Identifying Unmet Mental Health and Emotional Palliative Care Needs in Patients with Ehlers Danlos Syndrome

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Background
Ehlers-Danlos Syndrome (EDS)

What is EDS?

• Connective Tissue Disorder; Incidence: 1:2,500 to 1:5,000
  • 13 subtypes with varying presentation
  • Joint hyper-mobility and skin elasticity in several subtypes
  • Most subtypes include symptoms of pain and progressive debility
  • May include vascular complications, organ system damage, decreased esophageal function and shortened life expectancy

Why do patients with EDS need Palliative Care?

• High symptom burden and multi-layered patient and family needs in EDS may be improved with Palliative Care
  • Expert symptom management of a complex diagnosis
  • Enhanced quality of life for patients and families
  • Goals of Care and Advanced Care Planning
  • Access to multi-dimensional resources and support
• Palliative Care needs of patients and families with EDS are not well-studied despite potential benefits
Eight Domains of Palliative Care

National Consensus Project for Quality Palliative Care

Palliative Care (PC) is an extra layer of support for patients and their families while facing serious and life-limiting illness.

• Domain 1: Structure and Processes of Care
• Domain 2: Physical Aspects of Care

• Domain 3: Psychological and Psychiatric Aspects of Care

• Domain 4: Social Aspects of Care
• Domain 5: Spiritual, Religious, and Existential Aspects of Care
• Domain 6: Cultural Aspects of Care
• Domain 7: Care of the Patient Nearing the End of Life
• Domain 8: Ethical and Legal Aspects of Care

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Design: Descriptive, exploratory survey

• Recruitment: coordinated via International Society of Ehlers Danlos Syndrome – email ListServ, snowball sampling
• Part of a larger pilot study exploring a needs assessment of all eight domains of palliative care in patients with Ehlers Danlos Syndrome
• IRB: Expedited Review
• Thematic analysis of subcomponent (unmet mental health and emotional needs) free texted responses (n=120).
Results

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Overall Survey Responses:
• 317 clicks, 239 completed surveys with 30 additional partially completed surveys.

Responses to Descriptive Question:

“Do you have any emotional or mental needs that you feel aren’t well managed?”
• 122 participants answered “yes”, 117 participants answered “no”.

For those answering “yes” to this descriptive question:

“You have indicated that you have emotional or mental needs that you feel are not well managed. Please describe your emotional or mental needs that are not well managed.”
• 120 respondents free texted responses.
Results, Continued.

Unmet Mental Health and Emotional Needs

Themes Identified:

• Patients described experiencing psychological symptoms and disorders including anxiety, depression, and PTSD.

• Patients described hesitancy in talking with healthcare providers about their psychological symptoms.

• Patients used terminology such as “gas lighting” to describe interactions with healthcare providers.
Implications

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Clear need to address emotional and mental health needs of patients with EDS.

Study findings underline desire of patients with EDS to have access to mental health and emotional support resources.

Potential Recommendations:

- Develop interventions for addressing emotional and mental health needs within this patient population.
- Particular consideration should be given to in-home and remote support.
- Also consider physical energy required to access appointments.
Questions?
References


