HealthTree Foundation Diagnosis disclosure patterns among patients with plasma cell disorders

BACKGROUND

Disclosing or withholding information relating to a precancer or cancer diagnosis – including plasma cell disorders (PCDs) like monoclonal gammopathy, smoldering myeloma, and multiple myeloma – across social networks may impact how patients cope with their diagnosis and prognosis. The purpose of this survey was to investigate diagnosis disclosure patterns among patients with PCDs and identify areas for **interventions** that effectively utilize social support to navigate cancer diagnoses.

METHODOLOGY



We invited participants with PCDs to answer a **34 question online survey** about their diagnosis disclosure patterns and perceptions on HealthTree Cure Hub between April and December 2024. De-identified aggregated responses were analyzed.

RESULTS

Total Participants: **510 Patients**

*Almost all (98%) reported sharing their diagnosis.







79% participants reported that sharing information (with positive impact in their coping, with only 4% reporting a negative effect. *Study limitations include selection bias.



Patients with PCDs have a variety of motivations for sharing their diagnosis and generally perceive disclosure among their primary social networks to be beneficial to their coping. Oncologists may promote coping by encouraging disclosure.

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| u share the most information regarding your diagnosis? | |
|--|--------------------------------|
| 308 (60%) | |
| | |
| | |
| | |
| | |
| n you shared the most with, why did you share with them? | |
| | 429 (84%) |
| 296 (58%) | |
| 194 (38%) | |
| | |
| | |
| elt comfortable with sharing information abo | out your diagnosis? |
| 229 (45%) | |
| (31%) | |
| 9%) | |
| | |
| | |
| n with who you shared the most affect how | you coped with your diagnosis? |
| 253 (50%) | |
| 9%) | |
| | |
| | |
| 0 60 80 | 100 |
| Percent of Patients | 100 |
| | |
| | |
| the individual they shared the | ne most with) had a |



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