

“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 Systemic Sclerosis (SSc) have a more severe clinical phenotype and reduced survival compared to 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.

Methods: An international qualitative research study comprising seven focus groups (3 USA, 4 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: ‘systemic sclerosis’, ‘scleroderma’, ‘men’, ‘gender’, ‘masculinity’, ‘quality of life’, ‘erectile dysfunction’, ‘mortality’, ‘qualitative’

Key Messages

- SSc impacts masculine identity and roles with breadwinner and father/grandfather roles being notably affected
- Men many 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

Systemic sclerosis (SSc) is a complex autoimmune connective tissue disease, characterised by inflammation, fibrosis and vasculopathic alterations(1,2) of multiple 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)

Men with rheumatoid arthritis have been shown to employ different coping strategies to women and prefer practical over emotional support(7,8) reflecting findings in other long-term conditions.(9,10) The World Health Organisation suggest 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.

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 male patient research partner (AW). 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 (CF), held in a non-clinical room within the hospital, lasted approximately two hours, 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 obtained prior to each group.

Analysis: Data were analysed using reflexive thematic analysis following Braun & Clarke's six steps:(17)

1: Data familiarisation: The first author (CF) 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 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 eight years (range 1-29); HAQ score 0.99 (SD:0.86). Participants largely had diffuse SSc (74%), were White (76%), married (76%), retired (40%), with education level ranging from elementary to post-graduate (Table 2).

Seven focus groups (3 USA; 4 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' (Figure 1).

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. Whilst 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 bravado 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, whilst 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 emphasising 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 minimise 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, whilst retaining identity. For many participants this meant balancing time with family against managing SSc. Whilst some were able to set boundaries to look after their health, those with young children often prioritised 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 prioritising 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 prioritised 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 wouldn’t 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 amongst 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; 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 recognised 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, whilst 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 erectile dysfunction; 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 rheumatoid arthritis (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 GP. (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 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 men with SSc may play down 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 minimise 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 criticised 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 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.

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