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Original article

Cognitive difficulties in people with systemic sclerosis: a qualitative study

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Abstract

Objectives. This study used a qualitative approach to explore how people with SSc experience cognitive changes and how cognitive difficulties impact their functioning.

Methods. Four 90-min focus groups of adults with SSc and self-reported changes in cognition were recruited from a SSc research registry and targeted social media. A focus group guide elicited information from participants via open-ended questions. Content analysis was conducted using grounded theory methodology.

Results. There were 20 participants (mean age $=$ 55.5 (11.4) years) comprising 16 (80%) females, 14 (70%) Caucasians, and 11 (55%) people with diffuse cutaneous SSc. Study themes included cognitive difficulties as part of daily life experience, impact of cognitive difficulties on daily life functioning, coping strategies and information seeking. Participants used different terms to describe their experience of cognitive difficulties, and most encountered deficits in short-term memory, language difficulties, decreased executive function, difficulties with concentration and focus, and slow processing speed. Participants expressed frustration with their cognitive difficulties and used coping strategies to lessen their impact. Participants were uncertain about the causes and wanted to understand factors contributing to cognitive difficulties as well as how to manage them.

Conclusion. Participants with SSc reported cognitive difficulties that had a substantial negative impact on their lives. Improved understanding of cognitive changes could subsequently facilitate development of relevant therapeutic interventions or educational programmes for symptom self-management to reduce impact of cognitive difficulties in people with SSc.

Key words: systemic sclerosis, systemic scleroderma, cognitive dysfunction, activities of daily living, coping behaviour, self-management, qualitative research

Rheumatology key messages

- SSc patients reported cognitive difficulties that negatively influence their everyday life.
- SSc patients used various coping strategies but expressed uncertainty about the causes of cognitive changes.
- Interventions and self-management programmes may help mitigate effects of cognitive difficulties for people with SSc.

Introduction

SSc, or scleroderma, is a rare, incurable connective tissue disease that affects the skin and inner organs, most notably the lungs, gastrointestinal system and kidneys [1, 2]. Among rheumatic diseases, SSc is the most severe and life-threatening [3, 4]. Despite treatment advances, patients still face challenges in managing their chronic condition [5, 6]. People with SSc have high disease burden accompanied by chronic pain and fatigue, psychological distress and functional impairments that affect quality of life [6–9]. Characterizing

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aspects of disease burden through qualitative and quantitative research methods has facilitated intervention development to help SSc patients self-manage problematic symptoms [10, 11]. Despite these efforts, evidence suggests that cognitive difficulties could be pervasive and significant in SSc, affecting up to 87% of patients depending on the type of measurements and definition of cognitive impairment that mostly affect middle-aged and older SSc patients [12–15], but this domain is not well-understood.

Although evidence suggests an association between dementia and SSc [16], little is known about how people with SSc perceive their cognitive changes and how such changes impact daily life. In other rheumatic diseases, such as rheumatoid arthritis, fibromyalgia and SLE, cognitive difficulties are better characterized and associated with chronic pain, fatigue, poor mental health and inflammation [17–24]. Inflammatory proteins in blood during midlife are associated with increased risk for cognitive decline over a 20-year period [25]. Cognitive limitations negatively influence daily functioning, such as performance in regular physical tasks [26, 27] and work ability [28, 29], among people with other rheumatic diseases. The purpose of this qualitative study was to explore lived experiences of cognitive difficulties and impacts on daily life functioning.

Methods

Study design

Qualitative focus group methodology was chosen because it enables discussion and synthesis of experiences of phenomena that are not well known [30]. Focus groups were conducted until data reached saturation [31, 32]. A participatory action research approach was used to facilitate collaboration between patients and researchers. Patient partners were included as research team members, and they reviewed the focus group protocol [33]. One patient partner assisted in analysis coding and interpretation of findings. The University of Michigan Institutional Review Board approved this study (HUM00195698).

Participants

A convenience sample of people with SSc was recruited from both an existing SSc research registry ($n \sim 400$) and targeted social media ads. Inclusion criteria were adults aged $\geq$18 years; doctor-diagnosed SSc; report of cognitive difficulties within the prior 3 months; ability to read, understand and speak English; ability to access internet-connected devices; and being Michigan Medicine patients. Exclusion criteria were inability to provide consent; or any major comorbid neurological conditions that might influence cognitive function (e.g. stroke, dementia); and self-declaration of current alcohol or recreational drug dependence, or prolonged ($\geq$5 years) history of substance dependence.

Data collection

Eligible participants provided written informed consent and completed demographic questions and SSc characteristics questionnaires. They also completed the Patient Reported Outcomes Measurement Information System (PROMIS) Cognitive Function 8-item Short Form [34]. Upon survey completion, researchers scheduled virtual focus groups using secure Zoom conferencing. The first author (Y.C.) and an experienced qualitative researcher (S.M.) conducted all focus groups. The guiding questions were developed by the research team and SSc patient partners (see Supplementary Table S1, available at *Rheumatology* online). Each focus group session lasted ~90 min and was video recorded and transcribed verbatim.

Analyses

Descriptive statistics were conducted to summarize the demographics, SSc characteristics, and PROMIS cognitive function using SPSS Statistics 24.0 (IBM Corp., Armonk, NY, USA). Focus group data were analysed via a rigorous and accelerated data reduction (RADaR) technique [35] and content analysis used a grounded theory approach [36]. Research members (Y.C., A.D. and S.M.) read focus group transcripts repeatedly to get familiar with the content. Y.C. and A.D. identified descriptions relevant to experienced cognitive difficulties by conducting unit analysis. Open coding was first conducted to identify relevant codes, categories and themes. The codes were not established *a priori* but instead generated from focus group content. Y.C. and A.D. independently coded 40% of the transcript and then compared and discussed their results. Y.C. used the preliminary codebook to code the rest of the transcript, checked and verified by A.D. for accuracy and agreement. Discrepancies were resolved through discussion or via consultation with S.M. The codebook was refined during team meetings. The process was repeated for each focus group transcript. Researchers (A.L. and D.K.), rheumatologists and SSc experts independently reviewed the results and agreed they represented the participants' perspectives. Finally, the team utilized the Theory of Unpleasant Symptoms [37] to develop a conceptual model that recognizes potential contributing factors for cognitive difficulties and how cognitive changes impact SSc patients' daily life functioning.

Results

Twenty-seven people with SSc expressed interest in the study, but five did not meet the inclusion criteria so 22 were eligible and enrolled. The final sample included 20 participants because two individuals did not attend the focus groups. Table 1 summarizes participants' characteristics. The mean PROMIS cognitive function T-score was 38.8 (6.55), indicating people with SSc perceived poorer cognitive function more than 1 s.d. lower than the

Table 1 Sample characteristics ($n = 20$)

Characteristic	Value
Age, mean (s.d.), years	55.5 (11.4)
Sex, female, *n* (%)	16 (80)
Race, *n* (%)	
Caucasian	14 (70)
African American	4 (20)
Asian	2 (10)
Education levels, *n* (%)	
Some college	3 (15)
Associated degree	5 (25)
Bachelor's degree	5 (25)
Master's degree	5 (25)
Professional degree	2 (10)
Employment status, *n* (%)	
Employed full-time	5 (25)
Employed part-time	1 (5)
Homemaker	1 (5)
Retired	5 (25)
Disability	8 (40)
SSc subtype, *n* (%)	
Diffuse	11 (55)
Limited	8 (40)
Overlap (with SLE)	1 (5)
Disease duration since diagnosis of SSc, mean (s.d.), years	5.7 (4.16)
≤5 years, *n* (%)	13 (65)
6–10 years, *n* (%)	4 (20)
11–15 years, *n* (%)	3 (15)
PROMIS Cognitive Function, T-score, mean (s.d.)	38.8 (6.55)

PROMIS: Patient Reported Outcomes Measurement Information System.

US population. Four focus groups occurred during May and June 2021. Four main themes emerged: cognitive difficulties as part of daily life experience; the impact of cognitive issues on daily life functioning; coping strategies; and information seeking (Fig. 1).

Cognitive difficulties as part of daily life experience

Characteristics of cognitive difficulties

Participants used a variety of terms to describe their experience of cognitive difficulties, including 'foggy' and 'blankness' (Table 2). One participant characterized the experience as 'I am not on the same page as everyone else', and another said it was like 'coming up against a mental wall'. Some participants mentioned difficulty in describing their experience of cognitive problems, whereas some provided vivid analogies. For example, a participant explained cognitive difficulties as follows:

> *Like we're plugged into our local power company and we're working long and all, and we have an out-of-date backup generator that doesn't quite carry the load. All of a sudden, boom! Power goes out and we have to rely on the kind of depleted old... We're not going to function. We've lost our power.*

Deficits in short-term memory

All participants noticed a significant change in short-term memory after SSc diagnosis. Deficits included easily forgetting things, such as casual conversations with family and friends (Q1). Participants often described finding themselves going to a room and not remembering their purpose for being there (Q2). Several participants noted an inability to remember appointments or important tasks. One participant indicated that prior to SSc, she never needed to write down appointment dates and times; another said he never forgot an appointment before SSc (Q3).

Language difficulties

Eighteen (90%) participants noted trouble having clear and smooth communications with family and friends. Fifteen participants reported difficulty finding the right words in conversations. Two participants described that they used to be well-spoken and had extensive vocabularies before SSc. They felt frustrated at not recalling words that they wanted to use when speaking (Q4). They noted that they could not complete sentences or even initiate conversations. Four participants recalled spelling problems and feeling embarrassed when others noticed their errors (Q5).

Decreased executive function

Most participants (90%) reported difficulty in thinking, planning and performing goal-directed activities. Some expressed trouble analysing new information, recognizing that they could not function well cognitively as they once did. A 31-year-old participant explicitly said that prior to SSc diagnosis, she was able to solve complicated problems, but cognitive changes now impaired problem-solving and critical thinking abilities (Q6). Another participant mentioned that it now takes her longer to digest new information (Q7). A common theme among participants was loss of ability to multitask (Q8). Others identified cognitive challenges with organizing information, planning and decision-making. These tasks require advanced concentration and cognitive effort, sometimes causing fatigue (Q9). Additionally, one participant noticed that calculating simple maths in her head became difficult (Q10).

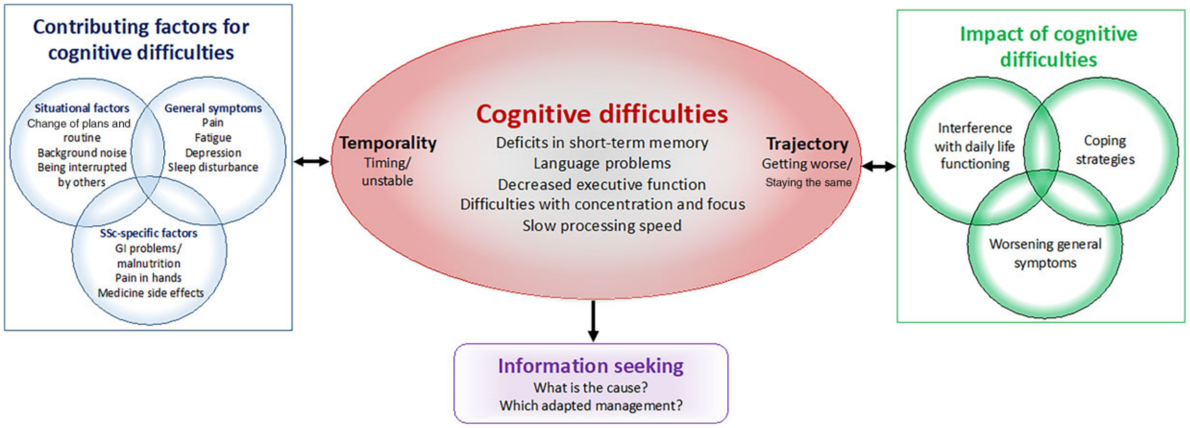
Difficulties with concentration and focus

Eleven (55%) participants described cognitive challenges with concentration and focus and poor performance at work. Similar to issues in focus group participation with losing train of thought, participants reported this issue when conversing with others. Some noted that they are easily distracted and have problems attending to activities like reading (Q11). Additionally, difficulties with focus created barriers to communication (Q12).

Slow processing speed

Seven (35%) participants described feeling slower in ability to process information and having difficulty thinking quickly (Q13). Another participant expressed a similar experience of slow processing speed when answering clients at work (Q14).

FIG. 1 Conceptual model of the lived experience of cognitive difficulties in patients with SSc



Interactions between situational factors, general symptoms (e.g. constant pain) and SSc-specific factors, such as GI problems (e.g. could not absorb nutrients), result in cognitive difficulties in patients with SSc and vice versa. The lived experience of cognitive difficulties is broad; however, the experience fluctuates and tends to get worse throughout the years after SSc diagnosis. Cognitive difficulties negatively impacted patients' everyday life. Participants used coping strategies in order to manage their lives. Cognitive problems worsened participants' general symptoms (e.g. increased fatigue). It was difficult for participants to understand what was causing their cognitive problems and how to manage them.

Temporality of cognitive difficulties

Participants described certain times of day or days of the week they felt more likely to experience cognitive difficulties. Ten participants thought their cognitive ability was worse in the afternoon or evening (Q15), whereas two participants mentioned that morning usually challenges them to think or make decisions due to poor sleep quality or SSc symptoms (e.g. hand pain) (Q16). Two participants indicated that towards the end of the week (e.g. Thursdays and Fridays), they typically feel decreasing cognitive abilities. Others (25%) noticed that cognitive ability fluctuates (Q17).

Trajectory of cognitive difficulties

Most participants described cognitive abilities decreasing over time (Q18). Participants have varied perceptions of when cognitive changes began. Eight participants noticed changes within 12–24 months after SSc diagnosis. One participant noticed changes immediately after starting a particular SSc medicine. Five participants did not immediately notice changes. Two thought changes might be COVID-related due to social isolation and decreased communication skills. Interestingly, the same participant who mentioned the treatment has affected his cognition noticed cognitive improvement after he stopped taking prescriptions for SSc symptoms (Q19).

Impact of cognitive difficulties on daily life functioning

Impact on emotional well-being

All participants experienced emotional disturbances specifically linked to cognitive changes (Table 3). Cognitive decline made participants feel embarrassed and upset. Some described frustration, depression, irritability and worry. Difficulty analysing information just heard or read and having slow processing speed hampered participants' confidence, leaving them frustrated (Q20). Some participants who left jobs due to cognitive difficulties felt a lack of confidence and low self-esteem (Q21). Several participants recognized that negative emotional responses further worsened cognitive function (Q22).

Impact on relationships/responsibilities

Seventeen (85%) participants described negative effects of cognitive difficulties on personal relationships. Several participants acknowledged that cognitive changes confounded family and friends, especially young children. One participant reported that her loss of train of thought caused confusion for her child, who often said, 'Mom, seriously, what just happened?' Many participants' partners cannot understand the extent of cognitive change (Q23). One participant expressed frustration and fear of a burden on her daughter because of memory issues (Q24). Another said his friends did not take his complaints of cognitive changes seriously; eventually, he left this friend group (Q25).

Impact on general symptoms

Cognitive problems were also thought to worsen general symptoms—particularly fatigue. Participants indicated that their limited cognitive ability during conversations causes them to ponder constantly whether they expressed thoughts how they wanted, resulting in being more easily fatigued (Q26). Several indicated that tasks took longer, they required more rest, and they had to limit social activities due to fatigue (Q27). Other

Table 2 Theme 1 and major categories identified by people with SSc

Cognitive difficulties as part of daily life experience			
	***n* (%)**	**Quote no.**	**Participant quote**
Category			
Deficits in short-term memory	20 (100)	Q1	Conversations you have with people that you completely forget. Because the next time you talk you say something and they're like well, I just told you that yesterday. And for the life of me, I still can't remember it, even when they tell me they told me, I still don't remember it.
		Q2	You walk into a different room and go, 'Why am I here?' You know. I'll be sitting in the living room on my iPad, I'll go to switch over to a different screen and I'm wondering why I'm there, or what I'm looking for.
		Q3	I've never in my life missed appointments. I'm always there early. I'm always prompt and all that. And lately, I missed an appointment. I was so frustrated. It just threw me into a tizzy. And that's not me.
Language problems	18 (90)	Q4	I'm not 50 yet. And, I wish I could use age as the excuse. I felt like I was a well-spoken person. But when you're thinking of a word and it's just something simple and you can't think of it.
		Q5	I was trying to write the word 'picnic' and all I could do was put 'P-I-C', and I could not think of the rest of the word. . . T [team-mate] looked at me, I looked at T, I said, 'T, how do you spell "picnic"? I'm so embarrassed'. He's like, 'You don't know how to spell "picnic"?'
Decreased executive function	18 (90)	Q6	Before scleroderma, I was able to figure out some or understand a very complicated process or a logical thinking, I'm trying to understand it but it's just a fog that I couldn't, I couldn't kind of figure out and I don't feel like I had that experience before.
		Q7	I have trouble trying to analyse anything. I will be reading a sentence and have to read it over and over.
		Q8	Whereas before, I could be doing five different. . . Thinking of five different things, singing, and playing the radio and no problem.
		Q9	It is just thinking about what you have to do and when you have to do it, and that organizing of things has been most exhausting for me.
		Q10	Numbers, adding up the orders and telling the customer how much cost. It took me a little while to get those numbers in my brain added up.
Difficulties with concentration and focus	11 (55)	Q11	When I'm reading, I used to be able to have distractions like family around or TV or whatever. And I seem to be struggling with it now. Just distractions easily get me off of what I'm trying to accomplish or trying to read and saying here.
		Q12	I don't initiate big conversations. I'll participate but in answer questions it's just very hard for me to focus that long on a conversation.
Slow processing speed	7 (35)	Q13	It's clearly a slow-down of the processing of what's going on in my brain as far as thoughts that either are in my brain or need to be spoken, everything slows down. Not everything is quick, quick, quick like it used to be. Everything is slow and you can only do one thing at a time.
		Q14	I'm always lagging behind. I still lag behind, and I can't answer quick—things quickly when we're talking to clients.
Temporality of cognitive difficulties			
Worse in the afternoon or evening	10 (50)	Q15	Like at the end of the day, I just start to get stupid silly. And I would never try to have a very. . . Like, if my husband and I needed to have a serious conversation or the kid, I would have. . . If I had a choice, I would not pick the end of the day.
Worse in the morning	2 (10)	Q16	My worst pains are in my hands, I mean it's consistent. And it's like I'm just pulling them out of a fire. But then, when you're concentrating on that, then you get the mental ability, you know the mental game. And it's like, when one overrides the other and you can't think because of what you're going through at the moment. I mean there's times—morning's the worst time for me. I mean I if somebody would ask me my name or where I lived, it'd be like—you have to think of it there for a minute.

(continued)

Table 2 Continued

Cognitive difficulties as part of daily life experience	*n* (%)	Quote no.	Participant quote
Unstable	2 (10)	Q17	Sometimes it comes and goes. Sometimes I'll surprise myself, I'll sit and have a conversation with someone. I'm able to find all the big words. Everything comes to me, like, it's a miracle. And then a half hour later, it'll be gone.
Trajectory of cognitive difficulties			
Worse	9 (45)	Q18	I remember that first year and the second year. It didn't seem like it cognitively changed at all. It's really only been, I would say about the last year and a half. Things that I don't remember or can't do. It's, it has gotten much worse.
Improved	1 (5)	Q19	I think my brain fog has improved. So that's, like I said, I've always put some medical treatment for scleroderma.

participants explained that problems with memory sometimes resulted in poor sleep (Q28).

Impact on work

Before SSc diagnosis, six participants worked full-time. Those who left jobs explained that SSc symptoms decreased cognitive function. Some working participants noted an inability to respond quickly when asked a question or difficulty finding words, particularly while at work (Q29). One participant stressed that she finally quit working because she believed that her cognitive ability declined (Q30). She also described her inability to learn as quickly as others decreased her confidence. She ended up quitting her job and has not worked since (Q31).

Impact on social functioning

Eight participants (40%) expressed that cognitive difficulties affected social function. Some reported that decreased memory caused difficulties in keeping track of or remembering recent conversations (Q32). Another mentioned that she often promised to phone someone, then entirely forgot. Besides memory difficulties, some are concerned with focus and concentration when deciding whether to meet friends (Q33). Several participants explained that difficulties with word choice make them not want to participate socially (Q34).

Impact on driving

Four participants (20%) mentioned that cognitive changes impact driving. They described forgetting where they drove, trouble focusing on driving, or not recalling familiar places (e.g. kids' school) that they have been to repeatedly (Q35).

Coping strategies

Participants discussed many coping methods for dealing with cognitive concerns, including using Post-It notes or electronic reminders (Q36, Q37) (Table 4). Some recommended engaging in mentally stimulating or cognitive activities, including learning new things or taking classes (Q38, Q39), playing brain activities such as crosswords, Sudoku, and trivia, or reading simple stories daily for brain stimulation (Q40). Physical activity emerged as an important strategy. One participant confirmed that being more active with her dog boosted her mental clarity (Q41). Several mentioned self-adjustment and adaptive strategies such as preplanning and not rushing reduced cognitive difficulties (Q42, Q43). Some participants also described avoiding situations and attempting to hide cognitive changes from those unaware of their condition (Q44). Others addressed the relationship between their cognitive difficulties and fatigue. Participants described the need for rest or naps to reset mental ability, so as to avoid mental fogginess. Some participant needed to 'recharge' during the day or else they might hit a mental wall and stop listening (Q45). Lastly, receiving help from family or friends helped participants remember certain things (Q46).

Information seeking

Most participants repeatedly expressed uncertainty about causes of their cognitive changes, but they considered general symptoms likely to exacerbate and worsen cognitive ability; pain, fatigue, depression and sleep disturbances were most common. Participants associated pain and depression with their concentration and focus (Q47, Q48) (Table 5). Seven participants wondered whether natural ageing processes might be causing cognitive changes (Q49), while seven others believed that SSc was the cause of these changes (Q50). One participant affirmed that SSc-specific factors worsened cognitive ability (Q51). Gastrointestinal symptoms were also thought to contribute to cognitive difficulties as a result of not properly absorbing nutrients (Q52). Several (35%) believed that SSc treatment side effects might negatively influence cognitive ability. One participant indicated that SSc treatment side effects caused cognitive issues, such as word choice (Q53). Further, three participants initially feared that they were experiencing early signs of dementia or Alzheimer's disease (Q54).

Situational factors were another trigger for cognitive difficulties. Situational factors refer to aspects of the

Table 3 Theme 2 and major categories identified by people with SSc

Impact of cognitive difficulties on daily life functioning			
Category	***n* (%)**	**Quote no.**	**Participant quote**
Emotional well-being	20 (100)	Q20	I feel dumb. Like, I get frustrated because I can't figure something out, or it takes me like forever to do a task. So I just get really down on myself.
		Q21	I have no confidence in getting another job. Even if I felt physically able which I'm not, I think cognitively, I would have doubts and self-esteem issues.
		Q22	The pressure, the stress, and then you want to be able to do whatever it is, then you're worried about how it's going to look if you make the wrong decision, and what is that person going to think, or you know what's going to happen to you if you can't remember this. It's snowballs, you're under pressure and you can't remember whatever it was and what's going to happen because of that, and so it just becomes this bigger and bigger issue, which makes it harder and harder to do what you need to do. All of those things are very much impacted. You know when you're in that time crunch or you are under stress.
Relationship with family and friends	17 (85)	Q23	She (the wife) told me to go get a fruit cup with, you know, jello and fruit in it. I got halfway there and I had to stop because I forgot what I was going to look for. I stand there and take a couple minutes to go. Oh, that's right. And then of course I was being watched. My wife was watching me, wondering, 'why are you standing there?'
		Q24	I can't remember dates for my daughter's events, my daughter had to kind of remind me. It is a disappointment that I can't remember the days now, I hate putting that burden on my daughter.
		Q25	I lost our circle of friends. They just couldn't, they didn't understand scleroderma, they didn't want to. I used to be really good at, I grew up in the 70s, music, you could play a song, name that tune, I could name the group, and I couldn't do that anymore. And my friends, because they refused to understand what I was going through, made fun of me. We were playing, we always played Canasta, and it's a pretty complicated game, and I hadn't played it in a while, I couldn't remember how to play it. And my friends were berating me because of it.
General symptoms	14 (70)	Q26	Like even after this Zoom. We're all going to be like beat, it's like am I expressing myself the way that I want to express myself? It's exhausting.
		Q27	Everybody wants to get the bonfire going when it gets 9:30, 10 o'clock I'm kind of whipped. I slide out and I feel that fatigue.
		Q28	I frequently wake up at like 3 a.m. like, 'Oh, I forgot to do this and I need to do this'. Because it's on my mind, my gears are turning and I can't go back to sleep because it keeps popping up, so it does, that's how it interrupts my quality of sleep.
Working	13 (65)	Q29	The thing that I have noticed the most lately has been difficulty with word retrieval. So, I work in a field that is highly specialized, and sometimes I just don't know the word that I'm supposed to say when I'm supposed to be describing something. And it's very frustrating, because I'll describe it, like all around the word. And everybody knows what I'm talking about, but this conversation could have been so much shorter if I just could have said this thing.
		Q30	Some of the things that you are used to knowing just like knowledge of things, you know, from my professional things that I can't remember anymore.
		Q31	Because you, you aren't performing well, you recognize your ability cognitively to perform things just isn't there. That was something I would have picked up really quickly and it took me longer to do.
Social functioning	8 (40)	Q32	I keep asking my friends, did I tell you about this? I have no memories of the situation, the moment that I'm telling them about. I could be telling one person multiple times about something that I wanted to share.
		Q33	When you're trying to set up time to spend with your friends or go out you have to think about, is it going to be overwhelming cognitively? Am I going to still be able to follow up conversation? Is the background noise too loud and confusing.
		Q34	Just talking to people I just feel. I just feel so stupid sometimes you know because I can't say the things I want to say, you know, so I just don't say anything.
Driving	4 (20)	Q35	I am in a familiar area, totally familiar. I'm driving down a road that I take to my kids' school all the time. I look around and go, 'Where am I?'

Table 4 Theme 3 and major categories identified by people with SSc

Coping strategies			
Category	***n* (%)**	**Quote no.**	**Participant quote**
Using organizers	17 (85)	Q36	I've actually stuck up Post-It notes on my front door. When, like, I'm packing for a trip or something I'm like, 'Don't forget the medicine', so I'll put a Post-It on my door. And sure enough, I was leaving for a trip and I was like, ready to go with my luggage and it said, 'Don't forget the medicine', and I had to go back and go get my medicine.
		Q37	I do use mine frequently my phone. But I can't remember to check my calendar, so I have alerts set up to remind me of an upcoming appointment. I usually do, I usually have the alerts set up. Like a day before. And depends on how far the destination is I have to get to, then I will have two hours before the actual appointment or whatever to allow me to get around and be on my way. I mean I definitely use my calendar on my phone a lot.
Engaging in mentally stimulating/cognitive activities	16 (80)	Q38	I always work, even though I stopped working officially a nine to five, I'm always learning new things, and. . . I've always been trying to do something, because I didn't want to decline cognitively by not working.
		Q39	I do take classes; like, I'll go to, uh, well it's been on Zoom—local library and see which enrichment classes that they have, or craft classes. . . anything that just keep my mind uh, up to date and to keep it functional, you know.
		Q40	I choose something that has a simple story, with a few characters, and that's easier for me to read and then I. And then I feel like I've accomplished something because I can get through a book.
		Q41	Since we got the dog I've been more active and it's just, it's made everything better. You know mentally and emotionally and physically. You know I feel and think better, like I actually will jog a little bit with her.
Self-adjustment and adaptive strategy	13 (65)	Q42	Every morning I write a list of the things I must do today, and I will put on there, definitely, like, the meetings that I have to attend or whatever task I have to do, and I even put on there, like, 'cook dinner'—I'll put everything. Just so that it helps me to plan my day, because I know I will run out of time, and I haven't given it enough—enough time. So, that's how I start out every day.
		Q43	I just have taught myself to take a step back and breathe for a few minutes, a few deep breaths.
Avoidance	9 (45)	Q44	I try not to put myself in situations where I'll be criticized by others who don't know my situation, creating as much of a situation as you can't reveal your deficiencies.
Recharge/nap	8 (40)	Q45	I'm really getting fatigued. And when I hit the wall, fatigue wise, I'm not worth too much. So I recharge, take a nap and I'm good for another six hours. But if I hit the fatigue, I'm terrible. Don't listen. Just clam up and want to close my eyes.
Receiving help from others	6 (30)	Q46	My trusty daughter, who remembers everything for me.

Table 5 Theme 4 and major categories identified by people with SSc

Information seeking			
Category	***n* (%)**	**Quote no.**	**Participant quote**
Uncertainty about the causes			
General symptoms	19 (95)	Q47	Because I think the scleroderma can physically slow us down, and obviously causes pain. And then I think that contributes to our, you know, mental focus and trying to concentrate on the things that we need.
		Q48	I think depression has a lot to do with it too that you just can't focus as well and things like that so when I am depressed it, it affects everything else.
Ageing	7 (35)	Q49	I'm only 51, not that cognitive changes can't happen at that age, but I don't feel that these things are a normal ageing process, the appearance of these problems coincided with my diagnosis, basically.
SSc-related	7 (35)	Q50	People don't really understand. They, because they can see the physical parts of the scleroderma, but they can't see the mental parts.
		Q51	I think the pain. . . Because my, my worst pains are in my hands, I mean it's consistent. And it's like I'm just pulling them out of a fire. But then, when you're concentrating on that, then you get the mental fatigue, you know the mental game. And it's like, when one overrides the other and you can't think because of what you're going through at the moment.
		Q52	If you have stomach issues like I have, and you can't eat as well as you should. And you could not absorb nutrients then the fog is going to be more active, I think. It's all related.
Medicine side effects	7 (35)	Q53	I was on medication treatments for scleroderma. It was like, you're talking in a sentence and your brain doesn't catch up. You're talking ahead of your thoughts. And, you're waiting for that word to kick in.
Early signs of cognitive diseases	3 (15)	Q54	You start thinking you have memory loss or Alzheimer's or something because simple little words, I'm forgetting the names of the flowers.
Other possible contributing factors			
Situational factors (e.g. triggers)	11 (55)	Q55	If something comes up, I I'll end up drop something—I end up dropping the ball.
		Q56	We are at the moment of decision making and then people are telling you five different decisions and you can't remember all of them. You can't make decisions because you don't remember.
		Q57	If I get interrupted and I'm walking down the hallway, and my husband says can you get me a glass of water or something and I'm like, okay, and then I totally go blank it'll be three hours before I remember what I was going to do.
		Q58	If I'm in the middle of something and someone distracts me. I lose my place of whatever I was doing. And then I get irritable. It's not only if someone else is in the room, but it's all the alerts on my phone that ding and beeps, the things that they do constantly.

physical environment that can influence individuals' experiences of cognitive changes [37]. For instance, if a daily routine needed to be altered and the participant had to rearrange her to-do list, she would not be able to adjust and would quit certain tasks (Q55). Receiving overwhelming information also emerged as a trigger for cognitive deterioration. A participant described that, when overwhelmed by information, such as when given many different options, she would not be able to make a decision because she could not remember any of the options (Q56). Being interrupted was also a trigger, such as if the participant was walking somewhere and a family member said something, the participant would forget what she was doing (Q57). Lastly, background noises, such as cell phone alerts, triggered cognitive difficulties (Q58).

After discussing multiple potential causes, participants confirmed that they would like to learn more about cognitive change and how to better manage it. No participants reported being offered any cognition-related information or management strategies from health providers. Most noted that providers have not mentioned or addressed cognitive difficulties. One participant refrains from mentioning this at doctor's visits for fear of being viewed as mentally unstable. Another participant mentioned that she does not want to take more medicine for cognitive difficulties. Finally, participants hoped healthcare professionals would develop education programmes about cognitive changes or self-management, or at least acknowledge cognitive problems exist for people with SSc.

Discussion

This study is the first to investigate lived experience of cognitive changes in patients with SSc. Consistently reported cognitive changes included deficits in short-term memory, language, executive function, and difficulties with concentration and focus, as well as processing speed. Cognitive difficulties adversely affected daily life functioning. Although participants had created coping strategies, most participants remained uncertain about the causes of cognitive changes and had not discussed this issue with their health providers.

The range of cognitive difficulties reported by patients with SSc is consistent with cognitive domains represented in the few quantitative research SSc studies using objective measurements [12–14]. However, previous research did not evaluate processing speed, which our participants described as a notable experience of cognitive difficulties, and is also reported in patients with SLE [38]. Like prior studies in patients with other rheumatic diseases, we found that cognitive impairments affected physical functioning and working ability [26–29]. This study also revealed issues with cognitive difficulties not measured in prior studies including impact on emotional well-being, relationships with others, general symptoms (including fatigue [39]), social functioning and driving. These issues should be considered when examining the effects of cognitive difficulties in patients with SSc.

While participants endeavoured to adapt to and cope with cognitive problems over time, they never mentioned health providers as resources for how to deal with cognitive decline. This suggests a missed opportunity in SSc clinical management. Health providers can play an important role in initiating conversations about cognitive difficulties and providing suggestions and resources for coping with cognitive changes. Proactively addressing these issues and developing interventions [40] and referring patients to occupational therapy, a discipline trained to help people adapt to cognitive and physical challenges due to chronic disease, might help to mitigate the impact of cognitive changes in people with SSc. Although therapeutic opportunities remain scarce, research is still needed to better understand the underlying causes of such cognitive difficulties.

This study has implications for future research to better understand aetiopathology and pathogenesis of cognitive changes in SSc. The results suggest that both general symptoms such as fatigue or sleep disturbance as well as SSc-specific symptoms (e.g. GI involvement) [41] could contribute to lived experience of SSc-related cognitive difficulties. In SLE, another connective tissue disease, inflammation is associated with cognitive impairment and could be the result of a disruption to the blood–brain barrier, SLE-related micro-angiopathy, or production of specific antineuronal autoantibodies, immune complexes and inflammatory mediators such as IL-6 or IFN-α [38]. Interestingly, the role of immune complexes, IL-6 [42] and IFN-α [43] has also been recently highlighted in SSc patients [44], although the neurological effects of these pathogenic mechanisms have not yet been determined. Recent MRI studies suggest that SSc vasculopathy could also affect the central nervous system [45, 46].

Similar to SLE, sub-clinical cognitive impairment might remain neglected in patients with SSc [38, 47]. Nevertheless, more evidence has shown that autoimmune rheumatic diseases could interplay with cognitive function. Besides SLE, other rheumatic diseases such as psoriatic arthritis and ankylosing spondylitis might account for some cognitive difficulties, and they also share some similar aspects with those reported in the current study regarding the most affected cognitive domains [48, 49]. Therefore, people with autoimmune rheumatic diseases could be more vulnerable to cognitive issues.

Our study was the first to provide a better understanding of the lived experience of cognitive difficulties in SSc patients. The project was developed after members of our SSc patient partner group identified cognitive difficulties as a significant problem that remains unaddressed in health care. The participatory action research approach adds validity and relevance of our findings to the SSc population. However, all participants were recruited from a single medical centre, limiting generalizability to people with SSc from other geographic regions. Second, given that neuropsychiatric symptoms are prevalent in SSc, the current sample might be naturally worried about any symptom, including their cognition which may inflate the impact of cognitive changes on daily living. Additionally, participants could have subjective cognitive decline or depression, which may potentially influence the results. Finally, as the sample included only four male participants, the results may not well-represent experiences of male SSc patients.

Future quantitative studies involving larger, more diverse samples that include SSc patients with and without cognitive concerns are required for generalizability and understanding patterns such as duration and contributing factors of cognitive difficulties among people with SSc. Those studies could reveal valuable information regarding an overall prevalence of cognitive difficulties in SSc and how demographics, SSc characteristics (e.g. SSc severity), treatment side effects and general symptoms (e.g. pain, fatigue, depressive symptoms) influence cognitive changes. Longitudinal studies would provide better understanding of the trajectory of cognitive changes and how such changes impact daily life functioning. Even so, further research must focus on measures and methods (such as ecological momentary assessment) that can detect cognitive changes in real-world settings. Such research is warranted to determine best practices regarding optimal self-management strategies for cognitive changes experienced in people with SSc. Finally, future studies should employ objective cognitive measures to evaluate any consistencies with self-reported cognitive difficulties and to better quantify the severity of cognitive impairments.

Conclusion

Participants indicated a significant impact of cognitive difficulties on their daily lives. Our findings represent an early step in increasing understanding of cognitive difficulties in people with SSc.

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Data availability statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Supplementary data

Supplementary data are available at *Rheumatology* online.

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