosure should be personalised to their family and child. For example, disclosure: - Can be performed in a gradual fashion. - Can be performed by them independently, by the healthcare provider in the presence of parents, or by the HPC-parent team. • When parents decide to postpone disclosure, ask them about their motivations and address their concerns and their fears. Disclosure should be discussed regularly. • Before puberty and before discussing hormonal replacement therapy, speak to the parents about possible reactions of children when informed of these treatments. Hormone replacement therapy should not be given to a child who does not know his diagnosis. • Many children, and not only those with Klinefelter syndrome, ask questions regarding their gender, their sexual orientation and their reproductive abilities. These topics should not all be explored with a child who is not ready. Ask parents about their preoccupations regarding their child.
During disclosure	• If parents want you to disclose the diagnosis, schedule an appointment with the child and his parents. Make sure you have plenty of time to discuss the diagnosis with the child and to support him. • Stay calm and open. Ask the child to tell you about himself. Encourage the child to ask questions and to express his feelings. • Use a teach-back approach. Ask the child to explain in his own words the information that was discussed with him. If necessary, clarify or add more information. • Certain elements of disclosure can be done by following the normal development of the child: - Around 5-7 years, children know about their gender and the stability of their gender; boys with Klinefelter syndrome generally need to be told that they are boys and that they will always be. - Using analogies (e.g. genetic code as a personal secret code) and stories often help the child to understand basic biological concepts. Use of colourful pictures, sticks, strings or modelling dough might also help small children understand chromosomes and cellular divisions. - For older children: Inform the child that this condition will not change his gender, identity or sexual orientation. Explaining that the additional X chromosome is partially inactive and that he is a male, as are the other boys in his classroom often helps. Associated medical conditions (autoimmunity, diabetes, venous insufficiency) may be discussed in an individualised fashion with older children. - For an adolescent: Discuss the pros and cons of hormonal replacement therapy. Reassure him that he will still be a male even if he decides not to take hormones; follow the pace of the child. You do not need to speak about fertility and future children if the adolescent is not asking any questions and seems to still struggle with his identity and his differences. • Tell the child that his parents and himself are not responsible for this condition. There is nothing anybody could have done to prevent this. • Reassure the child that this syndrome happens randomly and that it is not contagious. • Reassure the child that this syndrome will not kill him and become worse. • Tell the child that he does not have to be ashamed of this condition. • Be honest: if the child asks a question (e.g. about infertility), answer his questions. • Be careful with the words chosen. Words such as genetics, sex chromosome aneuploidies, syndrome, abnormality and disease might be misunderstood. Use simple vocabulary and check that the child understand the words chosen.
After disclosure	• Propose another appointment if necessary. Inform the family that you are available for more questions, and that these can also be answered by phone. • Call the parents a couple of weeks after the disclosure: follow-up the child's reactions and to clarify information if necessary. • Encourage parents to discuss of the Klinefelter syndrome with teachers. Informing teachers might help them to understand the child's difficulties and the teachers may help the child to cope with the diagnosis. Offer to speak with teachers if necessary. • Psychological support may be relevant. • Offer additional information that may best suit the child and his family. For instance, books written for children with genetic conditions, websites or blogs for families and meeting other families may be helpful. This information is often helpful to help children understand their diagnosis, realise they are not alone with this condition and accept their difference.

Table 2 Recommendations for parents about disclosing Klinefelter syndrome to a child

Recommendations for parents	
Before disclosure	• Knowing more about the diagnosis, other families and children who live with this condition can help. More understanding of the syndrome and family perspectives will help you and your child. Ask your healthcare provider to recommend resources such as written information, parent associations, blogs and forums as well as websites for families. • A psychologist can help you understand the possible reactions of your child when he learns about this diagnosis. • Healthcare providers can help you talk about this condition to your child. • Speaking about Klinefelter to your child can be done in a gradual fashion. Ask yourself these questions (when relevant): - When should I tell my family? When should I tell my child? - How will this affect my children? - Should anybody know at school, and when? When and how should he tell his friends? - Do I want us to speak about this with him without the doctor? Would I rather speak about his medical condition with a healthcare provider present, or would I rather have the healthcare provider speak about it while I am in the room? • Should both parents be there?
During disclosure	• Informing your child about his condition may happen when you least expect it and seizing those occasions is important. • Certain elements of disclosure can be done by following the normal development of the child: • Between the ages of 3 and 5 years of age, children often ask questions about the human body and their gender. You can start talking about body cells, chromosomes and genetic code. Using analogies (e.g. genetic code as a secret code) and stories might help the child to understand biological concepts. Using of colourful pictures, sticks, strings or modelling dough might also help the child to understand chromosomes and how cells divide. • When your child asks questions related to his health, or to his difficulties frequently associated with the syndrome (e.g. learning disorders), give more information about how chromosomes and genetics affect development. It might be the right time to talk about his personal story and to talk about the syndrome. • When children get older (frequently between 10 and 14 years of age), they may question their gender, their sexual orientation, their reproductive abilities. Plan how to answer these questions ahead of time. • If you decide to disclose the diagnosis by yourselves, choose a calm moment. Turn off the television or radio and make sure you have plenty of time to talk. Make sure you will not be interrupted by other family members, phone or other obligations. • Stay calm and open. Encourage your child to ask questions and to express his feelings. Even if it is sometimes difficult, do not interrupt him and listen to everything he has to say. Acknowledge his emotions ('you look stressed'). Tell him you are there for him. • Disclose information regarding the syndrome gradually. Disclosing too much information suddenly may harm children. • Use a teach-back approach: Ask him to explain in his own words what you discussed with him. If necessary, clarify or add more information. • Be careful with the words you chose. Some words are scientific and confusing, such as genetics, syndrome, abnormality and disease. It is not necessary to tell him that he received this chromosome from one of you (his parents). • Your child should know these things about his condition: - It is not deadly (he will not die from it, it will not get worse). - There is nothing you (his parents) and he could have done to prevent this. - It is not contagious and his friends cannot catch it. - He is not alone with this condition, and it is not a rare condition. He should not be ashamed of his condition. • When he gets older, discuss the pros and cons of hormone therapy. Reassure him that he will still be a male even if he decides not to take hormones.
After disclosure	• If you disclosed the diagnosis to your child, schedule an appointment with a healthcare provider to talk about the diagnosis and possible treatments. • Discuss of the Klinefelter syndrome with your child's teacher. Informing teachers might help them to understand your child's difficulties. Finally, teachers may help your child to cope with the diagnosis. • More information about the condition may help such as books written for children with genetic conditions, family support groups and meeting another child with the condition. • Ask your child if he wants/plans to tell others about this condition: brothers and sisters, friends, people at school or extracurricular activities. If yes, offer help in doing so. What will he say? How will he answer some questions? How will he react to some comments? It may be appropriate for you to inform his teacher/other adults in your child's life if your child is planning to inform his friends. For adolescents, disclosing the syndrome when there is a romantic relationship may be hard. Do not push your child to disclose his condition if he is not ready. • Psychological support may be needed.

questions arise about their particularities (23). Interestingly, Turner syndrome (45 XO) has some parallels with Klinefelter: it is a disorder of the sex chromosomes and also includes problems such as learning disabilities, physical characteristics and infertility. Although there are recommendations about when to disclose the diagnosis of Turner syndrome, no

such recommendations exist for Klinefelter syndrome. Generally, children seem ready to integrate this information between 5 and 13 years of age (24). Between 5 and 13 years of age, most diagnosed children perceive that they are different. Even though they are unable to describe specifically what makes them different, they feel that they have more difficulty than others around them and, if they have physical peculiarities, that they look different as well (14). David is now 11 years old and he is asking specific questions and he feels something is being hidden from him (14,18). It might be a relief for him to understand his challenges (14). Learning the truth could help David cope with his situation, decrease his anxiety and increase his self-care abilities. Finally, telling the truth may help David adopt realistic expectations about his learning abilities (25).

Delaying the disclosure of the diagnosis may harm David and his family. For instance, if the syndrome is not disclosed, David might think that he has a 'secret disease' (14,25). This secrecy might induce worries about his situation as well as feelings of shame or guilt. If parents wait longer for disclosure, it may also impact self-perception and parent–child bonding and future relationships (18). For example, a delayed disclosure of Turner syndrome in teenagers and young women leads to traumatic psychological experiences, as well as anger and mistrust, both of parents and the medical system (22). Furthermore, there is a risk that David may learn about his condition outside the hospital or home setting. For instance, as it happened to some of our patients, David might discover that he has an extra chromosome on examination of his karyotype obtained from his buccal swab, a laboratory activity that is practiced in some high school biology courses. When children start asking specific questions, the question is not if they will learn about their diagnosis, but when and how (22).

Even if parents are frequently preoccupied about psychological impacts of disclosing the diagnosis to their child, recent studies suggest that reactions are variable. For instance, Dennis et al. (2015) showed that 41–50% of the children had a neutral reaction (little reaction, disinterest for the diagnosis), 25–33% showed a positive reaction (relief, decreased anxiety) and 25–30% had a negative reaction (anger, anxiety, confusion) to the disclosure of a sex chromosome aneuploidy (21). Parents and HCPs should be prepared for adverse reactions and work together to help the child cope with the diagnosis.

PROFESSIONAL DUTY

When healthcare professionals are faced with an ethical dilemma, they have to consider several viewpoints, including their own values, biases and duties. HCPs working with children with Klinefelter syndrome are regularly exposed to a conflict involving the possibility to hide the diagnosis. From a moral perspective, is it acceptable to lie to a child? Some HCPs may consider that lying or hiding the truth to a child is morally unacceptable. Others may believe that, under certain circumstances relevant to a specific case, it might be justified and morally acceptable to withhold the truth (27). According to virtue ethics, there is no 'single rule to deal with all situations and no general rule by which we can decide on the right course of action' (26). When the decision is made in the best interest of the patient, in some cases, both options may be morally and ethically acceptable (26). One should realise that for the purpose of this discussion (disclosure of Klinefelter syndrome to a child), truth telling is generally delayed as opposed to being completely withheld.

Medical practices should be based on scientific evidence and on clinical judgment. However, to treat patients as individuals instead of as a diagnosis ('Klinefelter patient'), it is absolutely necessary to dispel the stereotypes. Indeed, in most medical textbooks, patients with Klinefelter syndrome are described as a relatively homogenous group, often next to the picture of a patient with all the physical characteristics, despite the fact that this syndrome is a heterogeneous condition (2,4,5). Furthermore, it is frequent for adolescents to be recommended hormonal therapy or to be referred to a fertility clinic for testicular sperm extraction. However, few studies demonstrate these interventions are beneficial during adolescence. It is possible that for some patients, these interventions would be more beneficial (or less harmful) later on in life (28,29). Even if these practices are frequently considered as 'gold standards', the lack of scientific evidence should prompt physicians to act with caution and humility. Care and services offered to the children and families should be personalised. If services were adapted to the patient's needs, disclosure of this syndrome would not be considered as an emergency. This context would allow HCPs to help parents disclose the diagnosis in a gradual fashion.

STRATEGIES AIMED AT A PERSONALISED DISCLOSURE

David's parents decided not to disclose the diagnosis because they wanted to prevent potential harm and protect him from stigmatisation. However, even though the parents' intentions were good, their decision may have a negative impact on David's psychological welfare (18,20). On the other hand, disclosing the diagnosis in spite of the parents' refusal may also have negative effects, especially if parents feel ill-equipped and uncomfortable about answering David's questions (18,22).

Ideally, after a diagnosis of Klinefelter syndrome, HCPs should partner with parents to disclose the diagnosis in a personalised fashion, respecting both the parents' wishes and fears and the child's development, challenges and personality. Discussing their preoccupations with the parents prior to disclosure might help HCPs identify their needs and those of their child. Parents frequently delay the disclosure of a genetic condition to their child because they are uncertain about their capacity to explain the syndrome to their child as well as to answer questions that he might have (18,22). Tables 1 and 2 provide a detailed description of different strategies that are generally helpful to both HCPs and parents during the disclosure process. The goal should not be to quickly disclose this diagnosis in a standardised fashion, but rather to view disclosure as a process that can be personalised in a step-by-step fashion.

CONCLUSION

Although parents generally make decisions that are in the best interests of their child, conflicts between their own preferences and the interests of their child may arise. HCPs can be uncomfortable when there is a misalignment between what parents believe to be in the best interest of their child and their child's preferences. The question of when and how to disclose a diagnosis of Klinefelter syndrome to a child is complex. As shown in Tables 1 and 2, different strategies might help the HCPs and parents achieve disclosure in a gradual and personalised fashion.

ACKNOWLEDGEMENTS

We would like to thank Monique Gonthier's family for optimising this article and helping us understand the family perspective on Klinefelter syndrome.

CONFLICT OF INTERESTS

Isabelle Tremblay, Guy Van Vliet, Monique Gonthier and Annie Janvier have no conflict of interests.

References

1. Herlihy AM, Halliday JL, Cock ML, McLachlan RI. The prevalence and diagnosis rates of Klinefelter syndrome: An Australian Comparison. *Med JAust* 2011a; 194: 24–8.
2. Girardin C, Lemyre E, Alos N, Deal C, Huot C, Van Vliet G. Comparison of adolescents with Klinefelter syndrome according to the circumstances of diagnosis: Amniocentesis versus Clinical signs. *Horm Res* 2009; 72: 98–105.
3. Visootsak J, Ayari N, Howell S, Lazarus J, Tartaglia N. Timing of diagnosis of 47, XXY and 48, XXYY: A survey of parent experiences. *Am J Med Genet Part A* 2013; 161A: 268–73.
4. Dondorp W, De Wert G, Bombard Y, Bianchi DW, Bergmann C, Borry P, et al. Non-invasive prenatal testing for aneuploidy and beyond: Challenges of responsible innovation in prenatal screening. Summary and recommendations. *Eur J Hum Genet* 2015; April: 1–3.
5. Abdel-Razic MM, Abdel-HamidI A, Elsobky E, El-Dahtory E. Further evidence of the clinical, hormonal, and genetic heterogeneity of Klinefelter syndrome: A study of 216 infertile Egyptian patients. *J Androl* 2012; 33: 441–8.
6. Boada R, Janusz J, Hutaff-Lee C, Tartaglia N. The cognitive phenotype in Klinefelter syndrome: A review of the literature including genetic and hormonal factors. *Dev Disabil Res Rev* 2009; 15: 284–94.
7. Bruining H, Swaab H, Kas M, Van Engeland H. Psychiatric characteristics in a self-selected sample of boys with Klinefelter syndrome. *Pediatrics* 2009; 123: e865–70.
8. Cederlof M, Gotby AO, Larsson H, Serlachius E, Boman M, Langstrom N, et al. Klinefelter syndrome and risk of psychosis, autism and ADHD. *J Psychiatr Res* 2014; 48: 128–30.
9. Mandoki MW, Sumner GS, Hoffman RP, Riconda DL. A review of Klinefelter's syndrome in children and adolescents. *J Am Acad Child Psy* 1991; 30: 167–72.
10. Boks MPM, de Vette MHT, Sommer IE, Van Rijn S, Giltary JC, Swaab H, et al. Psychiatric morbidity and X-chromosomal origin in a Klinefelter sample. *Schizoph Res* 2007; 93: 399–402.
11. Girardin CM, Van Vliet G. Counselling of a couple faced with a prenatal diagnosis of Klinefelter syndrome. *Acta Paediatr* 2011; 100: 917–22.
12. Herlihy AS, McLachlan RI, Gillam L, Cock ML, Collins V, Halliday JL. The psychosocial impact of Klinefelter syndrome and factors influencing quality of life. *Genet Med* 2011b; 13: 632–42.
13. Van Cleave J, Davis MM. Bullying and peer victimization among children with special health care needs. *Pediatrics* 2006; 118: e1212–9.
14. Grace RJ. Klinefelter's syndrome: A late diagnosis. *Lancet* 2004; 364: 284.
15. Boyce A, Borry P. Parental authority, future autonomy, and assessing risks of predictive genetic testing in minors. *Bioethic Inq* 2009; 6: 379–85.
16. Cummings CL, Mercurio MR. Ethics for the paediatrician: Autonomy, beneficence and rights. *Pediat Rev* 2010; 31: 252–5.
17. Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. New York: Oxford University Press, 2001.
18. Faux D, Schoch K, Eubanks S, Hooper SR, Shashi V. Assessment of parental disclosure of a 22q11.2 deletion syndrome diagnosis and implications for clinicians. *J Genet Counsel* 2012; 21: 835–44.
19. Gallo A, Angst D, Knafl KA, Hadley E, Smith C. Parents sharing information with their children about genetic conditions. *J Pediatr Health Care* 2005; 19: 267–75.
20. McConkie-Rosell A, Heise EM, Spiridigliozzi GA. Genetic risk communication: Experiences of adolescent girls and young women from families with fragile X syndrome. *J Genet Counsel* 2009; 18: 313–25.
21. Dennis A, Howell S, Cordeiro L, Tartaglia N. How should I tell my child? Disclosing the diagnosis of sex chromosome aneuploidies. *J Genet Couns* 2015; 24: 88–103.
22. Sutton EJ, Young J, McInerney-Leo A, Bondy CA, Gollust SE, Bisecker BB. Truth-telling and Turner syndrome: The importance of diagnostic disclosure. *J Pediatr* 2006; 148: 102–7.
23. Frias JL, Davenport ML. Committee on Genetics and Section on Endocrinology. Health supervision for children with Turner syndrome. *Pediatrics* 2003; 111: 692–702.
24. Bondy CA. The Turner syndrome consensus study group. Care of girls and women with Turner syndrome: A guideline of the Turner syndrome study group. *J Clin Endocr Metab* 2007; 92: 10–25.
25. McConkie-Rosell A, Spiridigliozzi GA, Sullivan JA, Dawson DV, Lachiewicz AM. Carrier testing in fragile X syndrome: When to tell and test. *Am J Med Genet* 2002; 110: 36–44.
26. Gupta VB, Willert J, Pian M, Stein MT. When disclosing a serious diagnosis to a minor conflicts with family values. *J Dev BehavPediatr* 2008; 29: 231–3.
27. Begley AM. Truth-telling, honesty and compassion: A virtue-based exploration of a dilemma in practice. *Int J Nurs Pract* 2008; 14: 336–41.
28. Majzoub A, Arafa M, Al Said S, Agarwal A, Seif A, Al Naimi A, et al. Outcome of testicular sperm extraction in nonmosaic Klinefelter syndrome patients: what is the best approach? *Andrologia* 2015; 47: 1–6.
29. Gies I, Unuane D, Velkeniers B, De Schepper J. Transition in endocrinology: Management of klinefelter syndrome during transition. *Eur J Endocrinol* 2014; 171: R67–77.