

The Men's Room at the World Scleroderma Congress (discussion in English and Portuguese)

In scleroderma the majority of patients are women, so that it looks as if there is less attention to men in daily functioning. Generally there is an agreement that men and women are different and this can generate the question 'Does anxiety/depression manifest itself in men as often as in women with scleroderma?'

When it comes to the occurrence of these feelings, there is generally no difference between men and women. However, there may be a difference in the way they express them and cope with them. Influenced by education and other social and cultural factors, it seems that women are still more at ease, than men, to express emotions that indicate "vulnerability". Although differences in this respect may have become smaller in the past decades, they still persist. Scientific literature does not give a clear answer to this question.

Only a couple of studies focusing on depression/anxiety in people with scleroderma exist. In one of them, women reported more depression but in another there were no sex differences for depression, only anxiety was reported as more present in women.

A men-only group encourages male patients to speak about different scleroderma-related issues happening in their lives. It can be easier to talk about daily life matters in a group that experience the same difficulties, frustrations and worries. Being in a group of same-sex participants can give a safer feeling of understanding and support, as well as enhancing participation and openness. This approach was used in Rome at the Systemic Sclerosis World Congress, where a small group of men joined to share their stories, daily difficulties, and the solutions they sometimes found to work for them. Topics we discussed were very diverse and it helped us see things differently.

A men-only session will be planned for the next 4th Systemic Sclerosis World Congress in Lisbon and I hope to see a large group of participants willing to share their experience so we (men) can all learn from these experiences and allow all participants to benefit from them. Finally, from my experience and from the feedback I got from other participants, sharing in a men's session helped us feel supported, understood and not alone.

We will be waiting for you.

Joep Welling
Member of FESCA aisbl board