

Supplementary file

Extended information on the methodology used

Introduction

This was a qualitative study based on the grounded theory with constant comparison. We aimed to develop higher level understanding that is 'grounded' in/derived from a systematic analysis of data whereby an iterative study design is used (cycles of simultaneous data collection and analysis) (1-3). A qualitative method is more warranted than a quantitative approach because the research focused on clarifying and interpreting patients' experiences about their occupational trajectory (4). The specific objective was to describe, from the patient's point of view, the factors influencing the occupational trajectory of patients with SSc and especially how these factors play a role. The study was approved by the Ethics Committee of the Ghent University Hospital. All patients gave written informed consent.

Participants

All participants had to fulfil the American College of Rheumatology or Leroy-Medsgers criteria for SSc (5).

At the beginning of the study, recruitment was focused on maximum variation in the patients' characteristics, such as age, family situation, type of work, work history, ... (6). Therefore patients indeed vary in such characteristics (*e.g.* age). This gives us the opportunity to explore problems and to deepen/widen our insights.

As the study proceeded, our sampling was further built on the results of the data analysis. To further assess

what (and how) really plays a role we strived for heterogeneity in these variables which, given the interim analysis, play a role (*e.g.* we sampled different disease duration categories of patients with more or less the same demographic status). In qualitative research this is called sampling on theoretical grounds (theoretical sampling). As the analysis progresses the sample is thus further selected purposefully. Participants are chosen for their ability to confirm or challenge an emerging theory (7). In contrast with quantitative approaches qualitative studies do not usually have predetermined sample sizes. Sampling stops when a thorough understanding of the phenomenon under study has been reached (7). Therefore 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). Fourteen interviews were conducted.

Data collection

Data were collected through semi-structured interviews carried out by a single researcher (SD). By talking with the participants we got in-depth information which was used inductively to allow meaning emerge from the data (8). The central topic of the interviews revolved around the experiences of living/working with SSc. The interviews were mainly structured by the input of the participants. Topics were only introduced after the participant's story was fully explored. The participants could choose to be interviewed either at home (n=8) or in the hospital (n=6). All interviews were audio-taped and fully transcribed.

Data analysis

Interviews were read and interpreted as a whole by the principal researcher (SD), in order to have an overall picture of the situation, and were then scrutinised with the focus on relevant details. The interviews were coded with NVivo 10 software tool (QSR International). Two researchers specialised in qualitative research (SV, MG) followed the process, read all transcripts, checked the interpretations, and discussed the analysis with SD. The results of the analysis was then discussed with two rheumatologists (VS, FDK). All information stated in the results section was revealed out of the interviews.

References

- HOLLOWAY I, WHEELER S: Grounded Theory. In HOLLOWAY I, WHEELER S, (Eds.): *Qualitative Research in Nursing and Healthcare*. USA, Wiley-Blackwell 2010: 173-91.
- LINGARD L, ALBERT M, LEVINSON W: Grounded theory, mixed methods, and action research. *BMJ* 2008; 337: a567.
- CHARMAZ K: *Constructing grounded theory: A Practical Guide Through Qualitative Analysis*. 1st ed., London, Thousand Oaks, New Delhi, SAGE Publications, 2006: 210.
- HOLLOWAY I, WHEELER S: *Qualitative Research in Nursing and Healthcare*. USA, Wiley-Blackwell, 2010.
- LEROY EC, MEDSGER TA: Criteria for the classification of early Systemic Sclerosis. *J Rheumatol* 2001; 28: 1573-6.
- HOLLOWAY I, WHEELER S: Sampling and Site Selection. In HOLLOWAY I, WHEELER S (Eds.): *Qualitative Research in Nursing and Healthcare*. USA, Wiley-Blackwell 2010: 137-50.
- KUPER A, LINGARD L, LEVINSON W: Critically appraising qualitative research. *BMJ* 2008; 337: a1035.
- KUPER A, REEVES S, LEVINSON W: An introduction to reading and appraising qualitative research. *BMJ* 2008; 337: a288.