

Identifying the Needs and Priorities of Informal Caregivers for People Living with Systemic Sclerosis

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Overview of Presentation

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1. What is an informal caregiver?

- What can caregiving for someone with a rare disease include? What did we know about caring for a loved one with scleroderma?

2. SPIN-CARE Research

- Focus group
- Survey

3. Available Resources

- Available supportive resources



Informal Caregivers

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- Informal caregivers provide **support** to a loved one.
 - Family or friends (e.g., parent, children, siblings, neighbour).
- Caring for a loved one can involve:
 - helping with chores;
 - managing medications.
- Most research on informal caregivers involves those caring for a loved one with a **common disease**.
 - E.g., Alzheimer's, dementia, cancer.



Informal Caregivers for a Rare Disease

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- Rare disorders are **complex** and **burdensome** and typically require an informal caregiver.
 - **50%** of rare disease caregivers reported feeling they had **no choice** but to take on their role.
- Caregiving can be a **rewarding role**.
 - **Closeness** with the care recipient.
- Caregiving is often perceived as **demanding, complex, and stressful**.
 - **1 in 5** caregivers report coping 'very well'.

Informal Caregivers for a Rare Disease

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- Caring for a loved one with a rare disorder can involve all the tasks associated with caring for a common disease.

This role also often involves



Informal Caregivers for a Rare Disease

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A 2019 national report found that **two-thirds (66%)** of **caregivers** for a loved one with a rare disease reported feeling **unsupported** by the **healthcare system**.



What is known about caregivers and SSc?

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- Very little.
- Only one previous study has aimed to determine the *experiences of people caring for individuals living with SSc*.
- 13 caregivers were interviewed and described their experiences.

Personal Impact	Existential Concerns	The Unique Disease
<ul style="list-style-type: none">• Feeling the impact (e.g. guilt, hopelessness)	<ul style="list-style-type: none">• Shifting in a different life/different role	<ul style="list-style-type: none">• Complications (e.g. frustration with diagnosis, complicated disease)
<ul style="list-style-type: none">• Stress and coping (e.g. hyper-vigilance, financial strain)	<ul style="list-style-type: none">• Finding meaning (career adjustment)	<ul style="list-style-type: none">• Isolating diagnosis (e.g. isolation within the disease)
<ul style="list-style-type: none">• Relational strain (e.g. social support, decreased spontaneity)	<ul style="list-style-type: none">• Mortality (e.g. the unknown, time, grief)	

Informal Caregivers and SSc

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- The study recommended areas for future research to improve the experience of those supporting a loved one with SSc.

Recommendations for Future Research

- Include **more** participants
- Gather **quantitative** data
- Recruit **male caregivers**

Objectives

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- The current research aimed to:
 - (1) Identify the **burden** experienced among caregivers of a loved one with a chronic condition, including SSc.
 - (2) **Develop a list** of **challenges** that caregivers to people living with SSc experience and possible **support services**.
 - (3) **Survey** caregivers to those with SSc to determine most **important** challenges and **prioritize the support services** most likely to be used.

Study One: Objectives

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Systematically identify and compare:

- The burden reported among **SSc caregivers** as compared to caregivers of other **chronic medical conditions**.



Overview of Methods

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Eligibility Criteria

Population	Caregivers to individuals with a chronic condition (rare or common)
Measure	Zarit Burden Interview
Country	Very high and high human development index

Zarit Burden Interview Items

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➤ Examples of Zarit Burden Interview items

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4

Overview of Results – Zarit Burden Scores

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N = 85 studies

Disease group	Number of studies	Number of participants	Pooled mean	Standard deviation	95% confidence interval
Amyotrophic lateral sclerosis	1	18	12.4	7.9	8.8 – 16.0
Cirrhosis	1	58	11.5	8.4	9.3 – 13.7
Essential tremor	1	57	6.4	8.4	4.2 – 8.6
Heart failure	3	200	12.6	-	9.5 – 15.7
Spinal cord injury	2	266	9.6	-	5.3 – 13.9
SSc	1	202	13.5	9.8	12.1 – 14.9

Conclusion

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- **Conclusions:** caregivers of people living with SSc reported the **highest levels** of **perceived burden** as compared to caregivers of other chronic conditions.
- **Gaps:** Most chronic conditions only included one study, additional research is needed.
- **Future directions:** **Intervention development** that considers these results can be guided by the aspects of burden reported as being most common among conditions.

Use of the Nominal Group Technique to Identify Stakeholder Priorities and Inform Survey Development: an Example with Informal Caregivers of People with Scleroderma

Open Access

Research

BMJ Open Use of the nominal group technique to identify stakeholder priorities and inform survey development: an example with informal caregivers of people with scleroderma

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Study Two: Objective

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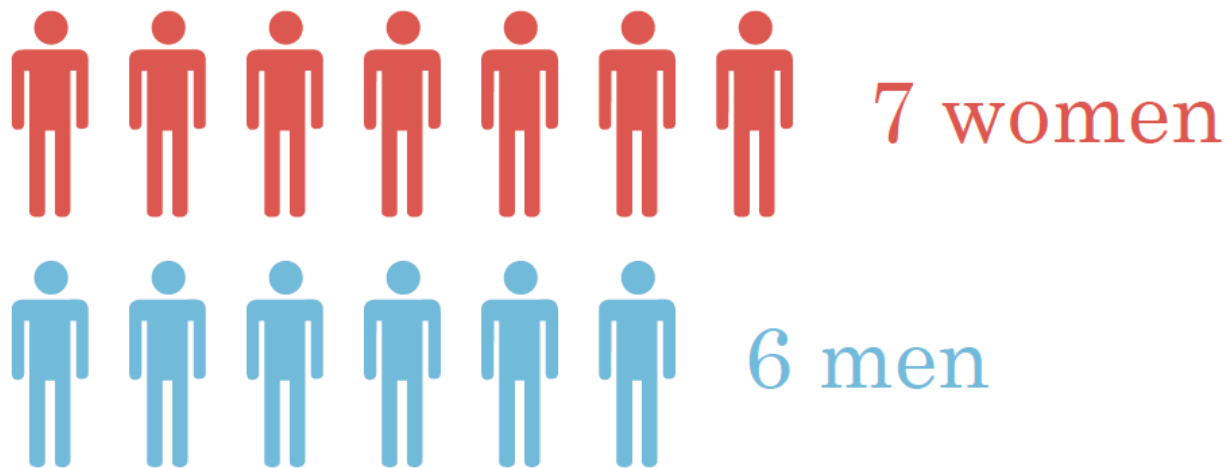
- Develop a list of **challenges** experienced by informal caregivers of people living with SSc.
- Develop a list of preferences for types of **support services** that caregivers would be likely to use.

Overview of Methods

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- Three **group discussions** were conducted at the Scleroderma Foundation (USA) and Scleroderma Canada conferences with caregivers to people with SSc.
- Caregivers were asked to:
 - **“Think about the challenges you have faced since taking on a caregiving role to somebody close to you with scleroderma”.**
 - **“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?”**

Focus groups with 13 individuals who provide care for a family member, partner, or friend with scleroderma.




Caregivers ranged from 28 to 76 years old.

Reported challenges

- Concerns about their own physical health
- Financial, and work-related problems
- Difficulty filling social roles and responsibilities
- Lacking information, resources, and support
- Feeling scared, anxious, and uncertain
- Helping their loved one cope emotionally
- Changing relationship dynamics with their loved on





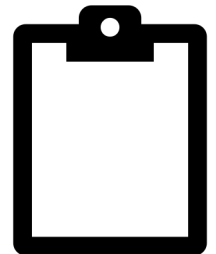
**Caregivers
generated 18
unique services
to support them**

- A newsletter for scleroderma caregivers
- Caregiver-led breakout groups at patient conferences
- Online psychological and educational support tools
- One-on-one support from another caregiver

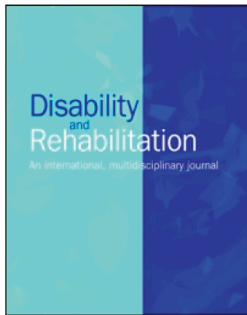
Conclusions

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- **Conclusion:** A final list containing **61 challenges** and **18 support service** survey items was generated.
- **Rarity:** Many reported challenges related to the **rarity** of the disease.
- **Future Directions:** These results led to the development of a survey for a larger number of SSc caregivers.



Challenges and Support Service Preferences of Informal Caregivers of People with Systemic Sclerosis: A Cross-Sectional Survey



Disability and Rehabilitation



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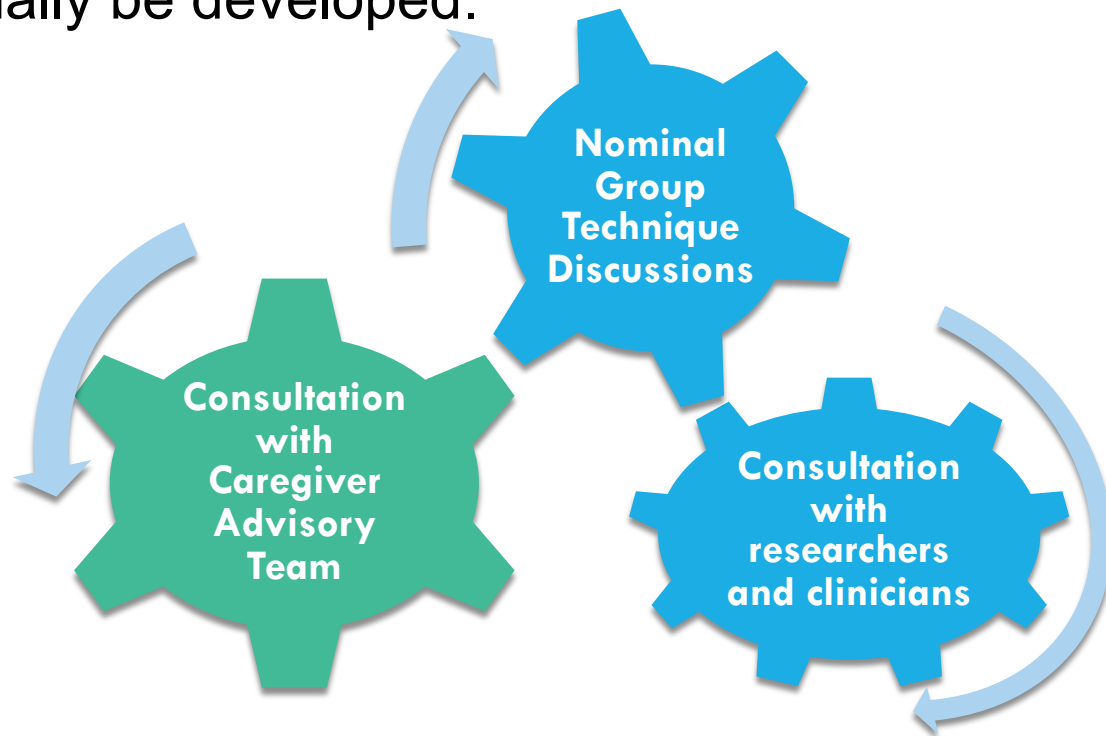
Challenges and support service preferences of informal caregivers of people with systemic sclerosis: a cross-sectional survey

Danielle B. Rice, Mara Cañedo-Ayala, Andrea Carboni-Jiménez, Marie-Eve Carrier, Julie Cumin, Vanessa L. Malcarne, Mariët Hagedoorn, Brett D. Thombs & Scleroderma Caregiver Advisory Team

Study Three: Objectives

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- Evaluate the ***importance of different challenges*** experienced by informal caregivers to persons with SSc.
- Identify ***priorities for support services*** that could potentially be developed.



Overview of Methods and Data Analysis

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Survey

- Caregivers completed an online questionnaire which included items generated from the group discussions (Study 2):
 - 61 challenges
 - 18 support service



Priorities

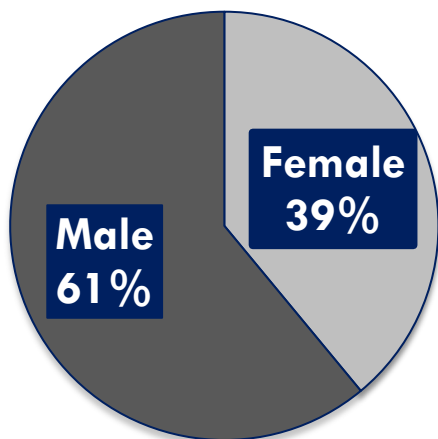
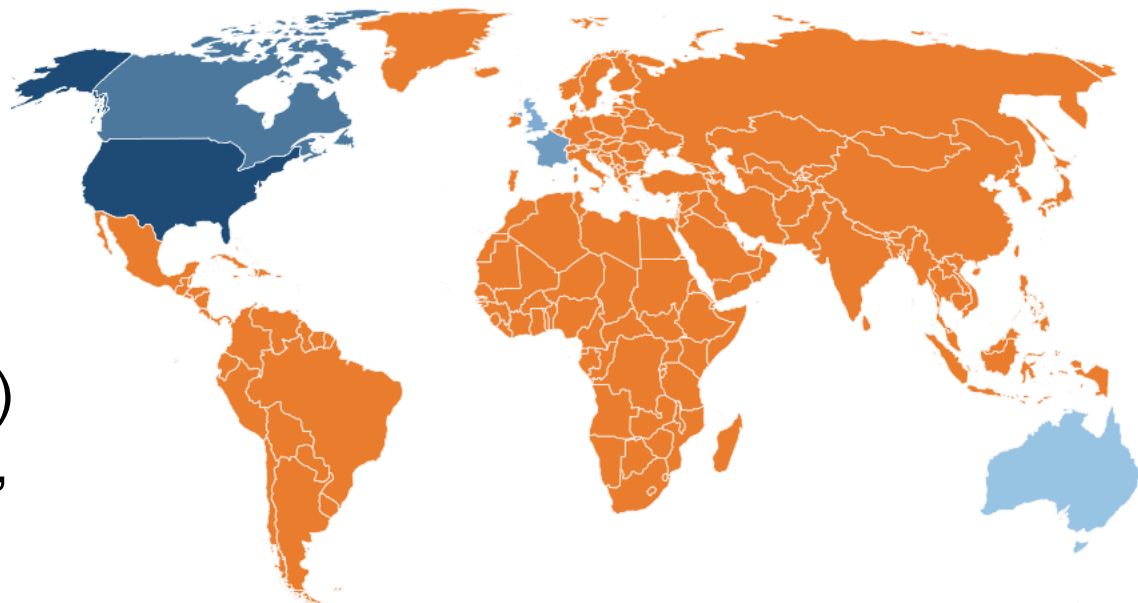
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Overview of Results

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- **202** informal caregivers completed the survey.
- **Relationship to care recipient:** **partner (72%)** parent (12%), child (7%), friend (5%), sibling (4%)



- **Mean (SD) age:** Female – 51.8 (15.4), Male – 60.6 (12.5)
- **Mean(SD) hours of care/week:** 14.0 (13.0) hours

Overview of Results

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Challenge Ratings

Providing emotional support to my care recipient on challenging days

92%

Being unable to help address my care recipient's pain or discomfort

84%

Helping my care recipient set reasonable limits on activities that have become difficult due to scleroderma

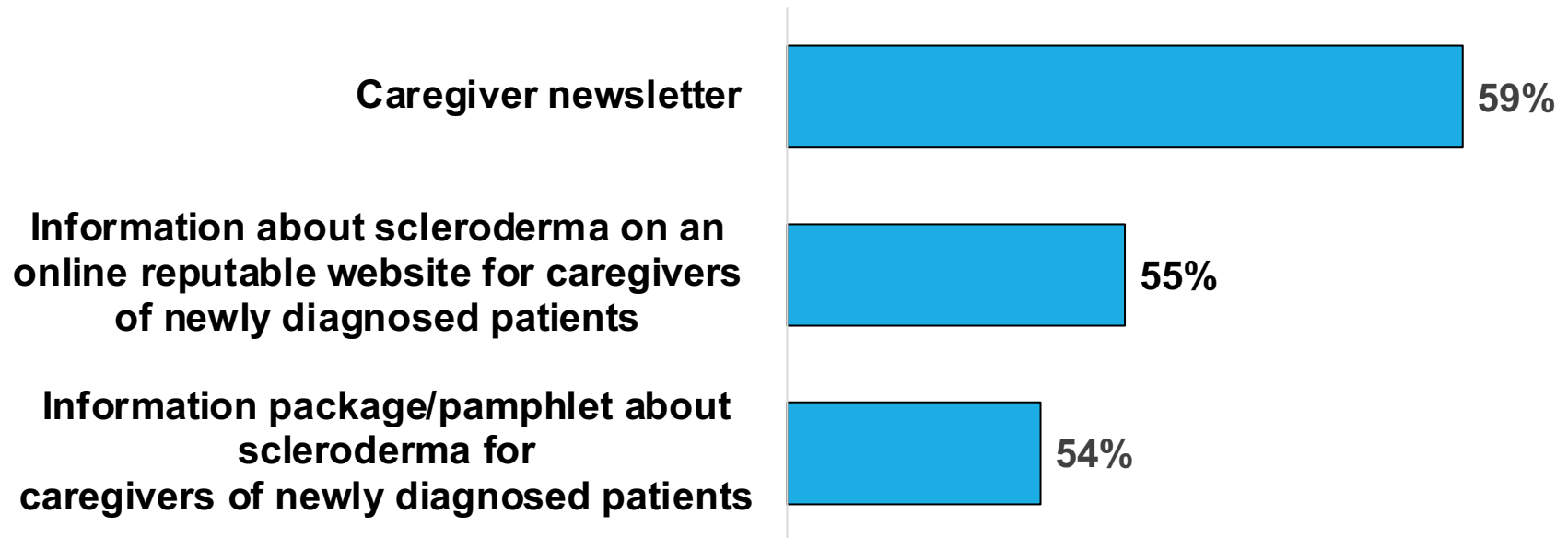
82%

Percent of caregivers that rated item as "important" or "very important"

Overview of Results

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Support Service Ratings



Percent of caregivers that rated the item as being "likely" or "very likely" to use

Conclusions

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Challenges



Supporting and helping to address the **emotional needs** of the care recipients and their **physical discomfort** are important difficulties for caregivers.

Support Services



Information-based resources, especially those delivered **soon after diagnosis**, are most likely to be used.



Support services that can be used **independently** were preferred to those involving interacting with others.

Limitations of Research

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Study One

- Results were synthesized from studies that were conducted **across various** diseases.

Studies Two and Three

- **Lack of diversity** (e.g., racial, socioeconomic status) across all studies.
- Participants had to speak English or French.
- Recruitment occurred through an ongoing patient cohort, patient organizations, and social media websites.

Study Three

- Did not explore **why** certain challenges or support services preferences were rated higher than others.

AVAILABLE RESOURCES

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