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ORIGINAL RESEARCH ARTICLE

Perspectives, perceptions, and expectations of subjects with frozen shoulder: a web-based Italian survey

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ABSTRACT

Introduction: Frozen shoulder (FS) is a musculoskeletal disorder affecting the glenohumeral joint. This condition leads to disability and a worsening in quality of life. Despite its considerable impact on patients and its economic burden, research on the psychological and social implications of FS—as well as patients' perspectives and needs—is limited. This study aims to explore the perspectives, perceptions, and expectations of individuals suffering from FS, providing a comprehensive understanding of their experiences and needs.
Methods: A cross-sectional observational study was conducted following STROBE guidelines. A 59-question survey was administered to Italian individuals diagnosed with FS from April 1 to July 1, 2023.
Results: All 110 participants completed the survey. Most preferred an experienced and empathetic physiotherapist (73.64%) and relied primarily on physiotherapy (49.09%) for FS management. Additionally, 45.45% were open to a multidisciplinary approach. Subjects reported reducing night pain (71.82%) and achieving full range of motion (ROM) recovery (70.91%) as their top priorities. Participants reported a notable shift in their mood from "pre" to "post" FS, with many experiencing fear and catastrophizing thoughts and perceiving a lack of social support. Furthermore, 27.27% were open to cortisone use, while 25.45% considered electrophysical agents beneficial for managing the painful phase of FS.
Conclusion: These results underscore a strong preference for empathetic physiotherapists and the value of a multidisciplinary approach. Addressing night pain and restoring ROM are crucial priorities—emphasizing the need for tailored and shared decision-making. Additionally, these findings highlight the importance of addressing psychological well-being alongside physical symptoms.

Keywords: Adhesive capsulitis, Frozen shoulder, Irritable mood, Psychological, Rehabilitation, Stress

What is already known about this topic

- *Frozen shoulder primarily affects working-age individuals and is characterized by severe pain, restrictions in multidirectional shoulder movement, and a significant economic burden. These issues have a stressful impact on physical, personal, and social aspects of individuals' lives.*

What does the study add

- *Individuals with frozen shoulder prefer skilled and empathetic physiotherapists, indicating a potential shift in treatment paradigms. The prevalence of catastrophizing tendencies and perceived lack of social support further underscore the need to address psychological well-being as part of patient care.*

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Introduction

Frozen shoulder (FS) is a condition affecting the glenohumeral joint (1,2), with a prevalence in the general population estimated to be between 2% and 5%, and with a higher incidence in women and subjects aged 40–60 years. The exact etiology of FS remains unclear, despite extensive research into its etiopathogenesis, biological characteristics, progression, fibrotic processes evolution, and joint changes (3,4), although several risk and predisposing factors have been identified—for example, diabetes mellitus, hypothyroidism, cardiovascular diseases, hyperlipidemia, and endotoxemia (5-8). Bilateral presentation, diabetes mellitus, thyroid disorders, and autonomic symptoms are recognized as biological factors associated with a poorer prognosis (5,6,9). In addition, psychological factors—for example, pain-related fear, depression, anxiety, catastrophizing (10), and self-perceived mental and physical health—significantly influence both subjective and objective clinical outcomes (11).

Despite its significant impact on subjects' lives (12-14), limited research has explored the psychological and social implications of FS. FS primarily affects subjects of working age, and it is characterized by severe pain, multiplanar shoulder movement restrictions, and a potentially significant economic burden. These factors alter the physical, personal, and social dimensions of those affected (12,13). FS symptoms impact various areas of life, including the work environment, and often lead to introversion and isolation (12,13). Moreover, family members are often called upon to support individuals with FS, sometimes leading to feelings of guilt over their dependency (13). Thus, the burden of FS extends beyond physical symptoms (15), affecting daily life through intense pain, disrupted sleep, perceived limitations, loss of independence, altered self-perception, and uncertainty about the condition (12,14). This may trigger emotional-cognitive alterations, influencing subjects' perception of pain and disability (16-18).

Several qualitative research studies have explored the psychological dimensions of subjects with FS (13,14,19), highlighting their subjective perspectives on rehabilitation. However, these studies often lack conclusive results on other specific issues—limited to understanding of subjects' experience and thereby hindering clinicians' ability to tailor effective management strategies and treatments.

Given the generally modest improvements seen in FS patients—particularly in terms of pain reduction and range of motion (ROM) recovery (20,21)—it is crucial to gain a deeper understanding of the psychological factors associated with FS. This includes examining patients' emotional states, the challenges they face during their condition and treatment, and their focus on achieving personal goals and returning to normalcy (13).

Therefore, the aim of this study is to explore the perspectives, perceptions, and expectations of subjects affected by FS through a cross-sectional survey.

Materials and methods

Study design

This study was designed as a cross-sectional observational study and conducted as an online-based survey. Results were reported following the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) checklist (22) and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (23) reporting guidelines. The study protocol has been submitted and approved by the Technical Scientific Committee of the University of Molise (Italy)—Prot. n. 10/2023. All the study-related procedures were performed according to the principles of the Declaration of Helsinki (24).

Setting, sampling, and recruiting

This study enrolled Italian and Italian-speaking subjects diagnosed with FS according to Kelley's guideline (25) criteria. Specifically, participants had painful shoulder with stable or worsening reduced external rotation with the arm by the side (<50% compared with the contralateral limb) over the past month, along with at least a 25% loss of active and passive ROM in two other planes, and negative x-ray (25). All subjects presented to the authors' private practice for their first physiotherapy consultation for FS, with no prior treatments.

Recruitment was voluntary and conducted over a 3-month period (from April 1 to July 1, 2023)—similarly to previous studies (26,27) and other international surveys (28-30). The timeframe was deemed adequate based on prior surveys on similar topics. Participants received no incentives, and duplicate responses were prevented using a single-user authentication. Additionally, no modifications were allowed after the survey completion. All potential participants were invited to participate via a link generated by Google Form.

Informed consent

All potential participants received a link to an information letter containing details about the investigators' identity, aim of the survey, inclusion criteria, data protection and dissemination of results, estimated time required for survey completion, and a clear informed consent statement ("If you voluntarily agree to participate in the survey, please scan this QR code or follow the link below; if not, you can close this document"). Access to the survey was granted only upon approving this consent. This method has been used in other surveys (29,30). The information letter is detailed in Appendix 1—Information Letter.

Survey development and pre-testing

The questionnaire was designed to investigate the perspectives, perceptions, expectations, needs, beliefs, and behaviors of subjects suffering from FS. Additionally, questions regarding other important priorities for FS subjects were included, for example, pain characteristics, awareness, treatment, disability, frustration due to prolonged and debilitating shoulder pain, impact on social relationships, skepticism from others, loss of independence, altered self-perception, experiences and expectations regarding healthcare providers, struggle for normalcy, and cognitive and emotional sense of uncertainty (12-14,19), as suggested by previous qualitative studies on this topic. The goal was to gather comprehensive insights that could inform better clinical management and improve outcomes for FS patients.

A draft of this cross-sectional survey was developed by six researchers—three physiotherapists and three orthopedic surgeons—specializing in shoulder diseases. Additionally, a psychotherapist was consulted to ensure the survey ability to assess psychological themes accurately. The final version of the survey, comprising 59 questions, was approved by the project lead and all team members.

Content validity was evaluated through a two-round pre-testing process. The initial round involved testing the questionnaire with four individuals who had previously experienced FS, followed by a second round with 10 subjects currently suffering from FS—in order to spot possible overlooked themes and clarify any confusing questions. Participants currently suffering from FS highlighted the need to address themes such as "unbearable pain," "long-lasting complaints," and "moments of discouragement." In response, the researchers and psychologist developed specific questions (Q47, Q51, Q52) to address these concerns, which were validated by the participants and incorporated into the final survey. Consensus on the survey structure was achieved through an online meeting with all involved parties.

Final version of the survey

The final version of the survey included 2 introduction questions (email address and consent to participate), 7 demographic questions, 3 questions on current levels of day and night pain and stiffness, and 47 topic-specific questions—as detailed in Appendix 2. All questions allowed for one response only. The demographic section comprised seven multiple-choice questions on sex, geographical origin, age, education, profession, time since FS onset, and number of clinicians consulted before diagnosis (Q3 to Q9). Additionally, three questions further assessed perceived day pain, night pain, and stiffness, utilizing a Numeric Rating Scale (NRS) (Q10, Q11, and Q12).

The questionnaire used a hybrid structure, combining multiple-choice (i.e., Q13-17, 23, 52, 58, and 59) and 5-point Likert scale questions (i.e., Q18-22, 24-51, 53-57). This approach is consistent with other previously published surveys (31,32) and aimed to gather detailed data on the importance that each subject attributes to various aspects of FS—with a particular focus on exploring fear and catastrophizing tendencies, in order to assess the psychological burden associated with FS.

Specifically, the technical questions covered: eventual prior diagnosis and imaging assessment (two questions, Q13 and Q14); expectation regarding health professionals and care process (four questions, Q15 to Q18); information about FS and its effects (four questions, Q19 to Q22); beliefs on treatment (four questions, Q23 to Q26); subjects' priorities (seven questions, Q27 to Q33); past (five questions, Q34 to Q38) and current (four questions, Q39 to Q42) mood; fear about their condition and the future (three questions, Q43 to Q45); expectation and catastrophizing thoughts related to pain, sense of self, struggle for normality (six questions, Q46 to Q51); social support, relationships, frustration, feeling of not being understood, loss of independence, skepticism from others (six questions; Q52 to Q57), and subjects' preferences regarding treatment (two questions, Q58 and Q59).

Data analysis

Data extraction and processing were performed using Excel—with all data stored in an encrypted, password-protected file. After survey completion, the anonymized data were forwarded for blind statistical analysis to a statistician (AT). Data analysis was performed using STATA 18 SE (33), with results reported as absolute and relative (percentage) frequencies of responses.

Results

Demographic

One-hundred and ten subjects were invited to complete the survey, and all provided their consent (100% completion rate), with no missing answers. On average, participants spent 11.22 minutes to complete the survey, as highlighted by the software.

Most participants were female (n = 72; 65.5%), aged 40 to 50 years (n = 47; 42.7%), and from northern Italy (n = 51; 46.4%). Most held a high school degree (n = 56; 50.9%) and were employed in non-physical jobs (n = 67; 60.9%).

Regarding the duration of FS, most participants had been experiencing symptoms for 5 months or longer (n = 69; 62.7%). Prior to diagnosis, most participants had consulted with one (n = 44; 40%) or two physicians (n = 30; 27.3%). Detailed demographic information is provided in Table 1 (Q3 to Q9).

Current level of day and night pain and stiffness

Participants reported a range of different day and night pain and stiffness levels. Most reported NRS pain scores between 5 and 8 during the day (n = 73; 66.4%) and between 7 and 10 at night (n = 68; 61.8%). Additionally, most rated their stiffness with an NRS score between 7 and 10 (n = 77; 70%). Detailed ratings of pain and stiffness are provided in Table 1 (Q10 to Q12).

Technical questions

Results showed that a significant number of FS patients had not undergone imaging investigations (n = 26; 23.6%). Among those who did, magnetic resonance imaging (MRI) was the most commonly prescribed, either alone (n = 24; 21.8%) or combined with x-ray (n = 17; 15.5%) (Q13). Interestingly, FS was frequently misdiagnosed as rotator cuff pathology (n = 48; 43.6%), with only 31.82% (n = 35) of cases receiving an initial correct diagnosis of FS (Q14).

Regarding interactions with physiotherapists, most participants (n = 81; 73.6%) preferred an experienced, empathetic, and caring physiotherapist (Q15). Moreover, the majority (n = 57; 51.8%) believed that physiotherapists should consider both anatomical and psychological aspects (e.g., fear, worry, anxiety, anger, lack of confidence) of FS. However, 30% of respondents (n = 33) indicated that functional outcomes should be the primary focus for physiotherapists (Q16).

Participants received several explanations about the natural history of FS from their clinicians. Some described three phases (freezing, frozen, and thawing) (n = 32; 29.1%), while others referred to two phases (pain predominant and stiffness predominant) (n = 17; 15.5%), and some did not specify any phases (n = 23; 20.9%) (Q17).

Most participants felt adequately informed ("disagree" = 37.3%; n = 41) (Q18) and supported ("disagree" = 36.4%; n = 40)

TABLE 1 - Demographic characteristics of respondents and answers for technical questions

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q1	Email	Anonymized	110	100
Q2	Consent form agreement. Do you want to complete the survey?	Yes	110	100
		No	0	0
Q3	Gender	Female	72	65.45
		Male	38	34.55
Q4	Italian Region of provenience	Northern Italy	51	46.36
		Central Italy	20	18.18
		Southern Italy	39	35.45
Q5	Age	≤39 years old	2	1.82
		40-50	47	42.73
		51-60	36	32.73
		61-65	18	16.36
		≥ 66	7	6.36
Q6	Educational level	Elementary school	3	2.73
		Middle school	9	8.18
		High school	56	50.91
		University degree	42	38.18
Q7	Work type	Mainly inactive (most of the time spent in the same position)	67	60.91
		Mainly dynamic (most of the time spent performing different activities/often changing position)	43	39.09
Q8	For how long have you been experiencing frozen shoulder?	More than 5 months	69	62.73
		3 months or less than 5 months	24	21.82
		More than a month and less than 3 months	17	15.45
		Less than a month or a month	0	0
Q9	How many doctors examined you before you were diagnosed with frozen shoulder?	1	44	40.00
		2	30	27.27
		3	24	21.82
		>3	12	10.91
Q10	On a scale from 0 to 10, where 0 means no pain and 10 means the worst pain you have ever felt, how would you rate your daytime pain?	0 no pain	5	4.55
		1	6	5.45
		2	2	1.82
		3	7	6.36
		4	7	6.36
		5	14	12.73
		6	17	15.45
		7	25	22.73
		8	17	15.45
		9	7	6.36
		10 worst pain ever	3	2.73

(*Continued*)

TABLE 1 - (*Continued*)

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q11	On a scale from 0 to 10, where 0 means no pain and 10 means the worst pain you have ever felt, how would you rate your nighttime pain?	0 no pain	7	6.36
		1	7	6.36
		2	2	1.82
		3	3	2.73
		4	10	9.09
		5	9	8.18
		6	4	3.64
		7	15	13.64
		8	22	20.00
		9	14	12.73
		10 worst pain ever	17	15.45
Q12	On a scale from 0 to 10, where 0 means no stiffness and 10 means the worst stiffness imaginable, how would you rate your stiffness?	0 no stiffness	0	0
		1	1	0.91
		2	2	1.82
		3	4	3.64
		4	5	4.55
		5	8	7.27
		6	13	11.82
		7	11	10.00
		8	34	30.91
		9	18	16.36
		10 worst stiffness ever	14	12.73
Q13	Which imaging tests have doctors recommended since your frozen shoulder diagnosis?	None	26	23.64
		MRI	24	21.82
		X-ray	17	15.45
		X-ray and MRI	17	15.45
		X-ray and MRI	10	9.09
		Ultrasound	9	8.18
		X-ray and ultrasound	7	6.36
		Arthro MRI	0	0
Q14	Before being diagnosed with frozen shoulder, did you receive a different diagnosis? If yes, please specify.	Yes, rotator cuff pathology (impingement, rotator cuff injury, tendinopathies)	48	43.64
		No, frozen shoulder is the first diagnosis I have received	35	31.82
		Yes, but I don't remember what	13	11.82
		Yes, periarthritis	10	9.09
		Yes, arthrosis	3	2.73
		Yes, rheumatologic issue	1	0.91
Q15	When considering physiotherapy treatment, what qualities or attributes do you prefer in a physiotherapist?	The physiotherapist should be expert, empathetic, and caring about my shoulder condition.	81	73.64
		I prefer a physiotherapist with specific expertise in managing shoulder pathology.	23	20.91
		I would like a physiotherapist who acts as a supportive partner and builds a relationship of trust.	5	4.55
		I prefer a straightforward approach where the physiotherapist focuses solely on assessing and treating the frozen shoulder.	1	0.91

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q16	In your opinion, what is the most important factor for your physiotherapist to consider?	Both anatomical and psychological (fear, worry, anxiety, anger, no confidence) aspects of frozen shoulder	57	51.82
		Functional outcomes (range of movement, pain, stiffness) about frozen shoulder	33	30.00
		More anatomical aspect than psychological one	17	15.45
		More psychological aspect than anatomical one	3	2.73
Q17	How did clinicians explain the development of your frozen shoulder?	They provided a detailed explanation, including the three phases of frozen shoulder, timing, and therapies.	32	29.09
		I received a satisfactory explanation about my condition, but no mention of phases.	23	20.91
		They provided a detailed explanation, including the two phases of frozen shoulder, timing, and therapies.	17	15.45
		I did not receive a clear explanation about my condition.	13	11.82
		They gave a brief explanation, including the three phases of frozen shoulder, timing, and therapies.	10	9.09
		Different clinicians provided varying explanations.	9	8.18
		They gave a brief explanation, including the two phases of frozen shoulder, timing, and therapies.	6	5.45
Q18	How much do you agree with the following sentences:	I totally agree	8	7.27
	I was not informed about my pathology.	I agree	21	19.09
		Neither agree nor disagree	15	13.64
		I disagree	41	37.27
		I totally disagree	25	22.73
Q19	I received unhelpful explanations that did not improve my ability to manage my condition.	I totally agree	5	4.55
		I agree	22	20.00
		Neither agree nor disagree	19	17.27
		I disagree	40	36.36
		I totally disagree	24	21.82
Q20	I received explanations that increased my anxiety and worried me about the potential for recovery failure.	I totally agree	8	7.27
		I agree	18	16.36
		Neither agree nor disagree	22	20.00
		I disagree	32	29.09
		I totally disagree	30	27.27
Q21	I received explanations that helped me cope with discouragement, reassured me, encouraged me, and allowed me to manage pessimistic thoughts about my condition.	I totally agree	20	18.18
		I agree	39	35.45
		Neither agree nor disagree	26	23.64
		I disagree	23	20.91
		I totally disagree	2	1.82

(*Continued*)

TABLE 1 - (*Continued*)

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q22	I received encouraging explanations that reduced my fear of movement as much as possible.	I totally agree	22	20.00
		I agree	48	43.64
		Neither agree nor disagree	16	14.55
		I disagree	22	20.00
		I totally disagree	2	1.82
Q23	Who do you believe is best equipped to manage your frozen shoulder?	Physiotherapist	54	49.09
		All aforementioned professionals when their expertise is needed	50	45.45
		Medical doctor (orthopedic, general practitioner, etc.)	3	2.73
		Medical doctor expert in pain management (algologist)	3	2.73
		Psychologist	0	0
Q24	To what extent do you agree with the following statement: If I put all my efforts into physiotherapy, I am confident I will fully recover from frozen shoulder	I totally agree	31	28.44
		I agree	44	40.37
		Neither agree nor disagree	20	18.35
		I disagree	14	12.84
		I totally disagree	0	0
Q25	These treatments are unhelpful, and I don't believe I will return to my previous condition	I totally agree	0	0
		I agree	21	19.09
		Neither agree nor disagree	20	18.18
		I disagree	42	38.18
		I totally disagree	27	24.55
Q26	If I put all my efforts into physiotherapy treatment, I will improve my situation, even if I don't achieve a complete recovery	I totally agree	4	3.64
		I agree	28	25.45
		Neither agree nor disagree	29	26.36
		I disagree	40	36.36
		I totally disagree	9	8.18
Q27	How much is important for you to achieve these results? Manage day-time pain.	Not important at all	1	0.91
		Unimportant	3	2.73
		Neutral	10	9.09
		Important	43	39.09
		Very important	53	48.18
Q28	Manage night pain.	Not important at all	1	0.91
		Unimportant	3	2.73
		Neutral	5	4.55
		Important	22	20.00
		Very important	79	71.82

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q29	Restore the full range of movement	Not important at all	0	0
		Unimportant	2	1.82
		Neutral	5	4.55
		Important	25	22.73
		Very important	78	70.91
Q30	Improve sleep quality	Not important at all	4	3.64
		Unimportant	0	0
		Neutral	5	4.55
		Important	35	31.82
		Very important	66	60.00
Q31	Improve autonomy in activities of daily living (showering, getting dressed, driving, etc.)	Not important at all	0	0
		Unimportant	1	0.91
		Neutral	9	8.18
		Important	35	31.82
		Very important	65	59.09
Q32	Improve occupational, leisure, and social activities	Not important at all	0	0
		Unimportant	2	1.82
		Neutral	18	16.36
		Important	29	26.36
		Very important	61	55.45
Q33	How much is important for you to be reassured by the physiotherapist about your clinical condition?	Not important at all	0	0
		Unimportant	1	0.91
		Neutral	18	16.36
		Important	49	44.55
		Very important	42	38.18
Q34	Which of these following sentences better describes your mood about frozen shoulder/adhesive capsulitis?	Not at all	19	17.27
	I'm feeling angry.	A little	16	14.55
		Moderately	32	29.09
		A lot	33	30.00
		Very much	10	9.09
Q35	I'm feeling sad/overcome.	Not at all	22	20.00
		A little	11	10.00
		Moderately	21	19.09
		A lot	33	30.00
		Very much	23	20.91
Q36	I'm feeling blue/low mood.	Not at all	17	15.45
		A little	15	13.64
		Moderately	24	21.82
		A lot	34	30.91
		Very much	20	18.18
Q37	I'm feeling powerless.	Not at all	23	20.91
		A little	19	17.27
		Moderately	29	26.36
		A lot	29	26.36
		Very much	10	9.09

(*Continued*)

TABLE 1 - (*Continued*)

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q38	I feel like I can react.	Not at all	1	0.91
		A little	21	19.09
		Moderately	25	22.73
		A lot	45	40.91
		Very much	18	16.36
Q39	How many times, BEFORE the onset of frozen shoulder/adhesive capsulitis, did you feel:	Never	6	5.45
	Angry	Rarely	43	39.09
		Sometimes	51	46.36
		Often	10	9.09
		Always	0	0
Q40	Sad/overcome	Never	12	10.91
		Rarely	36	32.73
		Sometimes	52	47.27
		Often	8	7.27
		Always	2	1.82
Q41	Blue/low mood	Never	18	16.36
		Rarely	33	30.00
		Sometimes	48	43.64
		Often	10	9.09
		Always	1	0.91
Q42	Powerless	Never	26	23.64
		Rarely	51	46.36
		Sometimes	27	24.55
		Often	5	4.55
		Always	1	0.91
Q43	How much do you agree with the following sentences?	I totally agree	0	0
	I'm afraid that moving my shoulder will make my condition worse.	I agree	25	22.73
		Neither agree nor disagree	21	19.09
		I disagree	47	42.73
		I totally disagree	17	15.45
Q44	I fear that frozen shoulder will cause irreversible damage to my shoulder.	I totally agree	2	1.82
		I agree	31	28.18
		Neither agree nor disagree	31	28.18
		I disagree	33	30.00
		I totally disagree	13	11.82
Q45	I fear I will never be able to return to my previous activities.	I totally agree	9	8.18
		I agree	41	37.27
		Neither agree nor disagree	22	20.00
		I disagree	25	22.73
		I totally disagree	13	11.82
Q46	How often have you had these thoughts?	Never	19	17.27
	I will never raise my arm as I used to do before	Rarely	10	9.09
		Sometimes	35	31.82
		Often	43	39.09
		Always	3	2.73

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q47	Pain is terrible and it will never end.	Never	23	20.91
		Rarely	15	13.64
		Sometimes	30	27.27
		Often	40	36.36
		Always	2	1.82
Q48	All I do to heal is useless.	Never	29	26.36
		Rarely	21	19.09
		Sometimes	38	34.55
		Often	20	18.18
		Always	2	1.82
Q49	My life is ruined.	Never	49	44.55
		Rarely	25	22.73
		Sometimes	27	24.55
		Often	8	7.27
		Always	1	0.91
Q50	I'm feeling overwhelmed by this condition.	Never	25	22.73
		Rarely	20	18.18
		Sometimes	38	34.55
		Often	26	23.64
		Always	1	0.91
Q51	I'm worried because I know this is a long-term pathology.	Never	9	8.18
		Rarely	18	16.36
		Sometimes	28	25.45
		Often	41	37.27
		Always	14	12.73
Q52	If you have experienced moments of demoralization or discouragement about your situation, how did you manage them?	I asked for advice to a clinician. He/she listened to me.	42	38.18
		I let off steam with a loved one.	22	20.00
		I have never had moments of demoralization/discouragement.	12	10.91
		I asked for advice to a clinician. He/she did not listen to me.	12	10.91
		I didn't share my discomfort with anyone.	11	10.00
		I felt abandoned and unable to manage those moments.	8	7.27
		I have taken the initiative to call a psychologist.	3	2.73
Q53	How well do you think people around you understand the seriousness of your situation? Are they supporting you in managing your pathology?	Not at all	9	8.18
		A little	46	41.82
		Moderately	29	26.36
		A lot	24	21.82
		Very much	2	1.82
Q54	How much do you agree with the following sentences? Other people fully understand my condition and they support me.	I totally agree	6	5.45
		I agree	30	27.27
		Neither agree nor disagree	35	31.82
		I disagree	29	26.36
		I totally disagree	10	9.09

(*Continued*)

TABLE 1 - (*Continued*)

	Question	Answers	Frequency (N = 110)	Percentage (%)
Q55	Other people fully understand my condition, but they don't support me as I wish.	I totally agree	1	0.91
		I agree	39	35.45
		Neither agree nor disagree	27	24.55
		I disagree	37	33.64
		I totally disagree	6	5.45
Q56	Nobody really understands my situation	I totally agree	12	10.91
		I agree	34	30.91
		Neither agree nor disagree	22	20.00
		I disagree	32	29.09
		I totally disagree	10	9.09
Q57	I don't feel supported at all	I totally agree	8	7.27
		I agree	23	20.91
		Neither agree nor disagree	24	21.82
		I disagree	39	35.45
		I totally disagree	16	14.55
Q58	If clinicians provide you with home exercises during the rehabilitation process, which method would you prefer to remember how to perform them?	Video with a phone and text messages	52	47.27
		Booklet	42	38.18
		No one preferred	11	10.00
		Draw made by your physiotherapis	5	4.55
Q59	Which additional therapy would you prefer to combine with physiotherapy to better manage your painful phase?	Cortisone (oral or injection)	30	27.27
		Therapeutic modalities (laser, diathermy, transcutaneous electrical nerve stimulation, shockwave therapy)	28	25.45
		Massage	18	16.36
		No one preferred	18	16.36
		Non-steroidal anti-inflammatory drugs	16	14.55

Data are reported as absolute and relative frequencies.

MRI = magnetic resonance imaging; N = number; Q = questions.

in managing FS (Q19). They also reported reduced anxiety and concerns about recovery failure due to the information provided ("disagree" = 29.1%; n = 32) (Q20).

Respondents agreed that clinicians provided helpful and reassuring information to manage discouragement ("agree" = 35.5%; n = 39) (Q21)—which contributed to increased encouragement and reduced kinesiophobia ("agree" = 43.6%; n = 48) (Q22).

While most participants primarily relied on physiotherapists for FS management (n = 54; 49.1%), they were also open to collaborative approach involving physicians, algologists, and psychologists when necessary (n = 50; 45.5%) (Q23).

Most participants believed that their efforts in physiotherapy would lead to complete recovery ("agree" = 40.4%; n = 44) (Q24), rather than just partial improvement (n = 28; 25.5%) (Q26) and found treatments to be beneficial (n = 42; 38.2%) (Q25).

Most participants identified several goals as "very important" (Q27-Q33): specifically, night pain (n = 79; 71.9%), full ROM restoration (n = 78; 71%), improvement of sleep quality (n = 66; 60%), autonomy in activities of daily living (n = 65; 59.1%), participation in social and leisure activities (n = 61; 55.5%), and daytime pain (n = 53; 48.2%). Lastly, reassurance from the physiotherapist (n = 49; 44.6%) was also considered "important."

Regarding the emotional impact of FS (Q34-Q38), many respondents stated they felt "a lot" angry (n = 33; 30%), sad or overwhelmed (n = 33; 30%), experiencing a blue or low mood (n = 34; n = 30.1%), and feeling powerless (n = 29;

26.4%). However, most respondents considered themselves to be reactive (n = 45; 40.9%).

Before FS onset (Q39-Q42), most respondents reported that they "rarely" felt angry (n = 43; 39.1%), sad or overwhelmed (n = 36; 32.7%), blue or experienced low mood (n = 33; 30%), or felt powerless (n = 51; 46.4%).

The survey also investigated respondents' fear (Q43-Q45). Most subjects with FS did not fear worsening their condition through shoulder movement ("disagree" = 42.7%; n = 47), or believe that FS will irreversibly damage their shoulder ("disagree" = 30%; n = 33). However, many were concerned they might never return to their previous activities ("agree" = 37.3%; n = 41).

Regarding catastrophizing (Q46-Q51), most respondents "often" thought that they would never regain full arm elevation (n = 43; 39.1%), that the pain was unbearable, that they felt trapped in a never-ending situation (n = 40; 36.4%), and that they were worried about the prolonged duration of their condition (n = 41; 37.3%).

Most respondents "sometimes" felt that all their efforts for healing were useless (n = 38; 34.6%), that they were overwhelmed by the situation (n = 38; 34.6%); however, they "never" thought that FS had ruined their lives (n = 49; 44.6%).

Six questions investigated social support, with most respondents reporting that they sought advice from a clinician who was ready to listen to them (n = 42; 38.2%) when they felt discouraged due to FS (Q52). A total of 41.8% (n = 46) felt that those around them had "little" understanding of the seriousness of their condition and provided inadequate support (Q53). In particular, 35 (31.8%) respondents were unsure whether people fully supported and understood their condition (Q54); however, most patients felt somewhat supported (n = 39; 35.5%) (Q57), although not as much as they would have hoped (n = 39; 35.5%) (Q55). Consistent with previous questions, 30.9% (n = 34) felt that others did not truly understand their situation (Q56).

To improve therapy adherence, participants preferred being filmed with a phone and receiving text messages for home exercises (47.3%, n = 52) (Q58). Most were also open to cortisone treatment (oral or injection) (27.3%, n = 30) or electrophysical agents (25.5%, n = 28) for managing the painful phase of FS (Q59).

Discussion

This study's main contribution provides a comprehensive insight into the psychological and social dimensions of FS. A key finding is the participants' strong preference for informed, empathetic guidance from healthcare professionals, particularly clinicians and physiotherapists. The survey also identified treatment priorities, emphasizing the need to alleviate night pain and restore ROM. Additionally, the study revealed significant levels of fear and catastrophizing among FS patients, which can affect treatment outcomes. These findings highlight the necessity for a multidisciplinary approach to FS management that addresses both psychological and physical aspects.

This study included 110 participants, predominantly females aged 40 to 50 years, consistent with FS demographics reported in the literature (34); most were from northern Italy and held non-physical jobs. This demographic information provides a typical profile of FS patients.

A notable issue was the high rate of misdiagnosis, highlighting the challenge of diagnosing FS, which is often only confirmed once stiffness is well-established (35). More than 20% of patients stated that imaging investigations were not prescribed, raising concerns about adherence to diagnostic guidelines and the potential underuse of tools that could identify other conditions mimicking FS and beyond physiotherapists' expertise (36). However, the utilization rate of MRI with or without x-ray appears relatively high compared to rates in other surveys (37-39).

Our sample reported a wide range of physical impairments due to FS—including both day and night pain and stiffness—revealing a considerable heterogeneity among respondents. Many participants reported moderate to severe pain and stiffness levels, emphasizing the significant impact of FS on daily life. Interestingly, participants viewed FS as affecting both biological and psychological aspects, with many believing that physiotherapists should address both in their treatment. This supports the need for a multidimensional approach to FS management, as emphasized in previous research (10,18).

Some participants noted inconsistencies in how clinicians explained the progression of FS, aligning with prior research (40) and trends in primary studies (34). Such inconsistencies may cause confusion, undermine trust, and affect treatment adherence (12,14). Despite this, most respondents were satisfied with the information provided, finding it helpful and supportive in managing their FS.

The respondents' perspectives on their condition revealed a mix of positive and challenging aspects. Many believed in the effectiveness of physiotherapy and anticipated a full recovery. However, they also reported persistent fear and concerns about long-term impact of FS on their daily activities—along with catastrophizing thoughts about pain and their future. These findings align with other qualitative studies (12,19), highlighting the ongoing struggle for normalcy experienced by those living with FS (12).

To the best of the authors' knowledge, this study was the first to ask participants to rate the importance of different priorities in subjects suffering from FS. Night pain, ROM restoration, and psychological reassurance emerged as key priorities for the participants, providing new evidence on this topic and suggesting treatments that align with patients' expectations. While a previous study identified pain relief as a main priority (14), our findings partially agree with this result but highlight additional concerns. Given that priorities may vary among individuals, clinicians should routinely investigate these preferences to enhance shared decision-making and patient engagement (41).

No consensus was found in the literature regarding whether psychological aspects could trigger FS or vice versa (42-45). This survey aimed to clarify this by examining the emotional experiences of FS patients. Participants reported a shift in their mood, with increased anger, sadness, and powerlessness after developing FS. These findings suggest that psychological distress is more a consequence than a cause of

FS, supporting previous research (12,13). The insidious onset, sleep deprivation, and significant pain and disability associated with FS—particularly in middle-aged individuals—may lead to the development or to the amplification of psychological symptoms. The prolonged recovery and limitations in using the affected arm may significantly impact daily life, work, and hobbies, contributing to psychological distress. FS significantly affects mental health, leading to feelings of anger, overwhelming, and powerlessness compared to before the onset of this condition—although some participants reported to be "reactive." Additionally, concerns about the underlying cause of pain could exacerbate catastrophizing and pain-related beliefs, further diminishing arm function and increasing disability (17,18).

Jones et al (14) reported that subjects often experience delays in receiving a definitive diagnosis of FS, a finding consistent with the experiences reported by participants in this survey, who consulted with multiple clinicians before receiving a diagnosis.

Delays or misdiagnoses, particularly during the initial phase, when pain and disability are most severe and quality of life is compromised, can worsen anxiety and depression. Such delays contribute to altered pain beliefs, unanswered questions, and uncertainty—potentially fostering distrust and leaving patients in a state of ongoing psychological fragility.

Similarly, social support emerged as a critical aspect in our sample. Many valued the understanding provided by clinicians but reported dissatisfaction with support from their social circles. This aligns with previous research, which describes FS as a hidden disability, leading to frustration over others' inability to recognize its seriousness (19). Additionally, family members often bear the burden of providing support, leading to feelings of guilt in the patients.

FS also contributes to disrupted routines, causing a sense of isolation and uncanniness, described as a form of anxiety and fear stemming from the realization of one's solitary existence (19).

The preference for technology-based support—like videos and text messages for home exercises—suggests that such tools could enhance treatment adherence.

Limitation of this study

This survey represents one of the most extensive studies providing valuable insights into the psychological and social dimensions experienced by subjects suffering from FS—highlighting the need for a comprehensive, patient-centered approach, as recommended in prior studies (18).

However, there are limitations. Self-reported data may be affected by participants' current emotional states, potentially leading to inaccuracies. While efforts were made to ensure content validity through literature review, expert consultation, and pilot testing, this survey's psychometric properties were not extensively validated. Additionally, participants' perspectives and needs may evolve over time. Social desirability bias may influence responses, especially regarding interactions with healthcare professionals. Additionally, the sample may not fully represent the Italian population, as participants were recruited from specific areas of Italy and from a single private physiotherapy practice, limiting the generalizability of the findings.

Implications for clinical practice

This survey highlights areas for improvement in physiotherapy practice. In terms of diagnosis, clinicians should carefully consider clinical presentation and disease progression, along with appropriate use of imaging, to reduce misdiagnosis of FS. Additionally, physiotherapists should enhance their therapeutic skills, as well as their abilities in communication, empathy, and patient care, as patients expect clinicians to be engaged and empathetic. Moreover, establishing a strong therapeutic relationship that aligns with patients' preferences is a key element of patient-centered care and has been positively linked to better clinical outcomes in physiotherapy (46). Notably, patients experience significant mood changes before and after FS—including increased feelings of anger, sadness, and low mood. Patients also emphasize the importance of feeling heard and reassured when expressing their fears. In light of these emotional changes and specific needs, adopting a biopsychosocial approach to patient care is essential. Additionally, catastrophizing thoughts and a lack of social support were noted—aligning with findings from previous studies (12-14,18,19). Physiotherapists should therefore be prepared to address these factors, as psychological interventions led by physiotherapists have shown promise in improving health outcomes (47). However, this approach may require additional training or collaboration within multidisciplinary teams to ensure the most effective and comprehensive care.

Clinicians should incorporate a holistic assessment of all patient domains from the initial evaluation and monitor these aspects consistently throughout rehabilitation, moving beyond the traditional biomechanical focus. From the patients' perspective, treatment priorities emphasize the need for physiotherapists to focus on relieving night pain and improving ROM, to better align with patient goals and increase satisfaction (41).

Future research

Given that this study included only Italian-speaking participants, future research should consider administering the survey in multiple languages to capture cultural nuances that might affect responses. While this study offers a snapshot of the participants' experiences, a longitudinal design would provide insights into how challenges and perceptions evolve over time. Such surveys could also help tailor rehabilitation approaches at the beginning and throughout therapy.

Incorporating more robust and validated measures could further enhance the reliability of the findings. Addressing these considerations in future research will deepen our understanding of FS and improve care and outcomes for affected individuals.

Conclusion

This survey highlights the complex challenges faced by individuals with FS, underlining the need for a comprehensive rehabilitation approach that addresses both physical and psychological aspects. Participants showed a clear preference for informed and empathetic physiotherapists and recognized the benefits of a multidisciplinary approach, suggesting a potential shift in treatment paradigms. Night pain and ROM recovery emerged as critical priorities, emphasizing the need for personalized interventions. The high levels of fear, catastrophizing tendencies, and perceived lack of social support highlight the need to address psychological well-being alongside physical symptoms—especially given the significant mood changes observed from “pre” to “post” FS. This study encourages future research on integrated, patient-centered approaches to FS management.

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