



Exploring the Challenges and Support Needs Among Caregivers of People Living with Scleroderma

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Agenda

- What is an informal caregiver?
 - What can caregiving for people with scleroderma involve?
 - What did we know about caring for people living with scleroderma?
- Objectives
 - Focus groups
 - International survey of caregivers
- Future goals
 - Currently available resources
- Questions



INFORMAL CAREGIVERS

- Informal caregivers provide support to a loved one.
 - Family or friends (e.g., parent, children, siblings, cousins, neighbour).
 - No training or financial compensation (1).
- Caregiving can involve:
 - Helping with daily chores.
 - Attending medical appointments.
 - Providing general support.
- Most research on caregiving has focused on those who care for people with cancer or dementia.
 - Caregiver burden and burnout have been well studied in these caregivers.
- Very little research has been done related to caring for someone with a rare disease.

INFORMAL CAREGIVERS – RARE DISEASES

- Approximately 350 million people are living with a rare disease worldwide (1).
- Caring for a loved one with a rare disease can involve:
 - Travelling long distances.
 - Consulting with multiple doctors.
 - Managing feelings of isolation (2-7).
- Professional support services are not typically available for people with rare diseases, and patients and caregivers often organize their own sources of support (8,9).

INFORMAL CAREGIVERS - SCLERODERMA

- Scleroderma, is a rare autoimmune connective tissue disease that can affect multiple organ systems (2).
- Scleroderma can look different from one person to another.
 - Similarly, the caregiving experience can vary greatly between caregivers
- People with scleroderma often rely on informal caregivers.
 - Level of support from caregivers can range from a couple of hours a week to many hours per day.

WHAT WE KNEW ABOUT SCLERODERMA CAREGIVERS

- Very little.
- One previous study considered the cost of informal caregivers for people with scleroderma.
 - Found that caregivers represent a significant cost in Spain, Europe and Canada.
- Previous PhD thesis aimed to answer the question: “what are the experiences of people caring for individuals living with scleroderma?”
- 13 caregivers were interviewed and described their experience of caregiving for a loved one with scleroderma (2).

PREVIOUS RESEARCH: SCLERODERMA CAREGIVERS

- Caregivers that were interviewed described 3 main experiences:
 - **Personal Impact:**
 - Feeling the impact (e.g. guilt, hopelessness)
 - Stress and coping (e.g. hyper-vigilance, financial strain)
 - Relational strain (e.g. social support, decreased spontaneity)
 - **Existential Concerns**
 - Shifting in a different life/different role
 - Finding meaning (career adjustment)
 - Individuality
 - Mortality (e.g. the unknown, time, grief)
 - **The Unique Disease**
 - Complications (e.g. frustration with diagnosis, complicated disease)
 - Isolating diagnosis (e.g. isolation within the disease)

PREVIOUS RESEARCH: SCLERODERMA CAREGIVERS

- Thesis concluded that caregiving for a loved one with scleroderma results in many challenges.
- Challenges varied greatly among caregivers.
- Suggested future research:
 - Include more participants and involve quantitative data to understand caregiving experience in more people.
 - Potential differences in men and women caregivers.

OVERARCHING GOALS – INFORMAL CAREGIVERS SCLERODERMA

- **Ultimate goal:** To share resources or support services that caregivers to persons with scleroderma would find helpful.
- Knowing that there was very little research about caregivers for loved ones with scleroderma we wanted to understand:
 - Challenges of informal caregivers to people living with scleroderma.
 - The burden that caregivers face.
 - The type of resources available for other types of caregivers and the usefulness of these resources.
 - The services that caregivers want in order to improve their quality of life and burden associated with caregiving.

CAREGIVER FOCUS GROUPS

- Project Goals:
 - Develop list of challenges experienced by informal caregivers of people living with scleroderma.
 - Develop a list preferences for types of support services that could potentially be developed.

CAREGIVER FOCUS GROUPS

- Approach:
 - Gathering information from a large number of caregivers is best accomplished via a survey.
 - Survey items can be generated using various methods, including the nominal group technique (NGT).
 - The NGT approach involves structuring group discussions in a way that allows individuals to directly generate items for a needs-assessment survey (12).

CAREGIVER FOCUS GROUPS

Methods:

- Three NGT discussions were conducted at the Scleroderma Foundation of the USA and Scleroderma Canada conferences with caregivers to people with scleroderma.
- Caregivers were asked to:
 - “Think about the challenges you have faced since taking on a caregiving role to somebody close to you with scleroderma”.
- Caregivers then wrote lists of all of the challenges faced.
- One master list of all compiled answers was created.
- Caregivers then rated each challenge that was brought up in the group based on how personally important it was to them.
 - 1 (“not important”) to 4 (“very important”).



CAREGIVER FOCUS GROUPS

Methods:

- Using the same approach as the first question, caregivers were asked next to:
- “Think about services that could be put in place to provide better support to scleroderma caregivers. What programmes, services or supports would be helpful in your role as a caregiver?”
- Caregivers then wrote lists of all of the support services that they thought would be helpful.
- One master list of all compiled answers was created.
- Caregivers then rated each support service that was brought up in the group based on how likely they were to use this resource if it was available.
 - 1 (“not at all likely”) to 4 (“very likely”).

CAREGIVER FOCUS GROUPS

Results:

- The three groups (N = 13) generated 89 challenge and 41 support service items.
- Lists were sent to the research team and the Scleroderma Caregiver Advisory Committee.
- After rewording, removing, or combining items, total of 61 challenge and 18 support service items.

CAREGIVER FOCUS GROUPS

- Commonly identified challenges:
 - Not having information about how to be a good caregiver.
 - Not knowing other people who understand what I'm going through.
 - Not having access to a caregiver support group.
- Commonly identified support services:
 - Internet-based psychological and emotional self-help tools.
 - Caregiver newsletter.



CAREGIVER FOCUS GROUPS

Item	Original item number prior to item reduction*	Mean rating of challenge importance (1–10)	Participants who rated the item (n)
Physical health concerns			
Experiencing fatigue and physical exhaustion	3, 84	6.3	8
Having trouble sleeping	8	5.0	2
Taking care of my health	Not applicable†		
Financial problems and work or employment problems			
Balancing caregiving and demands associated with my job	2	6.0	2
Having to take days off from work due to caregiving responsibilities	1, 63	4.3	8
Managing the cost of drugs and medical care	30	8.5	2
Managing loss of income due to my care recipient's inability to work	31, 72	6.4	8
Role strain			
Balancing caregiving and other family responsibilities	10	6.5	2
Managing last minute changes due to the unpredictability of the disease	64	3.8	6
Having to do all of the winter chores alone due to my care recipient's sensitivity to cold temperatures	79, 80	5.0	6
Having to handle all of the household chores on my own	45	6.0	5

CAREGIVER FOCUS GROUPS

Item	Original item number prior to item reduction*	Mean rating of service importance (1–10)	Total number of participants who rated the item
1. Caregiver internet-based chat group, forum or social network site without professional moderator	7, 20	9.0	6
2. Caregiver internet-based chat group, forum or social network moderated by a knowledgeable healthcare provider	8, 37	7.0	8
3. Caregiver-led breakout groups at patient conferences	9	9.5	2
4. Professionally led breakout groups at patient conferences	10, 27	8.4	8
5. Internet-based psychological and emotional self-help tools	12	10.0	2
6. One-to-one peer support (eg, the ability to call another caregiver on the phone)	13	9.5	2
7. Professionally led in-person caregiver support group	2, 14	7.8	6
8. Caregiver-led in-person caregiver support group	1, 15, 31	7.3	12
9. Professionally led telephone-based support groups for caregivers	4, 16	5.8	6
10. Caregiver-led telephone-based support groups for caregivers	3, 17	6.0	6
11. Professionally led internet-based, live interaction (teleconference, Skype) caregiver support groups	6, 18	7.7	6
12. Caregiver-led internet-based, live interaction (teleconference, Skype) caregiver support group	5, 19, 35	7.5	12
13. Caregiver newsletter	21	9.5	4

CAREGIVER FOCUS GROUPS

Conclusions:

- Final list of 61 challenge and 18 support service survey items was generated.
- Many challenges reported related to rarity of the disease.
- No current formal support services for caregivers of people with scleroderma, but some of the items identified (e.g. caregiver support groups, teleconference-based interventions, educational sessions) have been used by caregivers of more common diseases (e.g. dementia, asthma, cancer). (13-15)

FOCUS GROUPS → SURVEY

Project Goal:

- Survey items were generated in focus groups to distribute relevant challenges and support services to an international sample of informal caregivers of people living with scleroderma.
 - Evaluate the importance of different challenges experienced by informal caregivers to persons with scleroderma.
 - Identify priorities for support services that could be potentially be developed.

CAREGIVER SURVEY


Methods

- Informal caregivers to people with scleroderma were recruited through five patient organizations in North America, Europe, and Australia.
- Caregivers completed an online questionnaire which included the 61 challenges and 18 support service items generated from the NGT discussions.
- Challenges were rated from 1 (“not important”) to 4 (“very important”) based on the perceived importance of the item.
- Support services were rated from 1 (“not likely”) to 4 (“very likely”) based on the likelihood of using the service.

CAREGIVER SURVEY



A Survey of the Informal Caregiver Experience / Questionnaire sur l'expérience des aidant(e)s naturel(le)s

English 

Are you currently a caregiver for a friend or family member diagnosed with Scleroderma?

☐ Yes

☐ No

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CAREGIVER SURVEY

- 202 informal caregivers completed the survey.

Variable	Men	Women
Number, <i>n</i> (%)	123 (60.9)	79 (39.1)
Age, <i>mean</i> (<i>SD</i>)	60.6 (12.5)	51.8 (15.4)
Scleroderma subtype, <i>n</i> (%)		
Limited scleroderma or CREST	47 (38.2)	21 (26.6)
Diffuse scleroderma	57 (46.3)	43 (54.4)
Unknown or not specified	19 (15.4)	15 (19.0)
Age of person with scleroderma, <i>mean</i> (<i>SD</i>)	58.8 (12.5)	56.7 (14.6)
Years of providing care for care recipient, <i>mean</i> (<i>SD</i>)	31.9 (12.5)	28.0 (13.2)

CAREGIVER SURVEY

- Highest Rated Challenges:
 - Providing emotional support to my care recipient on challenging days - 92% (*rated as important or very important*).
 - Being unable to help address my care recipient's pain or discomfort - 84% (*rated as important or very important*).
- Highest Rated Support Service:
 - Caregiver newsletter - 58% (*rated as likely or very likely to use*).
 - Information about scleroderma on an online reputable website for caregivers of newly diagnosed patients - 55% (*rated as likely or very likely to use*).

CAREGIVER SURVEY

- Caregivers rated difficulty addressing emotional needs of the care recipient as especially important.
- Caregivers rated information-based resources highest, especially those delivered soon after diagnosis.
- They also rated support services that could be accessed and use independently higher than those that involved interacting with other caregivers or professionals.



CAREGIVER SURVEY

Comparisons Between Women and Men

- For 59 of 61 items women rated the challenges higher than men.
- Significant differences on five challenges:
 - Finding time for myself.
 - Not having access to a caregiver support group.
 - Finding assistance for things that my care recipient use to do.
 - Feeling ashamed to think about my own well-being or needs.
 - Noticing others' lack of knowledge and awareness about scleroderma.

CAREGIVER SURVEY

Limitations

- We did not explore why certain challenges or support services preferences were rated higher than others.
- Recruitment occurred through an ongoing patient cohorts, patient organizations, and social media websites.
- The survey was only available in English and French.
- Participants had to have access to a computer and internet.

CAREGIVER SURVEY

Conclusions

- Prior to the focus group study only one doctoral thesis had considered caregiving in scleroderma.
- Caregivers who completed the survey reported a preference for information-based resources over interactive support services.
- The use of information packages delivered online, hard-copy resources, and web-based psychoeducation interventions have been studied in more common diseases.
- These interventions could be helpful among informal caregivers of people living with scleroderma.

SUMMARY AND NEXT STEPS

- Prior to these studies, the experiences of informal caregivers of people living with scleroderma were unknown.
- The work described:
 - (1) identified the benefits of support services for caregivers of people with rare diseases and the facilitators in establishing and maintaining them
 - (2) created a scleroderma caregiver-generated list of challenge and support service items
 - (3) disseminated the list to an international sample of scleroderma caregivers and reported the most important challenges faced and the support services most likely to be used.
- Next steps will involve:
 - developing and testing resources that address caregiver challenges.
 - delivering resources in a format that can be accessed independently and soon after diagnosis.

AVAILABLE RESOURCES



Guide for Informal Caregivers



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Scleroderma Foundation Michigan Chapter's Guide for Caregivers

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QUESTIONS AND COMMENTS?



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