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Hand Issues on Scleroderma Patients

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Hand issues on scleroderma patients

— Ana Font Hernandez —
ICUR 2018

Background: a Rare Disease

Scleroderma means hard skin:

- *Sklēros*: hard in Greek
- *Dermis*: skin in Modern Latin

1873: Dr. Van Harlingen defines it as an "affection of the skin, characterized by diffuse symmetrical hardening, and generally accompanied by more or less pigmentation".¹

2018: autoimmune disease, not contagious, that can cause disability²

¹ "Dermatology.—Scleroderma." *Edinburgh Medical Journal* 19.6 (1873): 557. Print.

² Winter, Fabiola. "Dureza En Piel y Dificultad Para Mover Manos Son Síntomas De Esclerodermia." *Primer Minuto*, 8 July 2018, primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/.

Background: a Rare Disease

- The specific cause is unknown
- This condition can't be cured
- It is a chronic condition
- Affects women more than men
- Occurs between the ages of 30 and 50
- Symptoms:
 - Tightening of the skin
 - Joint pain
 - Exaggerated response to cold (Raynaud's disease)
 - Heartburn
- Treatments include medication, physical therapy, and surgery

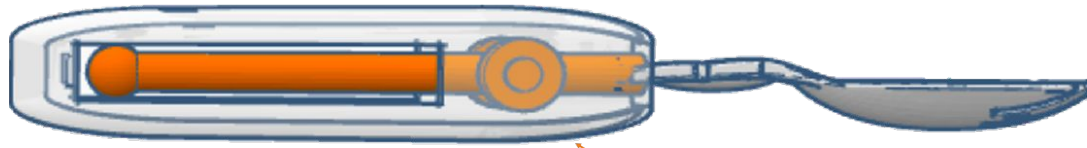
(one) Scleroderma Symptom



Romero, Mónica. Rehabilitación en la esclerodermia. Revista Paraguaya de Reumatología, [S.l.], v. 2, n. 2, p. 81-86, mar. 2017. ISSN ISSN 2413-4341. Disponible en: <<http://www.revista.spr.org.py/index.php/spr/article/view/44/87>>.

Winter, Fabiola. "Dureza En Piel y Dificultad Para Mover Manos Son Síntomas De Esclerodermia." Primer Minuto, 8 July 2018, primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/.

An Assistive Utensil: a Spork



Interior bar weight supported by roll joints

Roll joints allow weight bar to pitch during shaking

Testing on Scleroderma Patients

Methods:

1. Testing on real patients at Scleroderma Foundation group support meeting
2. Surveying patients at Scleroderma Foundation group support meeting
3. Surveying patients from around the globe
 - a. Social Media: 17 groups or pages in Facebook
 - b. Google Forms: 10 questions
 - i. 2 questions were no useful because the wording was confusing and the answers didn't make sense

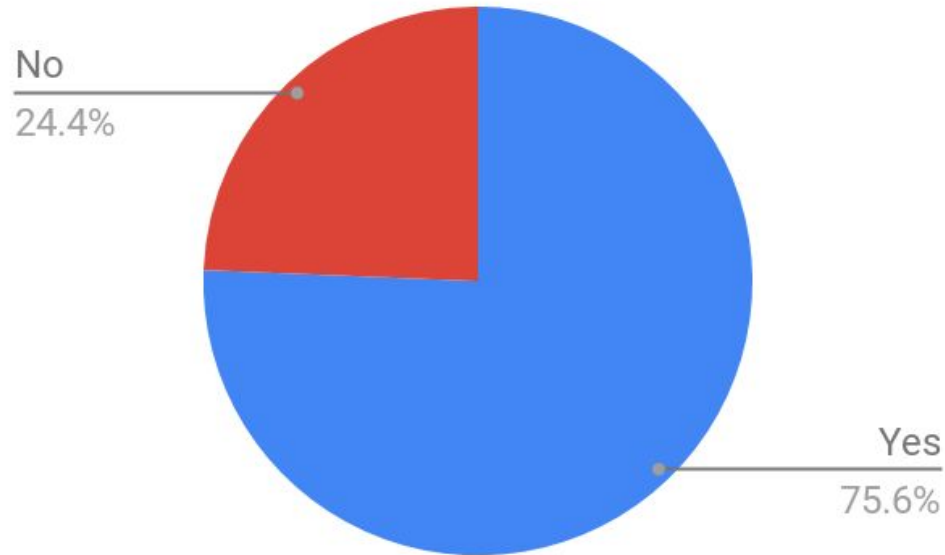
Testing on Scleroderma Patients

Collected responses from:

- United States
- Spain
- Puerto Rico
- Colombia
- Chile
- Mexico
- Peru

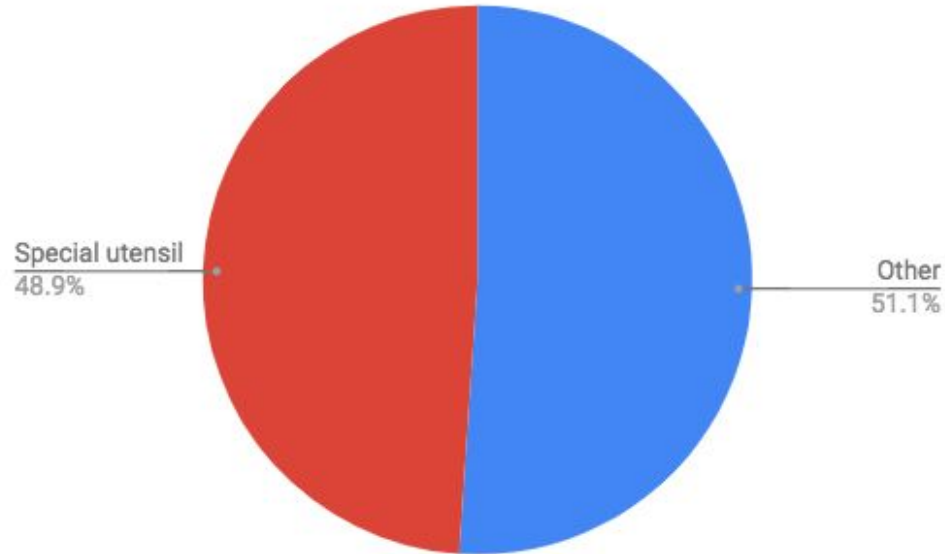
- Total responses: 78
(as of September 25th, 2018)
- Preliminary results: the spork is useless

Do you have trouble eating or using your hands in any way due to scleroderma?



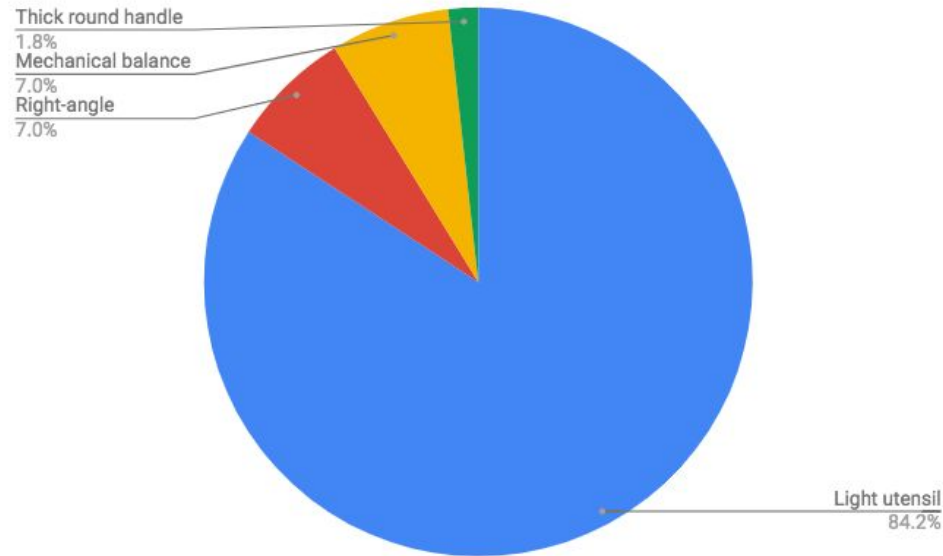
Total answers to question: 78

If you need special help to eat, what is most helpful to you?



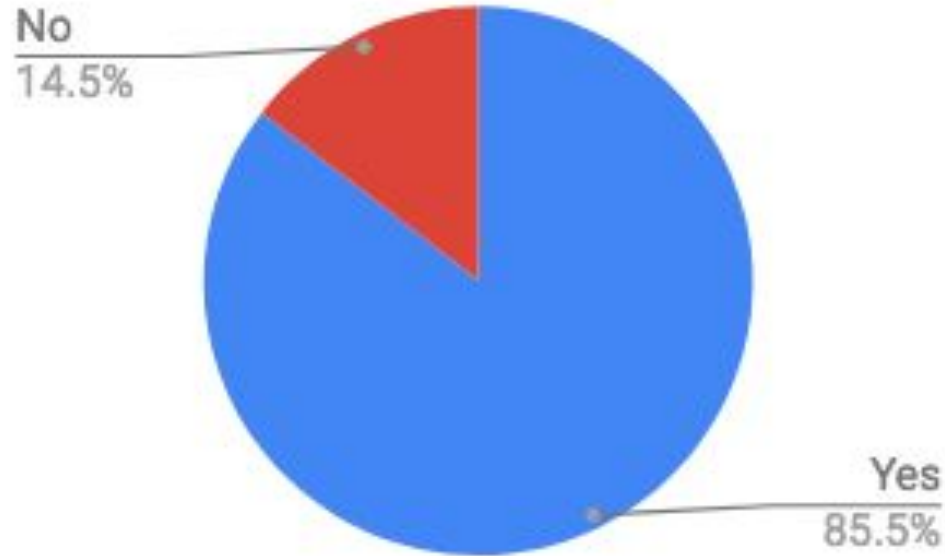
Total answers to question: 47

What feature of the device you use to eat do you value the most?



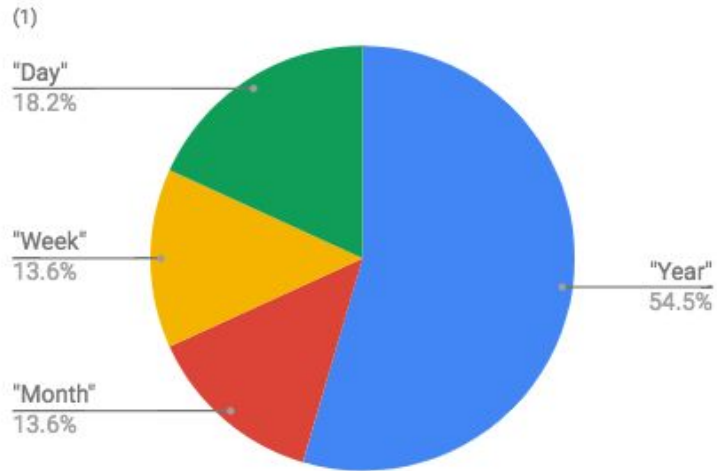
Total answers to question: 57

Has your grip changed since you started developing issues with your hands?

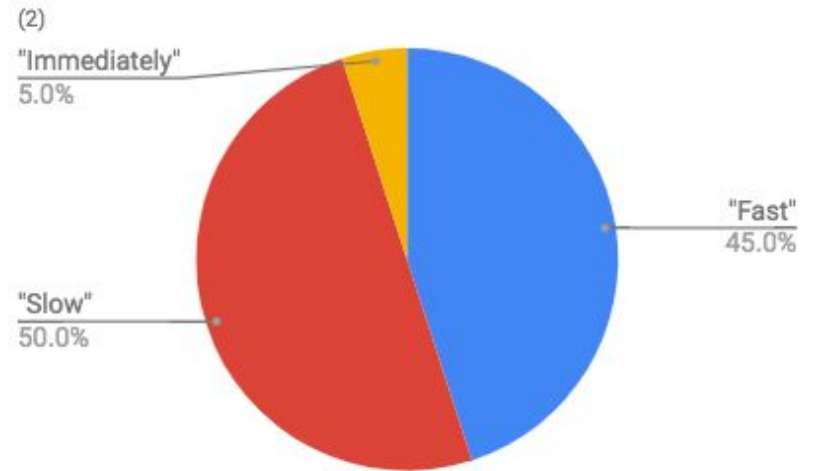


Total answers to question: 76

How often have your hands changed their form?

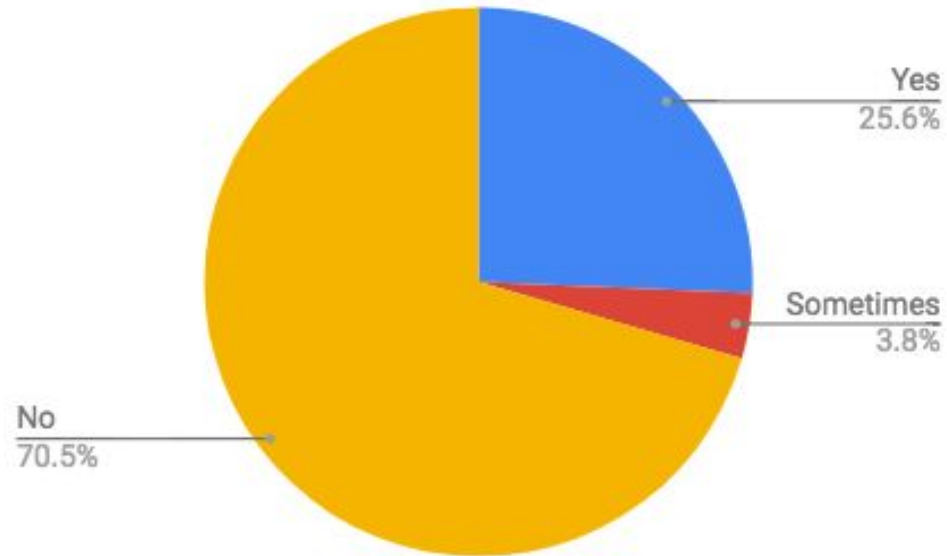


Total answers to question: 22



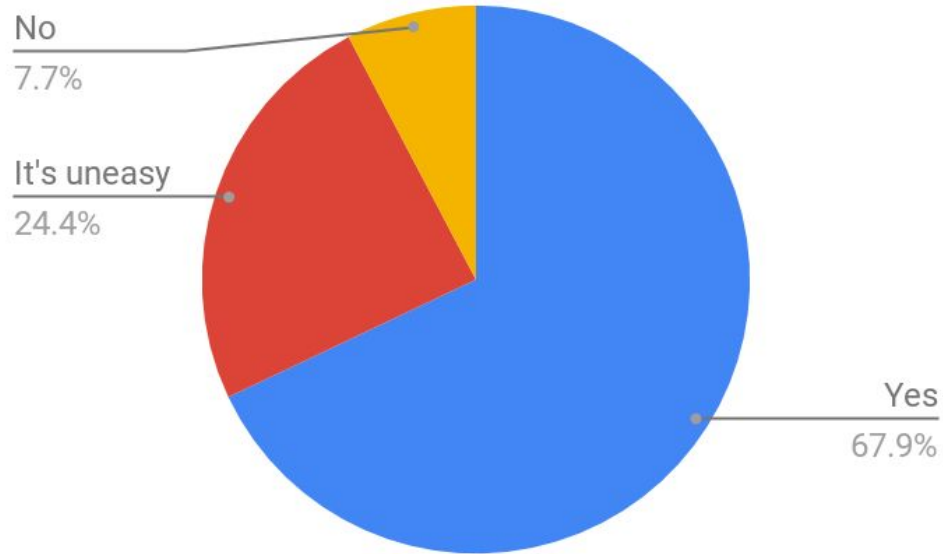
Total answers to question: 20

Do you suffer from hand tremors?



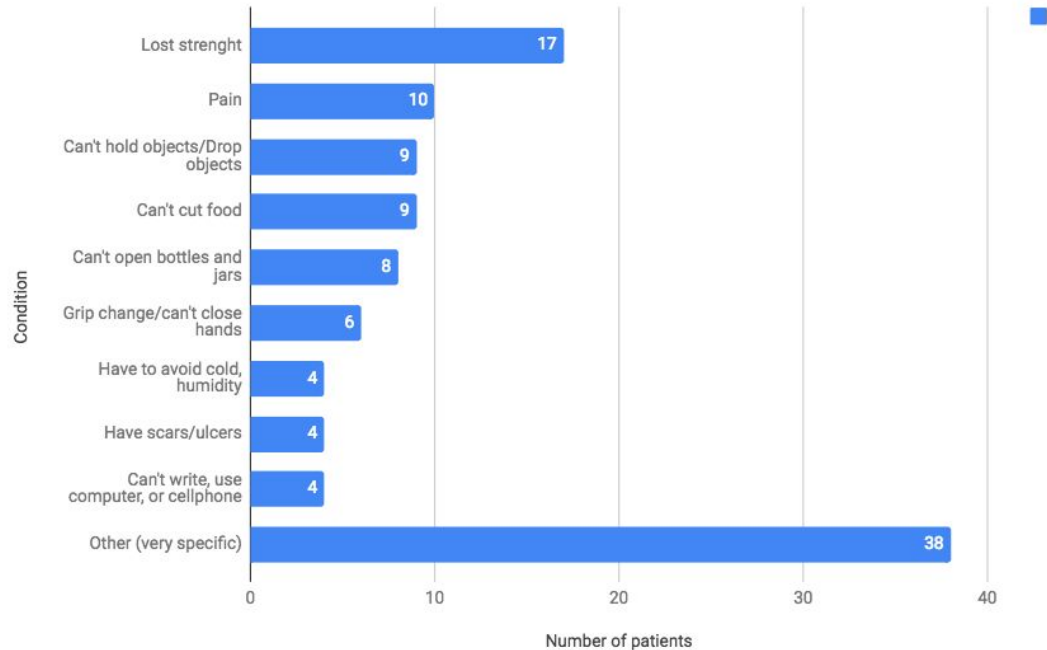
Total answers to question: 78

Are you able to use a cellphone without help?



Total answers to question: 78

What else should we know about your situation?



Total answers to question: 78. Multiple entries per answer.

Have your doctor asked for your DNA test?

Tú médico te ha hecho una prueba de ADN? / Have your doctor asked for a DNA test? / O seu médico pediu um teste de DNA? / Il tuo medico ha chiesto un test del DNA?



8% Sí / Yes / Sim / Sí



92% No / No / Não / Non ☑

Undo Vote

26 Votes

Other findings

- 58 Facebook groups with at least 6000 people
 - Not including Asia or Africa
- 2 million people suffer from scleroderma around the world
 - 300,000 recorded by this project, not including Asia or Africa
- Other diseases associated with scleroderma are
 - Lupus
 - Interstitial lung disease
 - Renal failure

A possible solution for scleroderma patients?

— Further research is needed —

Acknowledgements

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- Facebook Pages
- Google Forms
- My friends and family