Factors influencing the occupational trajectory of patients with systemic sclerosis: a qualitative study

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ABSTRACT

Objective. *To describe, from the patient's point of view, the factors influencing the occupational trajectory of patients with systemic sclerosis (SSc).*

Methods. *This was a qualitative study designed using grounded theory with constant comparison. Data were collected through semi-structured interviews with 14 patients who fulfilled the American College of Rheumatology or Leroy-Medsger criteria for SSc.*

Results. *Based on our interviews, we found that the occupational trajectory of patients with SSc is influenced by the continuous interplay between four groups of factors. The first group concerns the values patients attribute to work, including identity, normality, financial value, social contact, and structure. The meaning of these values and how they relate to each other underlies the desire to work. A second group of factors is those influencing the balance between daily life, work participation, and medical condition (e.g. job content, flexibility in organising work, and the willingness to ask for accommodations at work). The occupational trajectory is also influenced by external factors, including availability of support, knowledge of the disease, pressure to work, contact with medical professionals, and existing regulations and the patient's knowledge about them. Finally, the occupational trajectory is influenced by personal factors, including socio-demographics, psychological assets, and disease- and work-related personal factors.*

Conclusion. *The decisions patients with SSc take concerning work depend on an interplay between many factors and, especially, on the patients' personal interpretation of these factors. These need to be taken into account when helping patients with SSc determine their occupational trajectory.*

Introduction

Systemic sclerosis (SSc) is characterised by generalised microvasculopathy, fibrosis of skin and internal organs, and an antibody response against autoantigens (1). Between 18% and 61% of patients do not work and a significant number make other work transitions.

Nearly all studies have focused on rates of work participation and prevalence of related factors (2-4). A more comprehensive view focusing on the experiences and perceptions of patients is needed to refine interventions. In this qualitative study, we examined the factors influencing the occupational trajectory of patients with SSc.

Materials and methods

This was a qualitative study based on the grounded theory with constant comparison (5, 6). A qualitative method is more warranted than a quantitative approach because the research focused on clarifying and interpreting patients' experiences about their occupational trajectory (7). Fourteen semi-structured interviews were carried out. The interviews evolved around the experiences of living/working with SSc. The interviews were mainly structured by the participants' input. All participants fulfilled the American College of Rheumatology/ Leroy-Medsger criteria (see Tables I-II) (8). In the beginning recruitment focused on maximum variation in patients' characteristics. Later sampling was built on the results of the analysis. An iterative process was used for data collection and analysis wherein themes were identified and elaborated with new data until no additional insights concerning the research questions on which we focused could be extracted (data saturation). Consequently, data collection stopped when data were saturated (see also supplementary file 1) (9, 10). The local Ethics Committee approved

Table I. General characteristics of the study population (n=14).

Characteristic	Statistic
Age in years, median (range)	49 (35-71)
Sex, female, n	9
Subset, n	
LcSSc*	8
DcSSc**	6
Disease duration in years, median (range)	6 (1-28)
Marital status, n	
Married	8
Divorced, living with partner	3
Divorced, no partner	2
Widowed	1
Children living in the household, yes	7
Highest level of education obtained	
Lower secondary	2
Higher secondary	9
Vocational secondary	5
Technical secondary	4
Higher education – not university	1
Higher education – university	1
Other	1

*LcSSc: limited cutaneous SSc; **DcSSc: diffuse cutaneous SSc.

Table II. Work-related characteristics of the patients (n=14).

Work-related variable	n
Employment status	
100% employed	4
50% employed/50% sick leave	1
Retired	1
Receiving disability pension	8
Work sector*	
Public	5
Private	7
Self-employed	2
Profession*	
Seller	1
Painter and related activities	1
Farmer	1
Guard and related activities	1
Administration	1
Nursing, childcare, or care of others	6
Teacher	1
Prevention adviser	1
Accountant	1

*Patients not currently employed were asked for their last employment.

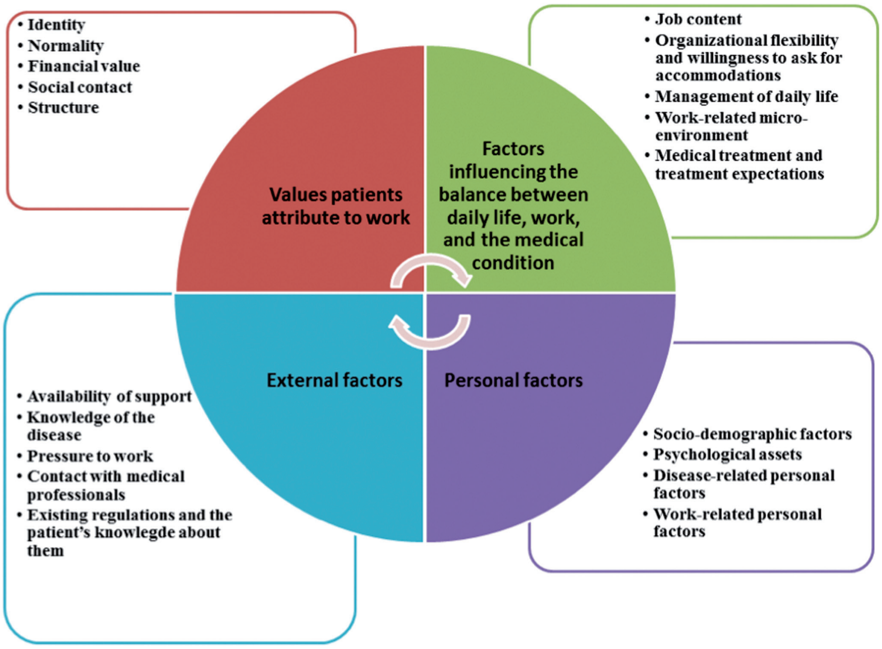

Fig. 1. The (interplay) of factors influencing the occupational trajectory of patients with SSc.

the study. All patients gave written informed consent. Results are visualised in Figure 1. Illustrative quotes of the results section are presented in Table III and referenced as Quote [Q]).

Results

Values attributed to work

• Identity

Patients want a job matching their educational level, that they can perform well, and that they find interesting as this allows them to express their individuality and to develop themselves (Q1). Patients may have to revise their criteria for a desirable job but will often not accept a job lacking the desired content as this gives feelings of loss. Others perceive the content as less important and give more weight to having a job. These patients take action for another job more easily. Younger patients, in particular, may lose part of their identity when being unable to perform the preferred job. With increasing age, other considerations may become more important. When people cannot attain identity through work, they search for other ways of expressing their individuality.

• Normality

Working contributes to the perception of being normal and contributing to society, whereas not working before the age of retirement is often associated with feeling abnormal, ashamed and useless. Patients find it abnormal to stop working before the age of retirement. In the beginning of the sick leave patients find it quite normal to be temporarily work disabled, but as the sick leave lengthens, feelings of abnormality increase. The latter also depends on the personal background, coping style and social microclimate (*i.e.* [perceived] others' thoughts) (Q2). Not working can disrupt other life domains which may create additional feelings of guilt (Q3-Q4). When people cannot attain normality through work, they search for alternatives to feel more normal *e.g.* spending more time with children.

• Financial value

Losing a paid job means giving up financial and personal security and therefore less control over decisions and, by extension, the whole life. Patients may feel a burden to society when disabled for a long time while not having reached retirement. Moreover, incorrect estimation of disease severity by the patient, surroundings, or society may underscore the need for a disability pension which may worsen feelings of guilt. The financial value of a job is important, regardless of living status *e.g.* being the person responsible for the earnings, or having a partner who works (Q5).

• Social contact

At work, patients can talk with colleagues about common topics. In addition they may have specific contacts, *e.g.* with patients. Having a job is one of the most important sources of social

Table III. Quotes of patients.

Quote 1:	It is always regrettable if you cannot return to your old job. I have never done anything else than being busy with wires, lights, and sockets. I loved that. It was pleasant because I could create things. That satisfied me.
Quote 2:	When you are able to work, you are a normal human being. Now there is something wrong. You cannot say you're normal.
Quote 3:	From that moment, my wife had to do almost everything in our business because I was disabled. In the long run, it was not possible for her to sustain this. She had less time for the household and the children. That is not normal. Normally, a woman has to be more at home and busy with the children.
Quote 4:	I needed to go away. When I was at home I saw the work and everything…. I could not cope with that. If I was away with my daughter, I could switch off my thoughts about not being able to work and to help my wife.
Quote 5:	Having a paid job, means being independent … having worked for my own money. Now that I feel better, I sometimes feel guilty to be free when all others are working.
Quote 6:	In the beginning I was very angry. You lose a lot of social contacts. By working, you see other people, you have colleagues, you can talk about things, and suddenly you have to stay at home. And then you sit there. Occasionally you can go to a friend…but not every day. A lot of people my age still work.
Quote 7:	You have to wake up and you know for what. You go to your job and that gives some kind of structure to daily life. If you are no longer able to work, you can lay in your bed until 10 o'clock.
Quote 8:	During my last job I had to work 85% in the cold. All the time I had to be in refrigerators. It was impossible to continue that job. You can consider the coldness as my enemy.
Quote 9:	If I have to go abroad, I try to go when it is not too cold in the country of my destination. It is an enormous advantage that I can arrange my work by myself, as I belong to the management.
Quote 10:	As an electrician, you have to be able to work in all situations, indoor and outdoor. If I had to work outdoors, I would have to ask a colleague to take over, and I don't want to do that.
Quote 11:	I have asked to work two days a week and not half days. If I have to go to work every day, I will not have the feeling of working part time. I need a lot of energy and time to get up in the morning. I need time to recover physically at night. So it will be better that I just have to be ready on time, 2 times a week instead of 5 days.
Quote 12:	Maybe they would understand but not completely. If I had to be in the hospital every six weeks, they would not understand it.
Quote 13:	What can I do? Unfortunately there are no initiatives, or not that I know … one should give people with a disability the opportunity to explore what they are able to do. I missed that. I miss that help because I did not know what I could do.
Quote 14:	Cancer is a known enemy. SSc is a vague disease. One year ago I had painful hands. Lately, I suffer from my stomach, intestines, esophagus … everything is so unclear.
Quote 15:	Being ill has serious financial consequences, which are not pleasant for my partner and children. I feel guilty about that. Is it my fault that we don't go on holiday? Of course! I find that terrible. I want to avoid problems in our relationship. I know my husband also would like to work less when he gets older. He already said to me that when I am on a disability pension, this will not be possible. So this is the reason to go back to work.
Quote 16:	I searched for information. I was told that it was financially better to stay on a disability pension and that in my situation, there was no advantage to remain independent. So I sold my business and stayed on a disability pension.

contact. Patients starting sick leave before retirement become more isolated (Q6). Patients living alone perceive work more as a source of social contacts than those living together (partner/children). When people cannot attain social contact through work, they search for alternatives *e.g.* volunteering and visiting surroundings. These alternatives are not always satisfactory.

• *Structure*

The mandatory nature of a paid job and the combination with other activities requires planning and creates structure. When patients are not working, they need to establish structure in another way (Q7).

Factors influencing the balance between daily life, work participation, and medical condition

• *Job content*

The ability of patients to perform their job depends on the content and the circumstances (Q8). As people feel less fit, they also perceive a physically challenging job as impossible. Patients perceive an administrative job as most suitable but some problems are perceived as difficult to overcome in any working situation, *e.g.* flexion contractures.

• *Organisational flexibility and willingness to ask for accommodations*

Some patients have the flexibility to organise their job according to the needs of the disease (Q9). The ease with which patients ask for help or adjustments depends on *e.g.* their knowledge of adjustments; coping style; thoughts about what others may think; and feelings of guilt (Q10). Those who ask for specific accommodations usually have had good experiences.

• *Management of daily life*

Patients feel physically less fit. They need more time for their tasks. Consequently, they perceive themselves as unable to manage all daily life activities and therefore they may hesitate returning to work. Returning to work is influenced by how patients set priorities *e.g.* patients foresee household help so they can work. Other patients first want to manage life without going to work (*e.g.* taking care of the household). When able to manage other activities, they will reconsider returning to work (Q11). Patients' perceptions about being able to manage daily life are also influenced by the patients' perception and interpretation of the work-related micro-environment (*e.g.* attitude of employer).

- *Medical treatment and treatment expectations*

Patients may perceive a medical treatment as a potential barrier to manage their work life balance *e.g.* they foresee problems if regular hospitalisation is necessary (Q12).

External factors

- *Availability of support*

Patients only have a vague idea about available/attainable jobs. Patients who have always performed the same job, in particular, do not easily envision other options and they do not know where to find help to make a job switch (Q13). Some also lack the courage to search for support or to explore options. Others indicate that they are willing to follow additional professional education.

- *Knowledge of the disease*

Symptoms of SSc are invisible and difficult to explain to others, making it difficult to clarify that they are real and severe enough to hinder them from working. Patients feel obliged to make others understand that their problems are legitimate. They perceive this as more difficult than for other diseases like cancer (Q14).

- *Pressure to work*

The feeling of being obliged to work is seen not only on a societal level but also at the family level. Patients feel guilty if they are unable to contribute to the family income. The beliefs patients have about what others think strongly influence their willingness to return to work (Q15).

- *Contact with medical professionals*

SSc is perceived as a generally unknown disease, even sometimes for physicians. The general practitioner is the physician to whom the patient initially goes with complaints and who refers to a specialist (seen as having the most expertise). Returning to work is not often explicitly discussed with physicians, not even with the medical adviser as he often only evaluates the work capacity. Although patients generally do not have frequent contact with a medical adviser, these contacts are important. Patients perceive contacts with physicians as very positive if they feel they have some knowledge of SSc and understand their personal situation.

Table IV. Personal factors influencing the occupational trajectory of patients with SSc.

Category of factors	Factors included in the respective category
Socio-demographic factors	Age, educational level, personal history, biography and living status
Psychological assets	Identity, beliefs, personality, need for social contact, feelings of helplessness, and ability and mechanisms for coping with others' potential reactions and perceptions
Disease-related personal factors	Coping, illness perceptions and beliefs, knowledge of the disease, potential adaptations, and existing regulations.
Work-related personal factors	Personal meaning of work, need for work, and intent to return to work.

- *Existing regulations*

Regulations influence the patient's trajectory. Moreover, patients have sometimes incorrect/incomplete knowledge of existing regulations, which they use as input for decisions. Moreover, patients do not always know where to get the necessary information. Some patients search for supporting measures matching their personal situation (Q16).

Personal factors

Personal factors influencing the trajectory fall into four groups (see also table 4): (I) socio-demographic factors (*e.g.* educational level); (II) psychological assets (*e.g.* identity); (III) disease-related personal factors (*e.g.* coping); (IV) and work-related personal factors (*e.g.* intent to return to work.

Discussion

We identified four groups of factors influencing the occupational trajectory. Because the values patients attribute to work steer the desire to work, these should be assessed. Patients unable to work need support to cope with the loss of their original way of work. In the current study we did not aim to give an overview of organ manifestations influencing the trajectory. Therefore other research methodologies, especially quantitative, are more suitable. Our data show that not the disease as such but the possibility of the management of the disease in the context of (personal) aspects of daily life, job characteristics, knowledge about regulations, etc. influences the trajectory. Therefore, among others, advice should be adapted to the specific situation and the patient's beliefs. Patients should be informed proactively about regulations as this can avoid decisions based on wrong/incomplete information. If the former job is no longer possible, the patient will need help in finding another job as choosing a second-choice job is not an easy decision. We also confirmed that personal factors play a role (11). These need to be considered when advising patients about work-related interventions.

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