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Clinical science

'I turned in my man card': a qualitative study of the experiences, coping styles and support needs of men with systemic sclerosis

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Abstract

Objectives: Men with SSc have a more severe clinical phenotype and reduced survival compared with women. No previous psychosocial studies have focused solely on men with SSc. This study aimed to explore experiences, coping strategies and support preferences of men with SSc.

Material and methods: An international qualitative research study comprising seven focus groups (three USA, four UK) of 25 men with SSc. Transcripts were analysed using reflexive thematic analysis.

Results: Three overarching themes and one underpinning theme were identified. In 'impact of SSc on masculinity', the men described an 'impact on roles and activities', reported 'sex, intimacy, and erectile dysfunction' as a salient issue that may be overlooked by clinicians, and experienced challenges to 'masculine self-image'. 'Dealing with SSc' meant 'always being prepared', 'becoming an expert' and 'balancing priorities' in responsibilities, activities and symptom management. In 'support for living with SSc' men were selective in '(Not) talking about SSc', would '(reluctantly) accept help' and described 'preferences for support'. Underpinning these experiences was 'facing an uncertain future' with some participants preferring not to focus on an unpredictable future, and others worrying about disease progression.

Conclusion: These novel data suggest SSc impacts male patients' masculine identity and roles, and although they will accept practical help, they may mask the full emotional impact. Sex and intimacy are important overlooked issues with erectile dysfunction often not discussed at diagnosis. Further research should develop a self-management intervention for men with rheumatic diseases with a combination of disease-specific and common core components.

Keywords: SSc, scleroderma, men, gender, masculinity, quality of life, erectile dysfunction, mortality, qualitative

Rheumatology key messages

- SSc impacts masculine identity and roles, with breadwinner and father/grandfather roles being notably affected.
- Men may downplay or mask the emotional impact of SSc with those closest to them.
- Sex and intimacy issues are important to male patients and should be raised by clinicians.

Introduction

SSc is a complex autoimmune CTD, characterized by inflammation, fibrosis and vasculopathic alterations [1, 2] of multi-organ systems along with associated emotional, social,

financial and societal burden [3]. Although less prevalent in men than women (reported between 3:1 and 11:1 [4, 5]), severe disease predominates in men with SSc, including higher reported internal organ involvement, and mortality [6].

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Men with RA have been shown to employ different coping strategies from women and prefer practical over emotional support [7, 8], reflecting findings in other long-term conditions [9, 10]. The World Health Organisation suggests that men need their own health strategy [11]. However, the few studies addressing psychosocial aspects of SSc and gender are quantitative and contain insufficient male participants to enable definitive conclusions on gender differences [6].

Supporting men to manage SSc in ways that enable preservation of masculine self-identity may be important for coping with SSc [12]. This study aims to explore the experiences of men with SSc and how SSc impacts their lives; how men currently cope with and manage SSc; and their preferences for support.

Patients and methods

Participants

Male patients with clinician-diagnosed SSc [13] aged over 18 years from one of four centres (Royal United Hospitals, Bath NHS Foundation Trust, UK; Royal Free London NHS Foundation Trust, UK; Michigan Medicine Health Center, Ann Arbor, USA; and Tulane University, New Orleans, USA) were invited to participate in in-person focus groups by a local research nurse or rheumatologist. Due to the rarity of SSc in men opportunity sampling from patient databases was used. Data collection continued until additional focus groups no longer generated new themes [14].

Process

Focus groups were conducted to elicit a broad range of perspectives and promote discussion between participants [15]. A topic guide (Table 1) was developed based on themes identified in a review of the extant literature and discussions with the study team, including a male patient research partner (A.W.). These followed an iterative process [16], with new concepts raised by participants explored in subsequent focus groups. A pre-study questionnaire captured demographic data and clinical features [13] (Table 2). Focus groups were conducted by the first author (C.A.F.), held in a non-clinical room within the hospital, lasted approximately 2 h, and were digitally recorded and transcribed verbatim. Ethics approval was granted by the South West—Frenchay Research Ethics Committee (ref. 19/SW/0074) and written informed consent was obtained prior to each group.

Analysis

Data were analysed using reflexive thematic analysis following Braun & Clarke's six steps [17].

- 1) Data familiarization: The first author (C.A.F.) formed preliminary ideas regarding areas of potential analytic interest by immersing herself in the data through repeated reading of the transcripts and checking against digital recordings.
- 2) Coding: Micro-level code labels were applied to all data and managed using NVivo 12 [18]. Coding was primarily semantic (explicit meaning) with some latent coding (implicit meaning), for example the concept of bravado described in Subtheme 1a. Analysis was inductive (data-driven), acknowledging existing researcher knowledge means some deductive (theory-driven) analysis is

Table 1. Focus group topic guide

What is it like to be a man with SSc?
What is a good day with SSc?
What is a bad day with SSc?
What do you do to manage your symptoms?
Do you ask other people to do things for you?
Have you made any changes to your life?
Do you miss doing anything since being diagnosed with SSc?
Have you given up any activities due to being diagnosed with SSc?
Have you ever been angry or frustrated because of your condition?
What do you do to manage your anger/emotions?
Do you talk to anyone about SSc?
Who?/Who do you see as your main support?
Have your expectations/ambitions in life changed?
What do you think of the care you receive from rheumatology?
Would you like to change anything about the care or support you receive?
What do you think is important to include in a self-management or information programme?
Who do you think should deliver this type of group? E.g. male/female? Clinician/patient?
Where do you think the group should be delivered? (at the hospital/elsewhere?)
Do you think women deal with SSc differently to men? (if so how?)
Do you see a difference between men and women in the waiting room?
Can you think of anything positive about being a man with SSc? (what?)
General follow-up questions:
What do you think about that? (<i>use think, not feel</i>)
Do you think that's different for women?

unavoidable. One coder is good practice in reflexive thematic analysis for consistency in 'meaning making' across the data.

- 3) Generating initial themes: Codes were clustered together into broader patterns of meaning, then all data related to each theme were collated across the full data set.
- 4) Developing and reviewing themes: The full study team reviewed the themes to ensure they appropriately described the dataset and provided a coherent narrative.
- 5) Refining, defining and naming: Preliminary themes were presented at conferences and discussed with patients and researchers outside the study team to ensure clearly demarcated themes with a strong core concept.
- 6) Writing up: Enabled finessing of themes to ensure an analytic narrative faithful to the data.

Results

Twenty-five men with SSc participated with a mean age of 58 years (range 37–78), mean disease duration of 8 years (range 1–29) and HAQ score 0.99 (s.d. 0.86). Participants largely had diffuse SSc (74%), and were White (76%), married (76%) and retired (40%), with education level ranging from elementary to post-graduate (Table 2).

Seven focus groups (three USA, four UK) were conducted with three to six participants in each to allow the men to feel comfortable discussing thoughts and feelings openly [19]. Three distinct but interconnected themes were identified reflecting the way men experience and manage SSc and the support they require: Impact of SSc on masculinity (Theme 1), Dealing with SSc (Theme 2) and Support for living with SSc (Theme 3), each containing three subthemes, all underpinned by the theme of 'Facing an uncertain future' (Fig. 1).

Table 2. Participant characteristics^a

	Overall	UK	USA
Participants, <i>n</i>	25	12	13
Focus groups, <i>n</i>	7	4	3
Age in years, mean (min–max)	58 (37–78)	59 (37–78)	58 (43–72)
Clinical diagnosis, dcSSc, lcSSc (<i>n</i>)	14, 5 ^b	2, 4 ^b	12, 1
Disease duration in years, mean (min–max)	8 (1–29) ^b	10 (1–29) ^b	7 (1–23)
HAQ score, mean (s.d.)	0.99 (0.86) ^b	0.94 (0.89) ^b	1.02 (0.87)
Ethnicity: White, Black or African American, Hispanic, Asian (<i>n</i>)	19, 3, 2, 1	10, 1, 0, 1	9, 2, 2, 0
Educational attainment: Elementary, Secondary, College, Undergrad, Postgrad (<i>n</i>)	3, 1, 6, 3, 3 ^b	0, 0, 3, 0, 3 ^b	3, 1, 3, 3, 3
Employment status: Full time, Part time, Retired, Unemployed due to SSc (<i>n</i>)	8, 2, 10, 5	3, 0, 7, 2	5, 2, 3, 3
Marital status: Married, Single, Widowed, Living with partner (<i>n</i>)	19, 1, 2, 3	9, 0, 1, 2	10, 1, 1, 1

^a Participant data missing from one UK site due to lost paperwork during COVID-19 lockdown, data retrieved from transcripts where possible if mentioned in focus group (age, ethnicity, employment, marital status), missing data marked with ^b.

^b Data missing from *n* = 6 UK participants.

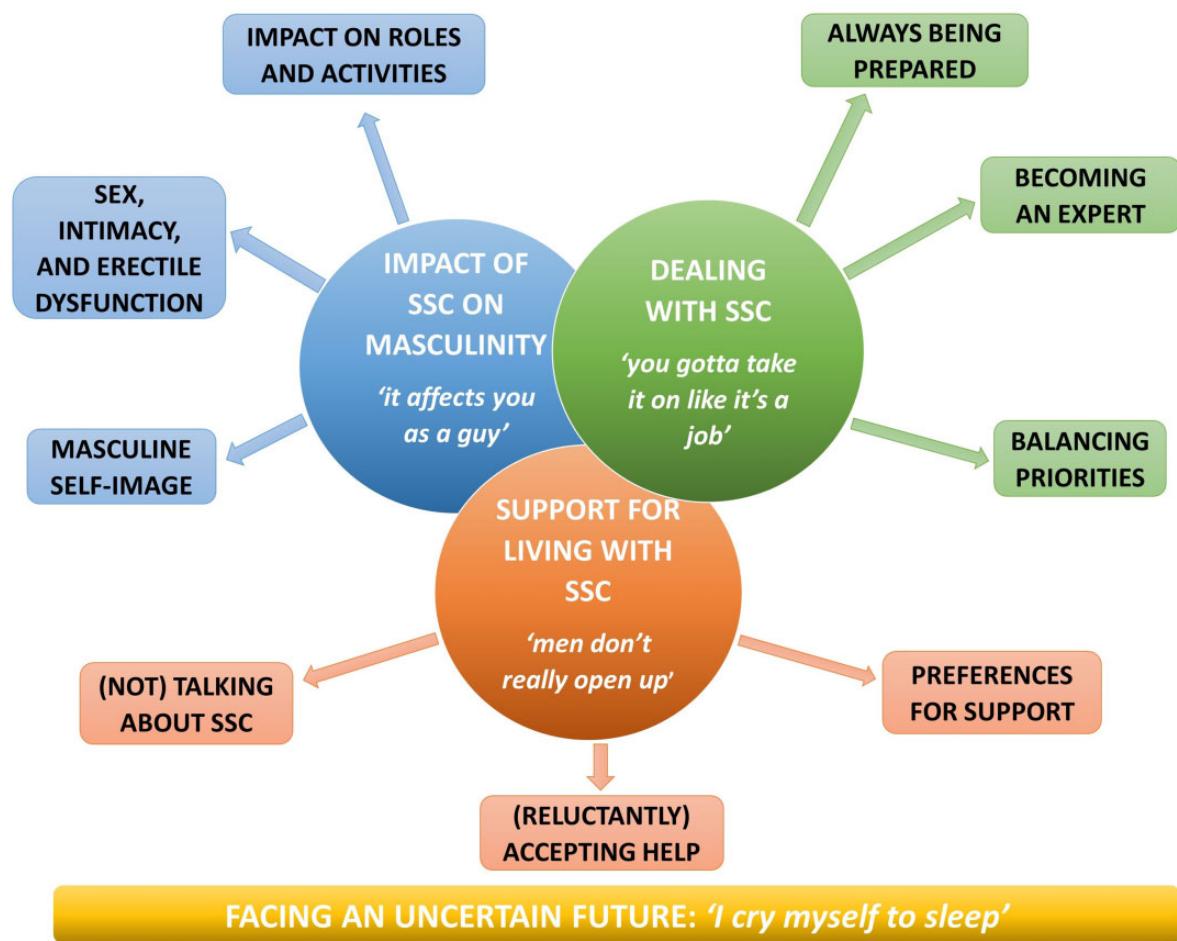


Figure 1. Thematic diagram of men's experiences of living with and managing SSc

Theme 1: Impact of SSc on masculinity: 'it affects you as a guy'

Participants described various challenges of living with SSc, which impacted their masculine identity.

Subtheme 1a: Impact on roles and activities

Loss of movement and the ability to take part in previously valued activities was voiced as an important issue, with both an emotional and physical impact. Participants reported this

impacting on all aspects of their life including tasks of daily living and hobbies, with some describing losing trust in their body to carry out tasks they were previously capable of. While some employed accommodations or accepted a slower pace, others either avoided certain activities completely, or pushed through, not wanting to seem 'weak':

USA2B: *It's frustrating and, most men they don't want to show, you know, you can't do anything.*

USA2C: *Weakness.*

USA2B: *Weakness, good word, so you battle through it.*

Many participants expressed the impact on their role in the family, and highlighted the value they placed on engaging in physical play with children:

UK3A: *I used to put both my kids on my shoulders, go to the park for about three or four hours sometimes. I can't even lift them and they want to play with me, they want to do things and I have to force myself to do these things with them, and as soon as like they're done I literally can't even feel my body I'm so numb.*

The impact of SSc on work was repeatedly raised, and these men found it particularly difficult to accept losing the role of 'breadwinner', which affected not only their financial situation, but also self-image, and sense of purpose:

USA3A: *I feel my self-worth, what do I do, I don't do anything anymore, besides live. I don't have a job anymore. [...] I'm not trying to feel sorry for myself it's just I ask myself, what am I here for?*

Participants who were able to continue working had made adjustments to enable this. This involved re-framing masculinity to centre taking responsibility for their health, and bravao was often protective in acknowledging limitations:

USA2B: *I want to stick around [laughs], so you drill that hole, you climb that ladder, I don't care what you think of me, whatever.*

Subtheme 1b: Sex, intimacy and erectile dysfunction

Nearly all participants raised impact on sex and/or intimacy as important to understanding their experience. Issues included erectile dysfunction (ED), loss of libido, and symptoms of SSc such as shortness of breath or skin involvement:

UK1B: *If there's one thing I could fix I'd say while I'm still only 60, I've got a few years left I'd like to fix that [ED].*

This loss of ability to 'perform' had a psychological impact on many participants, impacting their sense of masculinity:

USA3A: *When you can't perform, you can't perform and it, it takes a toll on you.*

USA3B: *I felt I had a serious problem.*

USA3C: *It is a serious problem.*

USA3B: *And it affects you, as a guy.*

Some participants had tried everything they could think of including introducing sex toys. They discussed concerns about the impact on their partners and expressed feelings of inadequacy, sometimes using humour to address this.

UK1A: *They might think well I'm going somewhere else, you know, the milkman [laughs].*

Despite ED and sexual function being raised as a key issue, the majority of participants explained this had not been

discussed with them at diagnosis and had to discover themselves that this is a symptom of SSc:

USA3A: *I figured well, I mean, it's all about blood flow so I kind of put two and two together, you know. I had to figure it out through my own self-study.*

Most participants had no preference regarding whether they discussed this with a male or female clinician, although participants noted they might use more clinical language with female clinicians, while being more direct with male clinicians:

UK3B: *I'll go into amateur doctor mode. Ejaculation or erection [...] With a male doctor, it will be, well I can't get a hard-on Doc.*

Participants explained they would prefer their clinical team to bring this up, as it can be embarrassing:

USA3A: *I think it's important that they ask the question first, 'cause it's a little embarrassing.*

USA3C: *It is kind of embarrassing, it's an embarrassing thing for a man.*

Subtheme 1c: Masculine self-image

Participants were generally unconcerned by visible facial differences caused by SSc, although noted this may have been an issue if younger. Some participants explained that visible differences provided legitimacy. However, nearly all participants raised loss of weight and muscle mass as impacting on self-image:

UK4A: *I've lost everything I've not got no definition. When I look at myself it's scary, even like the girls at work see me and go, you're not the same anymore.*

Some men raised concerns about other people's perceptions of them for being no longer able to do certain activities, impacting masculine ideals of competence:

USA1C: *It looks like I never learned to throw a ball and, I mean, whatever it's like, I don't, in a way I want to say I don't care what people think but there's part of me that definitely cares what people think.*

Masculine values of stoicism and self-reliance were also challenged by SSc, with participants emphasizing they did not previously seek medical help readily, and being seen as an 'invalid' conflicting with self-identity:

UK3A: *I am so proud in myself I don't want my wife or my family to look at me as an invalid.*

Theme 2: Dealing with SSc: 'you gotta take it on like it's a job'

Participants reported never being free of SSc symptoms and finding ways of dealing with this both daily and long term.

Subtheme 2a: Being prepared

Men often framed their strategies for dealing with SSc as constantly being prepared. They described using tools (e.g. pliers)

to help with tasks, and shared practical tips for managing SSc with each other in the focus groups. Participants reported keeping on top of their symptoms (e.g. constant moisturising), planning ahead to minimize symptom impact and using pacing techniques to spread their energy throughout the day:

UK3A: *It's like a power bar, I've got all this energy to last me throughout the whole day and you've got use it wisely.*

To manage the emotional impact of SSc, some participants would avoid things that brought unwelcome reminders:

USA1C: *I got a bunch of [button-down shirts] for work, but I just don't wear them because it's just easier not to have to encounter something where I think about it.*

Subtheme 2b: Becoming an expert

Participants reported needing to take responsibility and advocate for themselves due to the varying nature of symptoms experienced between patients:

USA2B: *You've definitely got to be proactive, everybody's different, you've got take your own case and you gotta take it on like it's a job.*

Participants expressed frustration at the rare nature of SSc causing gaps in their medical team's knowledge through both gaps in research and lack of awareness in primary care. They actively sought information about their condition and used various sources ranging from medical journals to Facebook groups. There were mixed views on whether social media was helpful, with some highlighting issues with unevidenced opinions, and others valuing access to a community with shared experiences. However, not all participants had equal ability to access or understand information:

USA3C: *I'm illiterate, most of y'all probably can read. I don't do with computers.*

Subtheme 2c: Balancing priorities

Dealing with SSc over time meant balancing different priorities to manage physical impact, while retaining identity. For many participants this meant balancing time with family against managing SSc. While some were able to set boundaries to look after their health, those with young children often prioritized their father role:

UK3A: *I still force myself to get up, to take the kids to school.*

Those who were able to continue working often had to balance responsibilities with symptom management:

UK1C: *I had to stop, I said to my client 'I'm sorry I've got to go back' and apparently I looked like a corpse so he said 'yeah come back next week' [laughs]. I did the sensible thing, I went home.*

Some men reported prioritizing things they wanted to do over symptom management, which tended to be a conscious decision having weighed up consequences:

UK1B: *When you go skiing, it was worth it, even though sometimes you're coming off the slopes and you're almost crying with the pain if you've got really cold, you still want to do it.*

Participants also balanced which symptoms they prioritized as treatment for some symptoms (e.g. hydrotherapy) could impact on others (dry skin). For some participants this included balancing short-term gains such as pain relief or improved appetite from smoking cannabis against longer term consequences of potential lung involvement associated with SSc.

Theme 3: Support for living with SSc: 'men don't really open up'

Participants discussed current engagement with support and preferences for receiving support.

Subtheme 3a: (not) talking about SSc

Most participants reported not talking about SSc beyond their medical team and immediate family due to protecting their privacy; the perception other people would not be interested; and not perceiving talking as masculine:

UK4A: *I can't talk to colleagues at work 'cause men don't really open up.*

Although participants reported talking to family, this tended to be restricted to physical impact of SSc, with most not opening up about emotional impact. Commonplace was a sense of responsibility to protect spouses and partners from the full impact, explaining they would play down or mask symptoms to prevent worry:

USA3B: *There are times where I feel sick and I want to tell people I'm sick but, I don't share it with my wife or my mom. I mean I'm the breadwinner, so I've got to try and stay positive and focussed as long as I can.*

Participants discussed sensitive topics in the focus groups and valued the opportunity to speak to other men with the same condition:

USA3B: *Just to sit down with a bunch of other men that's awesome, this is awesome to me.*

Subtheme 3b: (reluctantly) accepting help

Some participants were reluctant to accept help and reported trying to mask difficulties. For many, the severity and progression of SSc meant they had no choice but to accept help from others, which impacted feelings of masculinity, independence, and self-worth:

USA3E: *Do you know how it feels to have your wife to put your socks your shoes, help you put your underwears on, got to help you to get in the bathtub, that hurts, that really do hurt.*

Self-deprecating humour was often used to downplay this impact:

USA2A: *I just say here, I turned in my man card, open this for me.*

Participants who were able to do things for themselves found it important to be self-sufficient for as long as possible. Some found adaptations and others stopped certain activities to avoid relying on help from others. Many received help from partners with dexterity tasks (e.g. fastening buttons), and some appreciated partners intervening to encourage pacing for symptom management. When they did accept support, they valued this being given subtly with no fuss:

UK1C: *He's [husband] very supportive, generally when I'm feeling shitty and fatigued he will leave me alone. He'll say is there anything that you need that I can get for you.*

Subtheme 3c: Preferences for support

Support preferences varied among participants, but the majority raised the importance of education and information sharing. Suggestions included updates on current research; question and answer session with a member of the clinical team; practical advice such as navigating difficulties related to sex; and opportunities to share tips between patients with a mixed experiences from those who had tried a peer support buddy scheme. Most participants preferred an intervention to have a practical rather than emotion focus:

UK1C: *Rather than a group, people that just come together and have a bit of a moan about their symptoms, if you're getting something structured out of it.*

Participants discussed the importance of involving partners. They recognized their partners need support, and wanted partners to better understand them:

UK3B: *Somewhere along the line there should be a partner's day where we can carefully educate them about scleroderma.*

There was no clear preference for in-person or online interventions, with geographical distance being a key barrier to in-person groups even if preferred. Many participants preferred a flexible approach without a regular commitment. Participants had varied preferences on male only or mixed gender groups, but many explained group gender would change the conversation:

USA3A: *If we would have had half women in here and half men, I think the discussion of erectile dysfunction would not have been as lengthy.*

Underpinning theme: Facing an uncertain future: 'I cry myself to sleep'

Underpinning these experiences was the uncertain nature of SSc progression and associated worry. Concerns about internal organ involvement and mortality was raised by many participants:

USA1D: *I worry a lot about what's happening on the inside [...] how much is this going to shorten your life and what's it going to do to the quality of your life.*

Participants talked about potential future losses in an uncertain future, particularly experiences they would miss with

children and grandchildren, and felt responsible for ensuring their families could cope without them:

USA1C: *I've involved her [wife] a lot more in things like that [tax-returns], financial things like that, because I just don't really know what the future's like.*

Some participants preferred not to think about a future they felt no control over, while others openly discussed the emotional impact:

UK2C: *Well if it happens, it's going to happen isn't it, there's nothing you can do about it is there.*

UK3C: *I used to cry every night, every night I used to cry. I used to go sit and cry [...] I still get that, every so often, maybe once a week, once a month, once every three months, and then I cry myself to sleep.*

Many participants used dark humour to address mortality both with their friends and in the focus groups:

UK1A: *He [friend] says 'look, if you don't make it can I have your new drill?' [laughs] [...] that's just the way blokes deal with it.*

UK4C: *I've stopped buying green bananas [laughs].*

Discussion

Men's accounts highlighted a profound impact of SSc on masculinity in relation to roles and activities; sex, intimacy, and ED; and masculine self-image. They report dealing with SSc through 'being prepared', 'becoming an expert' and 'balancing priorities'. Participants were selective with whom and the degree to which they expressed themselves regarding SSc, and help was generally accepted reluctantly. Support preferences included information or education components rather than stand-alone peer support. Participants' experiences were underpinned by a focus on mortality with concerns about facing an uncertain future.

Impact on masculinity through loss or reduction of activities and altered family roles has been identified by the first author's previous research in men with RA [7]. However, while men with RA reported concealing their condition in public or pushing through pain, not all men in the current study were able to do this due to symptom severity. When participants were unable to work or had no choice but to accept help, this impacted their sense of masculinity, independence, and self-worth.

The majority of men raised impact on sex as a key issue affecting masculinity and raised concerns about the impact on their partners. However, sex and erectile dysfunction are not currently addressed in professional guidelines for managing SSc. These findings support research in men with inflammatory arthritis, suggesting an emotional, mental, and social impact beyond the physical act of sex [20]. Some scleroderma charity websites provide basic information about sex and advise patients to speak to their general practitioner [21]. However, our findings suggest men would prefer clinicians to address this.

These male patients tended to express being more likely to open up to partners and clinicians than friends, supporting the proposal men have poorer social capital than women [22, 23]. Yet, many reported masking the full impact of their

condition to protect partners from worrying, reflecting culturally (American and British) dominant masculine ideals of stoicism and emotional self-sufficiency [24–26]. It may therefore be important to provide a space where men with SSc feel able to discuss their condition openly.

The majority of participants reported a positive experience of taking part in the focus groups but valued an education and information component alongside peer support, aligning with a previous comprehensive literature review reporting that men with long-term conditions prefer support interventions to have a purpose, be structured and provide opportunities to gather new information with emotional support occurring as a by-product [9, 10]. The importance of including partners in a support package was also raised in the current study, which has been successfully modelled in prostate cancer with the 'man-to-man and side-by-side' intervention [27].

It is important for clinicians to be aware that men with SSc may play down the emotional impact or mask this with dark humour. Asking indirect questions such as about work or family can be more effective than directly asking about feelings [28]. Men would prefer ED to be discussed at diagnosis as a potential symptom of SSc, and for clinicians to raise issues relating to sex and/or intimacy to avoid embarrassment. Some men engage in risk-taking behaviours such as cannabis use, therefore encouraging open conversation may be important to discuss ways to minimize risk.

This study may have limitations in missing the voices of men who were unable to take part in scheduled focus groups, or the 'strong, silent' men who may be reluctant to participate in qualitative research [29]. However, some focus groups were conducted in evenings and lunchtimes for inclusivity. Focus groups can be criticized for producing consensus opinion or favouring the most dominant members of the group [30]. However, they were chosen for potential for group discussion to elicit ideas that may not arise from one-to-one interviews [31]. Participants had a range of demographic and clinical characteristics from UK and USA hospitals, reflecting a range of disease experiences, support networks, and care pathways, and is the first qualitative study to focus solely on men with SSc.

These novel data on men with SSc suggest that the condition impacts male patients' masculine identity and roles, and although they will accept practical help they may mask the full emotional impact. Sex and intimacy is an important overlooked issue, with ED often not discussed at diagnosis. Further research should explore facilitators and barriers to discussing sex and intimacy for both patients and professionals, and develop a self-management intervention for men with rheumatic diseases with a combination of disease-specific and core components.

Data availability statement

The data underlying this article cannot be shared publicly due to the nature of qualitative data making it possible for participants to be recognized from context through full transcripts. While the sharing of illustrative quotes is covered by participant consent and ethics, the sharing of full transcripts is not.

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References

1. Denton CP, Khanna D. Systemic sclerosis. *Lancet* 2017;390:1685–99.
2. Hughes M, Herrick AL. Systemic sclerosis [Internet]. *Br J Hosp Med* 2019;80:530–6.
3. Park EH, Strand V, Oh YJ, Song YW, Lee EB. Health-related quality of life in systemic sclerosis compared with other rheumatic diseases: a cross-sectional study. *Arthritis Res Ther* 2019;21:6161.
4. Royle JG, Lanyon PC, Grainge MJ, Abhishek A, Pearce FA. The incidence, prevalence, and survival of systemic sclerosis in the UK Clinical Practice Research Datalink. *Clin Rheumatol* 2018;37:2103–11.
5. Abbot S, Bossingham D, Proudman S, de Costa C, Ho-Huynh A. Risk factors for the development of systemic sclerosis: a systematic review of the literature. *Rheumatol Adv Pract* 2018;2:rky041.
6. Hughes M, Pauling JD, Armstrong-James L *et al*. Gender-related differences in systemic sclerosis. *Autoimmun Rev* 2020;19:102494.
7. Flurey CA, Hewlett S, Rodham K *et al*. "You obviously just have to put on a brave face": a qualitative study of the experiences and coping styles of men with rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2017;69:330–7.
8. Flurey CA, Hewlett S, Rodham K *et al*. Coping strategies, psychological impact and support preferences of men with rheumatoid arthritis: a multicentre survey. *Arthritis Care Res (Hoboken)* 2018;70:851–60.
9. Galdas P, Fell J, Bower P *et al*. The effectiveness of self-management support interventions for men with long-term conditions: a systematic review and meta-analysis. *BMJ Open* 2015;5:e006620.
10. Galdas P, Darwin Z, Kidd L *et al*. The accessibility and acceptability of self-management support interventions for men with long term conditions: a systematic review and meta-synthesis of qualitative studies. *BMC Public Health* 2014;14:1230.
11. (EURO) WHO. The health and well-being of men in the WHO European Region: better health through a gender approach. Europe: World Health Organization, 2018.

12. de Visser R, Smith JA. Mister in-between. *J Health Psychol* 2006; 11:685–95.
13. van den Hoogen F, Khanna D, Fransen J *et al.* 2013 classification criteria for systemic sclerosis: an American college of rheumatology/European league against rheumatism collaborative initiative. *Arthritis Rheum* 2013;65:2737–47.
14. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health* 2021;13:201–16.
15. Braun V, Clarke V. *Successful qualitative research*. London: Sage, 2013.
16. Ritchie J, Lewis J. *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.
17. Braun V, Clarke V. *Thematic analysis: a practical guide*. London: Sage, 2021.
18. International Q. NVivo 12, 2018. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
19. Grogan S, Richards H. Body image. *Men Masc* 2002;4:219–32.
20. Fernando Perez-Garcia L, Röder E, Pastoor H *et al.* It is not just about sex: viewpoints of men with inflammatory arthritis on the overall impact of the disease on their sexual health Inflammatory arthritis. *RMD Open* 2021;7:e001821.
21. Scleroderma & Raynaud's UK. Sexual health for men. <https://www.sruk.co.uk/scleroderma/managing-scleroderma/sexual-health-for-men/> (15 September 2022, date last accessed).
22. Charmaz K. Identity dilemmas of chronically ill men. *Sociol Q* 1994;35:269–88.
23. Conrad D. Social capital and men's mental health. In: D Conrad, A White, eds. *Promoting men's mental health*. Oxon: Radford Publishing, 2010: 26–38.
24. Connell RW. *Masculinities*, 2nd edn. Los Angeles: University of California Press, 2005.
25. Cramer H, Horwood J, Payne S *et al.* Do depressed and anxious men do groups? What works and what are the barriers to help-seeking? *Prim Health Care Res* 2014;15:287–301.
26. Seymour-Smith S. “Blokes don't like that sort of thing”: men's negotiation of a “troubled” self-help group identity. *J Health Psychol* 2008;13:785–97.
27. Arrington MI, Grant CH, Vanderford ML. Man to man and side by side, they cope with prostate cancer: self-help and social support. *J Psychosoc Oncol* 2005;23:81–102.
28. Brownhill S, Wilhelm K, Barclay L, Schmied V. ‘Big build’: hidden depression in men. *Aust N Z J Psychiatry* 2005;39:921–31.
29. O'Brien R, Hart G, Hunt K. “Standing out from the herd”: men renegotiating masculinity in relation to their experience of illness. *Int J Mens Health* 2007;6:178–200.
30. Sim J. Collecting and analysing qualitative data: issues raised by the focus group. *J Adv Nurs* 1998;28:345–52.
31. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995;311:299–302.

A 2nd generation, JAK1 preferential inhibitor for moderate to severe RA¹⁻⁶

While 1st generation JAK inhibitors are relatively non-selective,²⁻⁶ JYSELECA has over 5x greater potency for JAK1 over JAK2/3 and TYK2^{1*}

Balancing sustained efficacy⁷⁻¹¹ with acceptable tolerability^{1,12}

Indicated for the treatment of moderate to severe active rheumatoid arthritis in adult patients who have responded inadequately to, or who are intolerant to one or more disease modifying anti-rheumatic drugs.¹ May be used as monotherapy or in combination with methotrexate.¹

*From biochemical assays, the clinical relevance of which is uncertain. JAK, Janus kinase; RA, rheumatoid arthritis; TYK, tyrosine kinase.

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strengthofbalance.co.uk

Refer to Summary of Product Characteristics (SmPC) before prescribing, and for full prescribing information.

JYSELECA[®] filgotinib 100 mg or 200 mg film-coated tablets.

Indication: Jyseleca is indicated for the treatment of moderate to severe active rheumatoid arthritis in adult patients who have responded inadequately to, or who are intolerant to one or more disease modifying anti-rheumatic drugs (DMARDs). Jyseleca may be used as monotherapy or in combination with methotrexate (MTX). **Dosage: Adults:** 200 mg once daily. Taken orally with/without food. It is recommended that tablets are swallowed whole. **Laboratory Monitoring:** Refer to the SmPC for information regarding laboratory monitoring and dose initiation or interruption. **Elderly:** A starting dose of 100 mg once daily is recommended for patients aged 75 years and older as clinical experience is limited. **Renal impairment:** No dose adjustment required in patients with estimated creatinine clearance (CrCl) ≥ 60 mL/min. A dose of 100 mg of filgotinib once daily is recommended for patients with moderate or severe renal impairment (CrCl 15 to < 60 mL/min). Not recommended in patients with CrCl < 15 mL/min. **Hepatic impairment:** Mild/moderate hepatic impairment: no dose adjustment required. Severe hepatic impairment: not recommended. **Children (< 18 years):** Safety and efficacy not yet established. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients. Active tuberculosis (TB) or active serious infections. **Pregnancy/Warnings/Precautions:** See SmPC for full information. **Immunosuppression:** Combination use, with immunosuppressants e.g., ciclosporin, tacrolimus, biologics or other Janus kinase (JAK) inhibitors is not recommended as a risk of additive immunosuppression cannot be excluded. **Infections:** Infections, including serious infections such as pneumonia and opportunistic infections e.g. tuberculosis (TB), oesophageal candidiasis, and cryptococcosis have been reported. Risk benefit should be assessed prior to initiating in patients with risk factors for infections (see SmPC). Patients should be closely monitored for the development of signs and symptoms of infections during and after filgotinib treatment. Treatment should be interrupted if the patient

is not responding to antimicrobial therapy, until infection is controlled. There is a higher incidence of serious infections in the elderly aged 75 years and older, caution should be used when treating this population. **Tuberculosis:** Patients should be screened for TB before initiating filgotinib, and filgotinib should not be administered to patients with active TB. **Viral reactivation:** Cases of herpes virus reactivation (e.g., herpes zoster), were reported in clinical studies (see SmPC). If a patient develops herpes zoster filgotinib treatment should be temporarily interrupted until the episode resolves. Screening for viral hepatitis and monitoring for reactivation should be performed. **Malignancy:** Immunomodulatory medicinal products may increase the risk of malignancies. Malignancies were observed in clinical studies (see SmPC). **Fertility:** In animal studies, decreased fertility, impaired spermatogenesis, and histopathological effects on male reproductive organs were observed (see SmPC). The potential effect of filgotinib on sperm production and male fertility in humans is currently unknown. **Haematological abnormalities:** Do not start therapy, or temporarily stop, if Absolute Neutrophil Count (ANC) < 1 × 10⁹ cells/L, ALC < 0.5 × 10⁹ cells/L or haemoglobin < 8 g/dL. Temporarily stop therapy if these values are observed during routine patient management. **Vaccinations:** Use of live vaccines during, or immediately prior to, filgotinib treatment is not recommended. **Lipids:** Treatment with filgotinib was associated with dose dependent increases in lipid parameters, including total cholesterol, and high-density lipoprotein (HDL) levels, while low density lipoprotein (LDL) levels were slightly increased (see SmPC). **Cardiovascular risk:** Rheumatoid arthritis patients have an increased risk for cardiovascular disorders. Patients should have risk factors (e.g., hypertension, hyperlipidaemia) managed as part of usual standard of care. **Venous thromboembolism:** Events of deep venous thrombosis (DVT) and pulmonary embolism (PE) have been reported in patients receiving JAK inhibitors including filgotinib. Caution should be used in patients with risk factors for DVT/PE, such as older age, obesity, a medical history of DVT/PE, or patients undergoing surgery, and prolonged

immobilisation. **Lactose content:** Contains lactose; patients with rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take filgotinib. **Pregnancy/Lactation:** Filgotinib is contraindicated in pregnancy. Filgotinib should not be used during breast-feeding. Women of childbearing potential must use effective contraception during and for at least 1 week after cessation of treatment. **Driving/Using machinery:** No or negligible influence, however dizziness has been reported. **Side effects:** See SmPC for full information. **Common (≥1/100 to <1/10):** nausea, upper respiratory tract infection, urinary tract infection and dizziness. **Uncommon (≥1/1000 to <1/100):** herpes zoster, pneumonia, neutropenia, hypercholesterolaemia and blood creatine phosphokinase increase. **Serious side effects:** See SmPC for full information. **Legal category:** POM. **Pack:** 30 film-coated tablets/bottle. **Price:** UK Basic NHS cost: £863.10. **Marketing authorisation number(s):** Great Britain Jyseleca 100mg film-coated tablets PLGB 42147/0001 Jyseleca 200mg film-coated tablets PLGB 42147/0002 Northern Ireland Jyseleca 100mg film-coated tablets EU/1/20/1480/001 EU/1/20/1480/002 Jyseleca 200mg film-coated tablets EU/1/20/1480/003 EU/1/20/1480/004. **Further information:** Galapagos UK, Belmont House, 148 Belmont Road, Uxbridge UB8 1QS, United Kingdom 00800 7878 1345 medicalinfo@glog.com Jyseleca[®] is a trademark. **Date of Preparation:** January 2022 UK-RA-FIL-202201-00019

∇ Additional monitoring required

Adverse events should be reported.

For Great Britain and Northern Ireland, reporting forms and information can be found at yellowcard.mhra.gov.uk or via the Yellow Card app (download from the Apple App Store or Google Play Store).

Adverse events should also be reported to Galapagos via email to DrugSafety.UK.Ireland@glog.com or 00800 7878 1345

References: 1. JYSELECA SPC. Available at: www.medicines.org.uk. Last accessed: June 2022. 2. Angelini J, et al. *Biomolecules* 2020;10(7):E1002. 3. Banerjee S, et al. *Drugs* 2017;77:521-546. 4. O'Shea JJ, et al. *Nat Rev Rheumatol* 2013;9(3):173-182. 5. Traves PG, et al. *Ann Rheum Dis* 2021;01-11. 6. McInnes IB, et al. *Arthr Res Ther* 2019;21:183. 7. Combe B, et al. *Ann Rheum Dis* 2021;doi:10.1136/annrheumdis-2020-219214. 8. Genovese MC, et al. *JAMA* 2019;322(4):315-325. 9. Westhovens R, et al. *Ann Rheum Dis* 2021;doi:10.1136/annrheumdis-2020-219213. 10. Combe B, et al. *Arthritis Rheumatol* 2021;73(suppl 10). <https://acrabstracts.org/abstract/clinical-outcomes-up-to-week-48-of-filgotinib-treatment-in-an-ongoing-long-term-extension-trial-of-rt-patients-with-inadequate-response-to-mtx-initially-treated-with-filgotinib-or-adalimumab-during-th/>. Last accessed: June 2022. 11. Buch MH, et al. *Arthritis Rheumatol* 2021;73(suppl 10). <https://acrabstracts.org/abstract/clinical-outcomes-up-to-week-48-of-ongoing-filgotinib-ra-long-term-extension-trial-of-biologic-dmard-inadequate-responders-initially-on-filgotinib-or- placebo-in-a-phase-3-trial/>. Last accessed: June 2022. 12. Winthrop K, et al. *Arthritis Rheumatol* 2021;73(suppl 10). Available at: <https://acrabstracts.org/abstract/integrated-safety-analysis-update-for-filgotinib-in-patients-with-moderately-to-severely-active-rheumatoid-arthritis-receiving-treatment-over-a-median-of-2-2-years/>. Last accessed: June 2022.

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