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### 3. Informal Caregivers for Scleroderma Focus Groups

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**Objectives:** Systemic sclerosis (SSc), or scleroderma, is a rare, chronic, autoimmune connective tissue disease characterized by abnormal fibrotic processes and excessive collagen production. People diagnosed with SSc experience debilitating symptoms, including functional disability, pain, fatigue and extensive disfigurement. Many people with SSc depend on informal caregivers. Informal caregivers are people who provide unpaid support for a family member or friend with a health condition. Little is known, however, about the experience of informal caregivers of people with rare diseases, including SSc. This study explored (1) challenges experienced by informal caregivers of people with SSc, and (2) their preferences for potential support services.

**Method:** Participants were 18 years or older and provided unpaid support or care for a friend or family member with SSc. Three structured focus groups were conducted during SSc patient conferences held in the United States and Canada. Each structured focus group was conducted by trained moderators and lasted approximately 60-90 minutes. A nominal group technique was used to address each research objective. Participants were asked to independently identify a list of key considerations. Next, each participant stated and explained their listed challenges and desired support services related to caregiving one at a time in a round-robin format. Moderators typed a master list containing all items stated by the participants. This list was then reviewed by the group to remove or merge overlapping items. Once a final list of items was generated, participants independently rated the items on a scale from 1 (not at all important) to 10 (extremely important).

**Results:** A total of 6 males and 7 females participated in the focus groups. Participants' mean age was 60 years. Participants were providing care for a partner (62%), parent (8%), child (15%), or friend (15%). The highest rated caregiver challenges reported were not having access to a caregiver support group, others' lack of awareness of scleroderma, understanding the emotional needs of their caregivee, and managing emotions as a caregiver. The highest rated support services were internet-based chat groups or forums with knowledgeable health care providers, internet resource sites designed for caregivers, internet based psychological and emotional support tools (e.g. guidance on cognitive tools), specific sessions or workshops focused on caregiver needs, and online informational resources explaining physiological symptoms of SSc.

**Conclusion:** A variety of challenges were identified by informal caregivers for a person with SSc. Internet-based support services may be one way to address these challenges.