

RHEUMATOLOGISTS' ATTITUDES TOWARD PALLIATIVE CARE AND MEDICAL ASSISTANCE IN DYING

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BACKGROUND

Despite major advances in the treatment of systemic rheumatic diseases over the last several decades, a patient population remains—those with systemic vasculitis, scleroderma, inflammatory myositis, and severe courses of SLE and RA—who still suffer from life-limiting diseases with high symptom burden and, often, limited life expectancies.

One study by *Bourgarit et al.* demonstrated a median survival time of 3 months amongst 60 patients with a fulminant course of vasculitis. And, in patients with severe organ damage from systemic rheumatic illnesses, the degree of impairment may be similar to that of metastasis cancer.

Systemic rheumatic illnesses also carry with them increased comorbidities, which may shorten life expectancy. Most patients with rheumatoid arthritis die of heart failure, primarily due to chronic cardiac insufficiency. For example, patients with rheumatoid arthritis, psoriatic arthritis and systemic lupus erythematosus have a higher risk of cardiovascular, peripheral vascular and cerebrovascular disease, and patients with rheumatoid arthritis have a higher incidence of lymphoma. As a result of these comorbidities and complications, life expectancy reduced by approximately eight years compared with the general population.

Nonetheless, patients with advanced rheumatologic illnesses have little access to specialist palliative care services, and there is a paucity of data in the literature on their palliative care needs. Moreover, there are no studies to date that describe the referral practices of Canadian Rheumatologists to specialized palliative care, and barriers or facilitators to such referrals.

This study aims to define the referral practices of Canadian rheumatologists to palliative care and to explore rheumatologists' attitudes toward palliative care and medical assistance in dying (MAiD).

METHODS

We created a survey instrument to identify palliative care referral practices, attitudes and important physician characteristics.

All rheumatologists who are members of the Canadian Rheumatology Association (CRA) were invited to complete the questionnaire via an online link to the survey website.

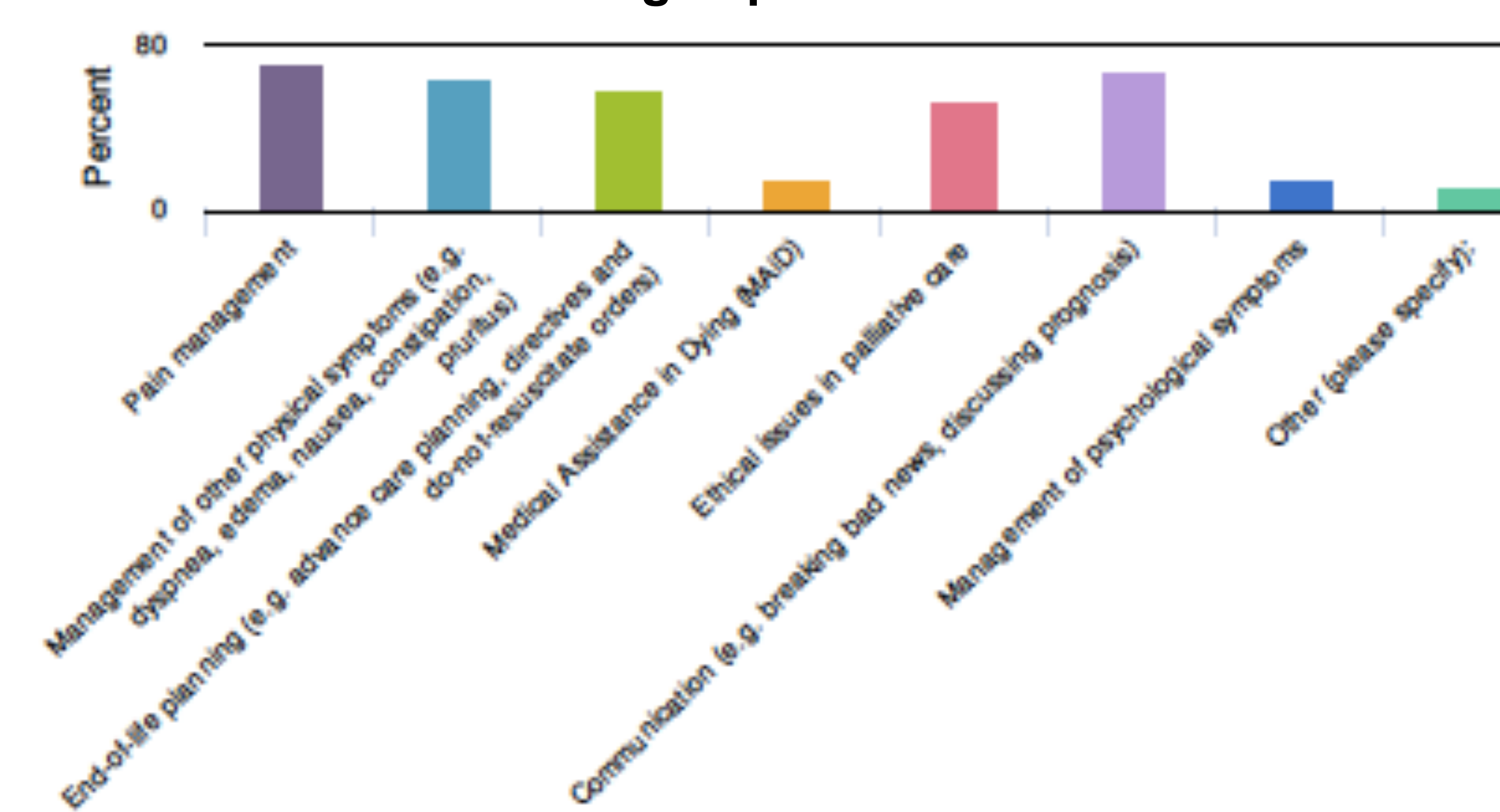
Responses were received anonymously by the online survey program, *Survey Gizmo*, aggregated and analyzed using descriptive statistics.

RESULTS

37 (19%) of rheumatologists completed the survey. 22 (60%) self-identified as academic physicians. The majority were general rheumatologists (n=30, 83%), caring for adult patients (n=33, 89%).

68% reported exposure to palliative care during medical training, covering pain management (n=23, 77%), management of physical symptoms (n=21, 70%), end-of-life planning (n=19, 63%) or communication skills (n=21, 70%).

Chart 1. Previous training in palliative care

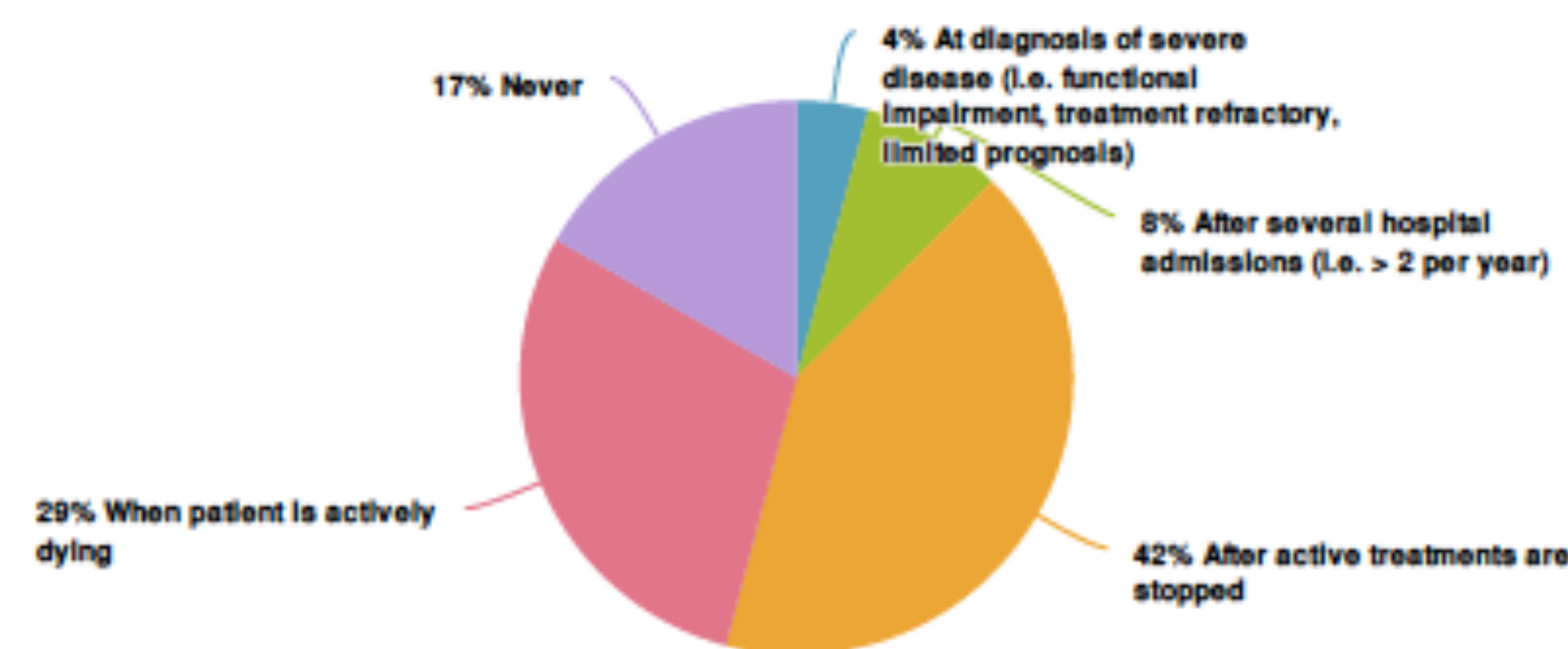


Rheumatologists categorized up to 50% of their inpatients and 10% of their outpatients as having advanced rheumatologic disease with significant functional limitation or poor prognosis.

RESULTS

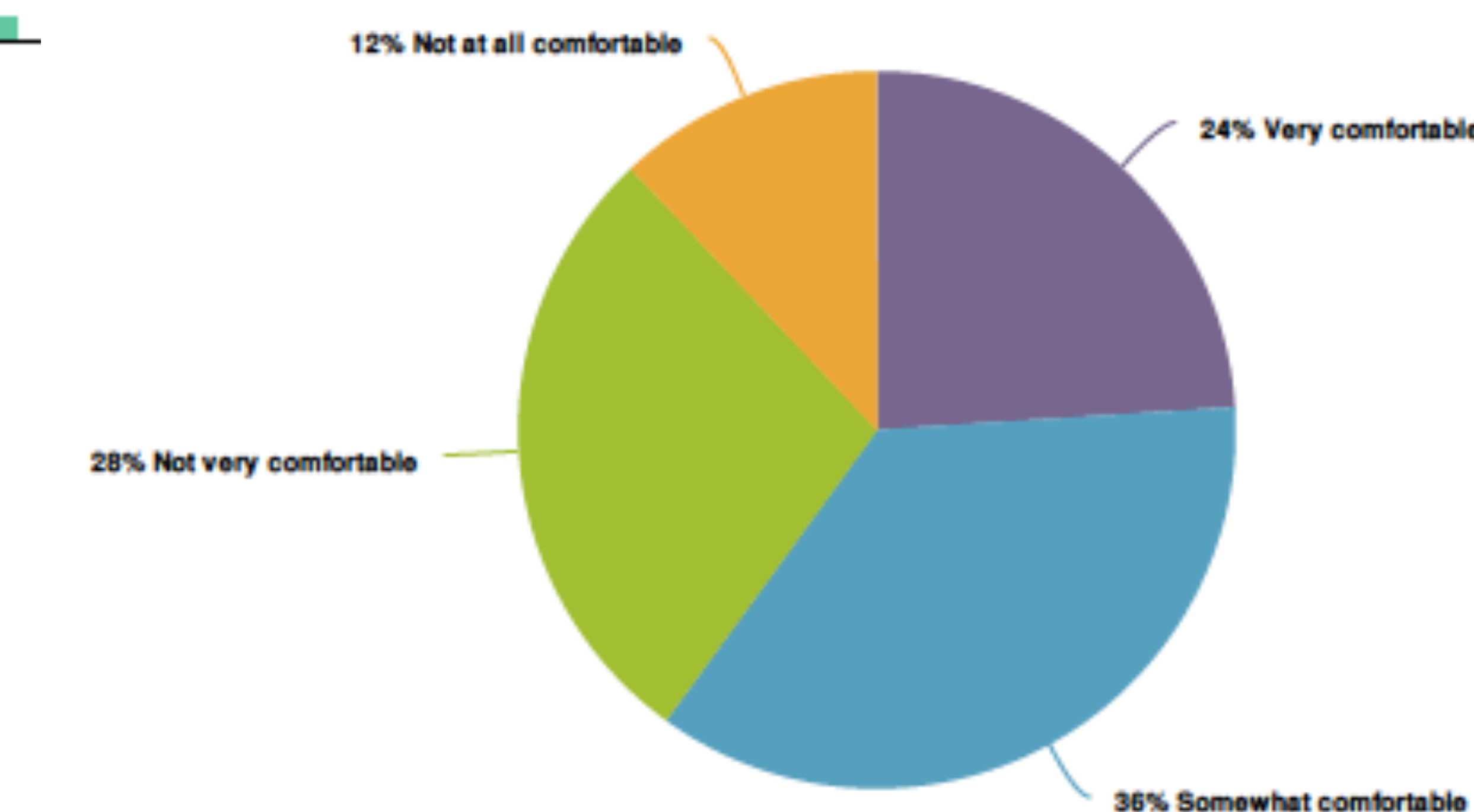
44% (n=16) reported access to palliative care services for their patients, and 36% (n=13) were aware of local palliative home care services. 54% (n=19) had never referred a patient to palliative care. For those who had, they did so most often for uncontrolled symptoms and prognosis less than 1 year (n=22, 66%), or for terminally ill inpatients requiring assistance with discharge planning (n=24, 60%).

Chart 2. Time of referral to palliative services



14% (n=5) reported feeling “very comfortable” identifying patients with life-limiting rheumatic conditions who might benefit from a palliative approach to care. 22% (n=5) were “very comfortable” discussing this approach with their patients.

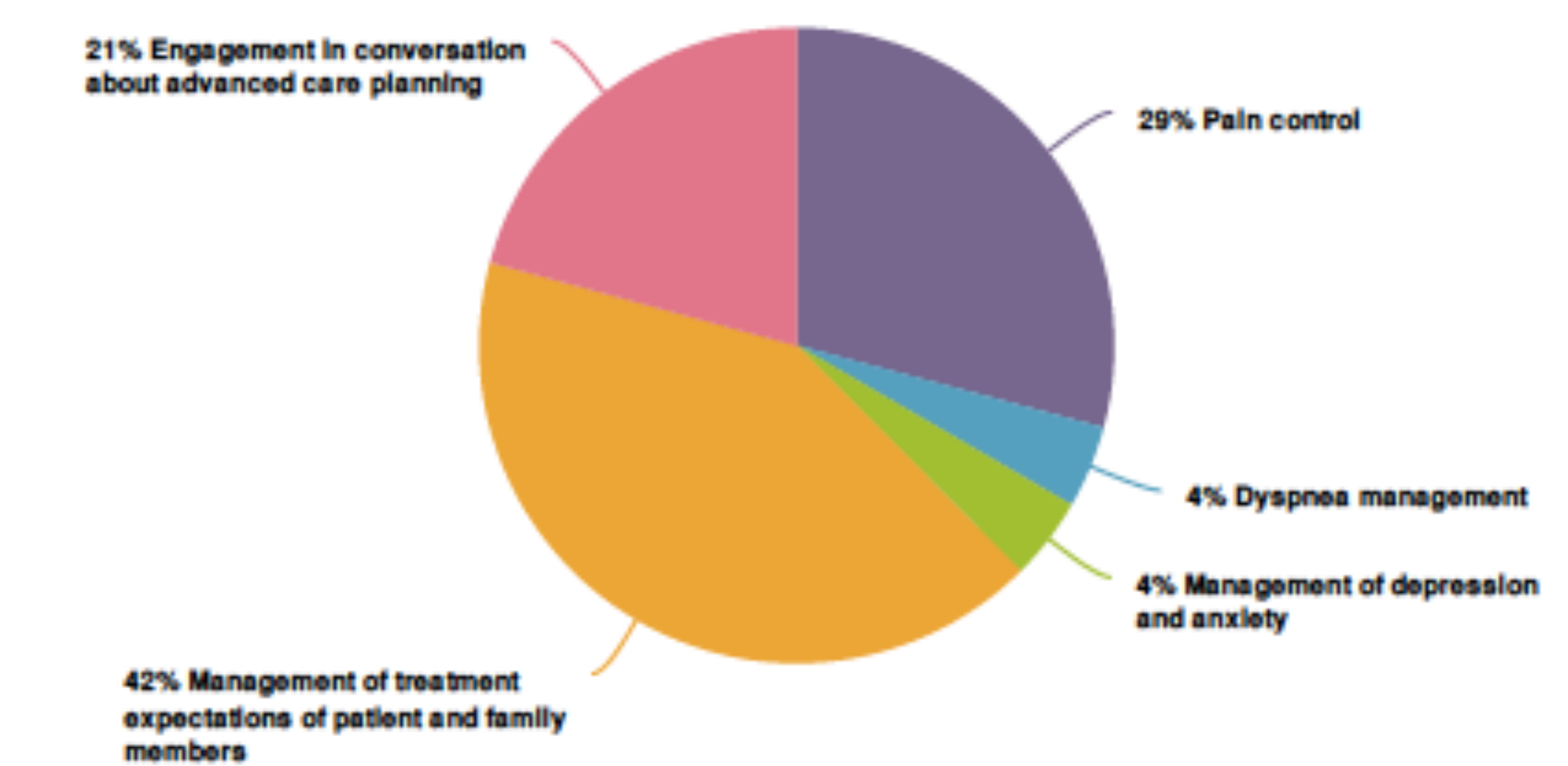
Chart 3. Comfort in discussing goals of care and advance care planning with patients



RESULTS

42% reported that managing treatment expectations of patients and family members was the most challenging aspect of treating patients with life-limiting rheumatologic conditions.

Chart 4. Most challenging aspects of palliative care



While 33% (n=12) of rheumatologists had been approached by a patient requesting MAiD, many rated their knowledge of eligibility criteria (n=17, 47%) and of the assessment and approval process (n=19, 53%) as “poor”.

CONCLUSIONS

This study is the first to describe self-reported referral practices of rheumatologists to palliative care services, and to identify attitudes of these physicians towards palliative care consultation. The results expose gaps in knowledge of, and comfort with, palliative care services for patients with life-limiting rheumatic diseases, as well as barriers to accessing these services for patients with non-cancer illnesses. Further work is needed to engage rheumatologists about the role that palliative care teams can play in providing higher quality care to patients with advanced systemic rheumatic illnesses toward the end of life.

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