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Title: Understanding the Needs of the IgG4-Related Disease Community by Taking a Patient-Centric Approach

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SCOPE OF WORK:

An inaugural congress was held in Milan, Italy, in October 2023 for members of the IgG4-related disease (IgG4-RD) community. Patients and caregivers participated in a series of roundtable discussions in Italian focusing on quality of life (QoL) and provided a valuable lens into the IgG4-RD experience. Additionally, 146 patients affected by IgG4-RD participated in a structured survey with questions designed to interrogate specific aspects of their experience. From these separate approaches emerges a series of challenges which were described both qualitatively and quantitatively.

MATERIALS AND METHODS:

At the congress, 50 patients split into groups to discuss and identify sources of concern within 5 predetermined QoL areas: subjective experience, limitations in activities, emotional difficulties, socioeconomic impact, and unmet needs. After each of 5 groups identified 4 subthemes within their QoL area, the groups reunited and voted on which of the 4 was the most impactful to them in

each area. This same process was replicated for the 40 caregivers who attended. In a separate but aligned effort, an online survey in Italian was developed and disseminated to patients with IgG4-RD who attend a clinic in Italy to better understand the patient journey and assess unmet needs.

RESULTS:

Within the emotional difficulties area of QoL, 51% of congress patients selected “new reactivations and worsening of QoL” as their top concern. In parallel, caregivers highlighted emotional burdens related to the “uncertainty of the future,” “the burden of caretaking and caretaking in the best way,” “a sense of helplessness,” and “loneliness and confusion in the path to care.” In other QoL areas, they also mentioned the “limited ability to plan future events” and the “need for increased psychological/emotional support.”

Proper access to information in the context of an illness is associated with a greater sense of agency and improved stress management. However, 64% of the 137 survey respondents said it took more than 1 month to find information about IgG4-RD after the first symptoms or after diagnosis, and 34% said it took more than 6 months. In the roundtable, the need for improved access to and quality of information arose multiple times.

CONCLUSIONS:

Using these 2 separate tools, several themes and unmet needs were identified that remain of interest to this community. Building more connections and offering more meeting opportunities would be impactful ways to support the community. Increasing the degree of clinical coordination across multiple disciplines would also benefit this population, especially for those traveling long distances for care. In the roundtables, both patients and caregivers described the need to take off work, and 38% of surveyed patients live more than 50 km from the specialist(s) they visit.

	Greatest Interest or Concern in Each QoL Area
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	Patients	%	Caregivers	%
Subjective experience	Understanding the cause of the disease	30	Lack of information for proper support in the disease journey	48
	Uncertainty about the future	28	Need for continuity of care	28
	Impact of incorrect diagnoses on symptoms and treatment	26	Opportunity for sharing and support in the disease journey	20
	Loss of autonomy	16	Limited involvement in emotional dynamics	5
Limitations in activities	Decrease in energy in work activities	47	Anxiety and fatigue	38
	Limitation of social activities	28	Limitation in planning future activities	38
	Limitation/interruption of leisure activities	13	Limitation in travel and social activities	15
	Reduction in sexual desire	13	Limitation in food preparation/consumption	8
Emotional difficulties	Concerns about new reactivations and worsening of quality of life	51	Uncertainty about the future	28
	Work-related concerns related to a decrease in physical fitness, professional dissatisfaction, and a reduction in self-esteem	30	Burden of caring for the patient and caring in the best way	28
	No emotional difficulties related to the disease	11	Sense of helplessness	25
	Sharing concerns with family members	9	Confusion and loneliness in the path leading to diagnosis	20
Socioeconomic impact	Economic cost to access a reference center	35	Need for dissemination of information about the disease	50
	Cost of diagnostic tests	26	Nonrecognition of disability	30
	Cost of medications not covered by the national health system	20	Economic problem due to the distance from the reference center	10
	Loss of workdays	20	Involvement of family members (need to take time off work)	10
Unmet needs	Multidisciplinary coordination to organize instrumental tests	47	More events like this (conferences/meetings)	69
	Recognition of the disease for 104 recognition (disability certificate)	28	Psychologist/emotional support	21
	Creation of a protocol	11	Sexual problems	5
	Awareness of the disease	15	Existence as a family member	5