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The psychological and social impact of Klinefelter's Syndrome: Report for the Klinefelter's Syndrome Association

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Executive Summary

Aims:

In collaboration with the Klinefelter's Syndrome Association (KSA) we agreed to plan and deliver an impact study. This comprised two elements: an interview with KSA members and a questionnaire aimed at helping us to address the following areas:

- Participant's experiences of having KS, and where they feel they have been most in need of information and support.
- The impact of KS as a condition affecting the whole of life, including quality of life issues such as the impact of KS on an individual's ability to work, their finances, relationships, etc.
- Identifying the most appropriate services and approaches needed in delivering support to individuals with KS and their carers in response to their identified needs.
- To disseminate the results of the research, on behalf of people with KS, with a view to influencing policy and/or improving service provision.

How we did it:

We carried out two research studies. The study materials were designed working in collaboration with the KSA Committee (ie study 1: interview schedule; study 2: questionnaire selection and elements to cover in the demographic and physical profiling sections).

Study 1 was a qualitative project exploring the participants' subjective experiences. Thirteen participants took part in one-to-one interviews, and six took part in a focus group. Data from the questionnaire study were also included. These comprised the 41 answers to the open ended questions from the questionnaire and 36 critical incidents (where study participants wrote about a time when KS had been a significant problem for them).

Study 2 was a questionnaire project designed to objectively measure the psychological distress and quality of life of the participants. As well as demographic information on study participants, we also undertook physical profiling and collected medical information relating to the symptoms of KS they were experiencing and any other medical conditions they might have. Four standardises questionnaires were employed: the Hospital Anxiety & Depression Scale, the Derriford Appearance Scale (measuring levels of social anxiety and social avoidance, the short form of the World Health Organisation Quality of Life measure

(WHOQoL-Bref) and the Rosenberg Self Esteem Scale. We also included an amended version of the Honey & Mumford Learning Styles questionnaire. In order to explore the impact of KS and its treatment on psychological adjustment and daily functioning more broadly, five Visual Analogue Scales were included. Three hundred people from the Members list at the KS Association were contacted by letter and sixty-two people responded, giving a response rate of 21%.

What we found:

Study 1: The experiences of the men with KS that we interviewed were unique, however there were some similarities in their accounts, for example, their experiences in relation to low levels of testosterone. Differences appear to relate to when they received a diagnosis; the greater the delay (40+ years of age) the greater the risk of long term health problems and disability; the earlier a diagnosis the sooner the access to testosterone and the greater the understanding of KS. Equally their personalities, the understanding and reactions of significant others (for example, parent's and siblings), and life events appeared to influence the impact KS had on each of their lives. Seven minor themes emerged from the data, which were common to all stories. These were: 1. *Diagnosis*; 2 *Testosterone/The Treatment*; 3. *Health care/health problems*; 4. *Appearance*; 5. *Self identity*; 6. *Relationships*; and 7. *School and Education*. Three major themes were identified: 1. *Diagnosis and Management of KS; 2. The Self*; and 3. '*Me, KS and others'* with all three relating significantly to the effects that low testosterone has had. During the analysis a core theme emerged of "***Emotional Impact"*** which was central to each of the three major themes. The emotional impact of KS, for some men, has been significant and as such has defined them as a person and influenced the life choices they have made.

Study 2: 60% of study participants were reporting clinical levels of anxiety and 34% had clinical levels of depression (as measured by the Hospital Anxiety and Depression Scale). Depression was significantly worse if men reported it as a symptom of KS. Individuals with low level self-esteem had increased levels of general anxiety and depression as well as raised levels of social anxiety and social avoidance and reduced quality of life. The results also suggested that levels of worry about KS and the individual's perceived severity of their condition may have a part to play in the wider impact of the condition. However, it should be remembered that KS is a syndrome and that for those individuals who have very few, or no symptoms, then the reverse pattern would be true. So, high levels of self-esteem were associated with low levels of general anxiety and depression, low levels of

social anxiety and depression and increased quality of life. The key may be the extent to which an individual perceives themselves to be affected by the condition.

This may change as men with KS age since the data suggests that older men reported more symptoms associated with having KS. It was interesting to note the difference between the symptoms the study participants recognised as being part of their KS and the list of symptoms that the medical community recognise. For instance, mood swings, headaches and fatigue are not usually mentioned in the medical research literature. Data suggests that the symptoms associated with KS can have a significant negative impact on levels of psycho-social functioning, particularly in relation to quality of life. These data suggest that the impact that KS can have on men's genitalia in terms of size inhibition may have a significant psychosocial impact, in particular in relation to penis size.

Results from the learning styles questionnaire indicated that half of the study participants preferred to have time to reflect on new information (ie they had a preferred reflective learning style) and 63% preferred information presented to them in a written format.

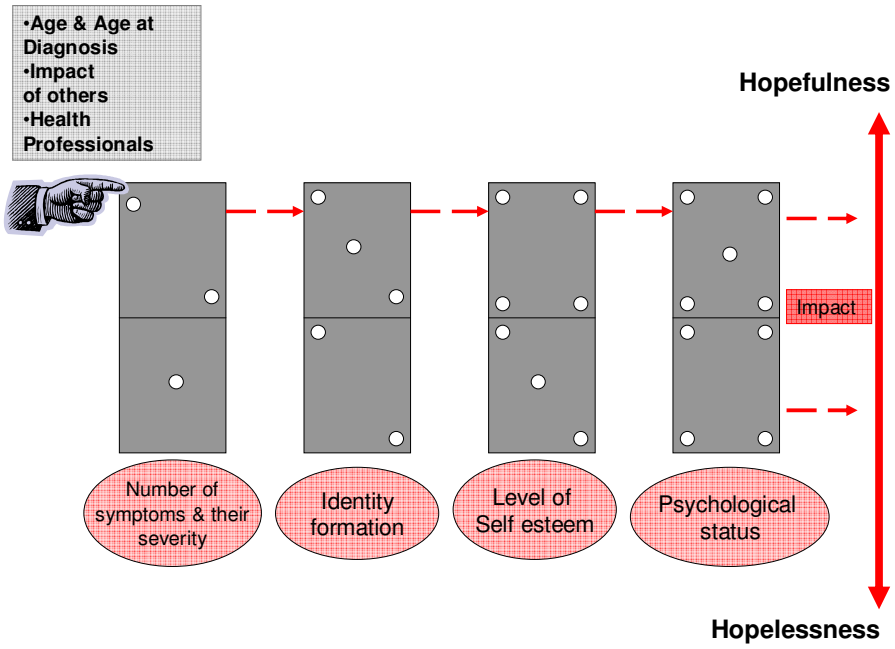
Conclusion and Implications:

Findings highlighted a number of concerns and identified the unmet psychosocial needs of men with KS.

- Diagnosis can take a long time and the prolonged lack of testosterone can have far-reaching negative effects for the individuals concerned.
- There were a significant number of people with KS who might do better in the healthcare system if information was presented to them in a written format, with time allowed for them to consider it before talking it over with a healthcare professional. It would certainly suggest that the current NHS climate of short appointments and limited written information may be disadvantaging some of the individuals who took part in this study.
- The psychological impact of the condition seems to hinge around the number of symptoms and the degree to which an individual perceives that they are affected.
- There are more symptoms associated with KS than the medical community necessarily recognise and these can have a profound impact on the psycho-social functioning of the affected individuals.
- Identity formation seems to be difficult for some of the men with KS and support in coming to terms with this seems to be largely absent.

- Low self-esteem was associated with increased levels of general anxiety and depression, raised levels of social anxiety and social avoidance and reduced quality of life. The reverse was also observed, where high self-esteem was associated with reduced levels of general anxiety and depression, low levels of social anxiety and social avoidance and high ratings of quality of life.
- Depression and anxiety in men with KS needs treating appropriately. Depression was significantly worse if the men reported it as being a symptom of KS. Attribution of poor psychological functioning matters, possibly because if it is a symptom of a permanent condition then there is no hope of avoiding its impact.
- KS is clearly a syndrome since experiences were unique and significant for each of the men who took part in the research. The emotional impact of the condition lay along a continuum from hopefulness to hopelessness where an individual's age, degree of family support, the attitudes and understanding of others, level of self-esteem, time of diagnosis and implementation of testosterone replacement influenced the men's location along the continuum.
- The impact of KS can be described in terms of a "domino effect" (see Figure 1 below) where "symptoms", "identity", "self-esteem" and "psychological status" are the dominos. These dominos may start to topple as a result of age, reactions from other people or as a result of experiences with healthcare professionals. As an illustration, if your first sexual experience is not good, then this might start to topple the dominos. You might suddenly realise that your penis size is a problem, which then might start you questioning your future identity as someone's partner, this can make you wonder if you have any value to others which can lead to a severe reduction in self-esteem. Low self-esteem is strongly associated with poor psychological status which can lead to a general feeling of hopelessness and thoughts such as, "Why should I bother?"

Figure 1: The domino effect



Recommendations:

- Men with KS would benefit from emotional support and one to one counselling at specific stages throughout their journey, beginning at diagnosis continuing through treatment and on to the continued and constant daily management of the condition.
- Depression and anxiety in men with KS requires treatment. It should be noted that depression is significantly worse if men see it as a symptom of KS.
- A review of group support is recommended to address the specific emotional needs across the lifespan, for example, fertility and sexual relationship issues for young adults.
- Increase awareness and understanding of the condition and its psychosocial impact both within the general population and across the medical community, in particular all non-endocrine specialist staff. Social workers and staff involved with employment and education services at all levels should also be targeted as part of any awareness-raising activities.
- KSA to generate a one page information sheet that men with KS can give to healthcare professionals.
- The provision of information to men with KS requires careful consideration. The majority of men in this study would probably do better with information presented in a written format with time to consider it before talking it over with a healthcare professional.

- Training for healthcare professionals to enable them to better understand and communicate with patients on certain sensitive issues that may need to be discussed such as size of genitalia and breasts, infertility and the impact of these.
- To lobby for GP training to include genetic problems and how to recognise these.
- To get the NHS website updated to show how the impact of KS is very different for each person.