

We're in It Together: A Participative, Shared Decision-Making Approach to Supporting MS Patients and Families Considering Alemtuzumab Treatment Initiation



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Introduction

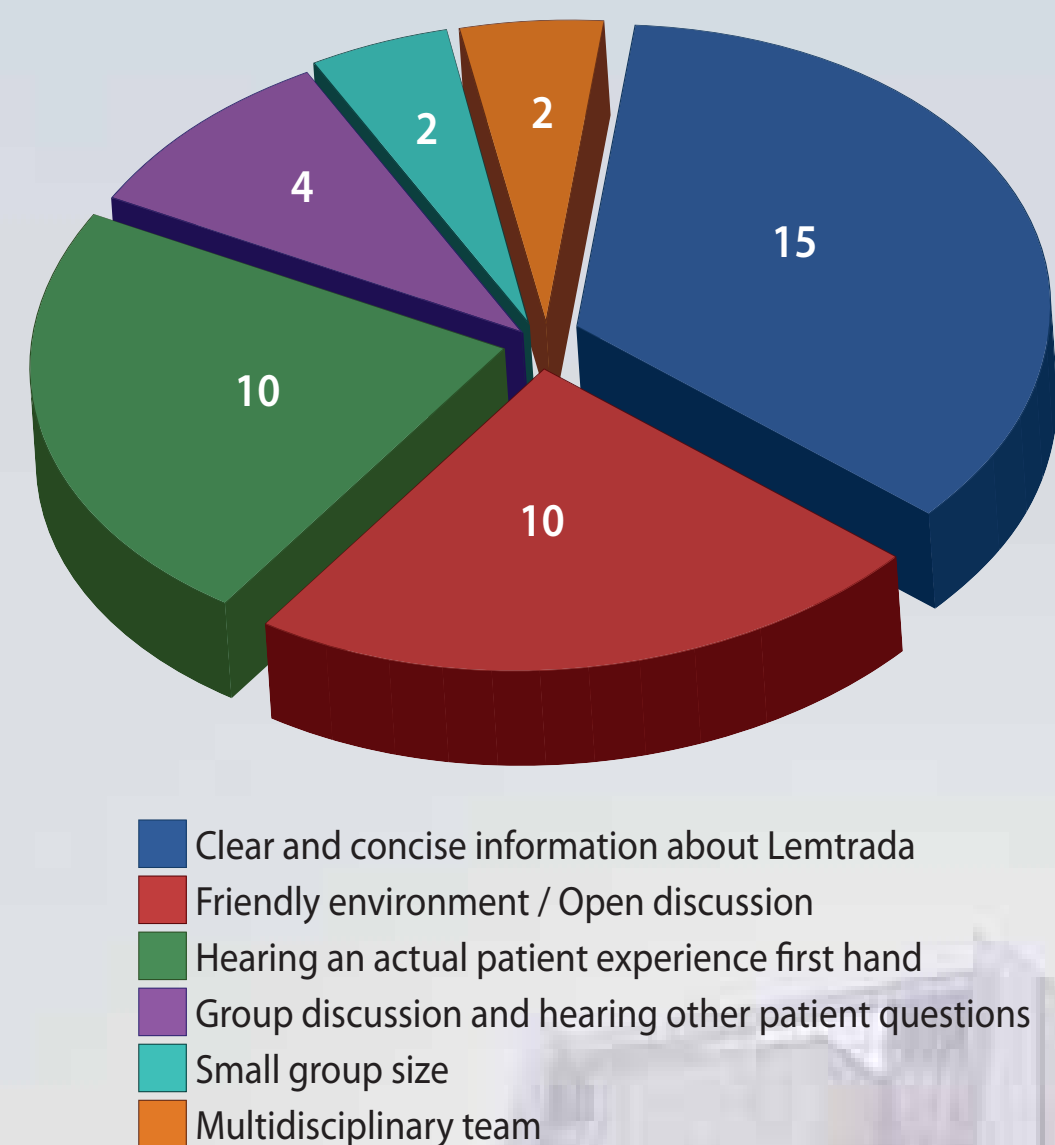
- ▶ Starting a second line disease modifying therapy such as Alemtuzumab can be a stressful experience for MS patients and their family members
- ▶ Patients and families often have many questions and concerns at this time, given the risk/benefit profile of the medication and the need for long-term follow-up
- ▶ According to recent Best Practice Guidelines for Alemtuzumab, providing information and support are important components of the medication initiation process, as they can improve the patient experience, enhance patient knowledge, facilitate communication, and promote follow-up" (McEwan et al., 2016).
- ▶ However, physicians often describe time constraints as the most common barrier that prevents them from effectively communicating with patients and engaging in shared decision making (Godolphin, 2009)
- ▶ Delivering patient education and support in a group format using a collaborative partnership approach could enhance efficiency and enhance the care experience for patients starting Alemtuzumab and their families

Methods

- ▶ A collaborative patient/provider partnership approach was used to develop group sessions to provide information and support to MS patients contemplating treatment initiation with Alemtuzumab and their families
- ▶ An interdisciplinary team (MS Neurology Fellow, an MS Nurse Clinician, and a Nurse from a patient support program) developed and conducted these monthly bilingual sessions. A patient partner, currently treated with Alemtuzumab, was also present at each session to share his/her experiences
- ▶ The objective of each session is to enhance knowledge, promote shared decision making, and ensure informed consent
- ▶ Each session lasted 1.5 hours, with an average of 5-10 people in attendance (patients & family members)
- ▶ Active group participation was encouraged during the sessions, which addressed the following topics:
 1. treatment risks and benefits
 2. medical screening and insurance authorization requirements
 3. what to expect on a typical infusion day
 4. the importance of adherence to long-term follow-up
- ▶ The team has conducted 9 sessions to date, with a total of 38 patients and 31 family members in attendance
- ▶ Pre and post questionnaires were developed to evaluate the patient and family experience of care, including perceived level of support by the team, knowledge of the therapy, as well as level of confidence and desired role in treatment decision making

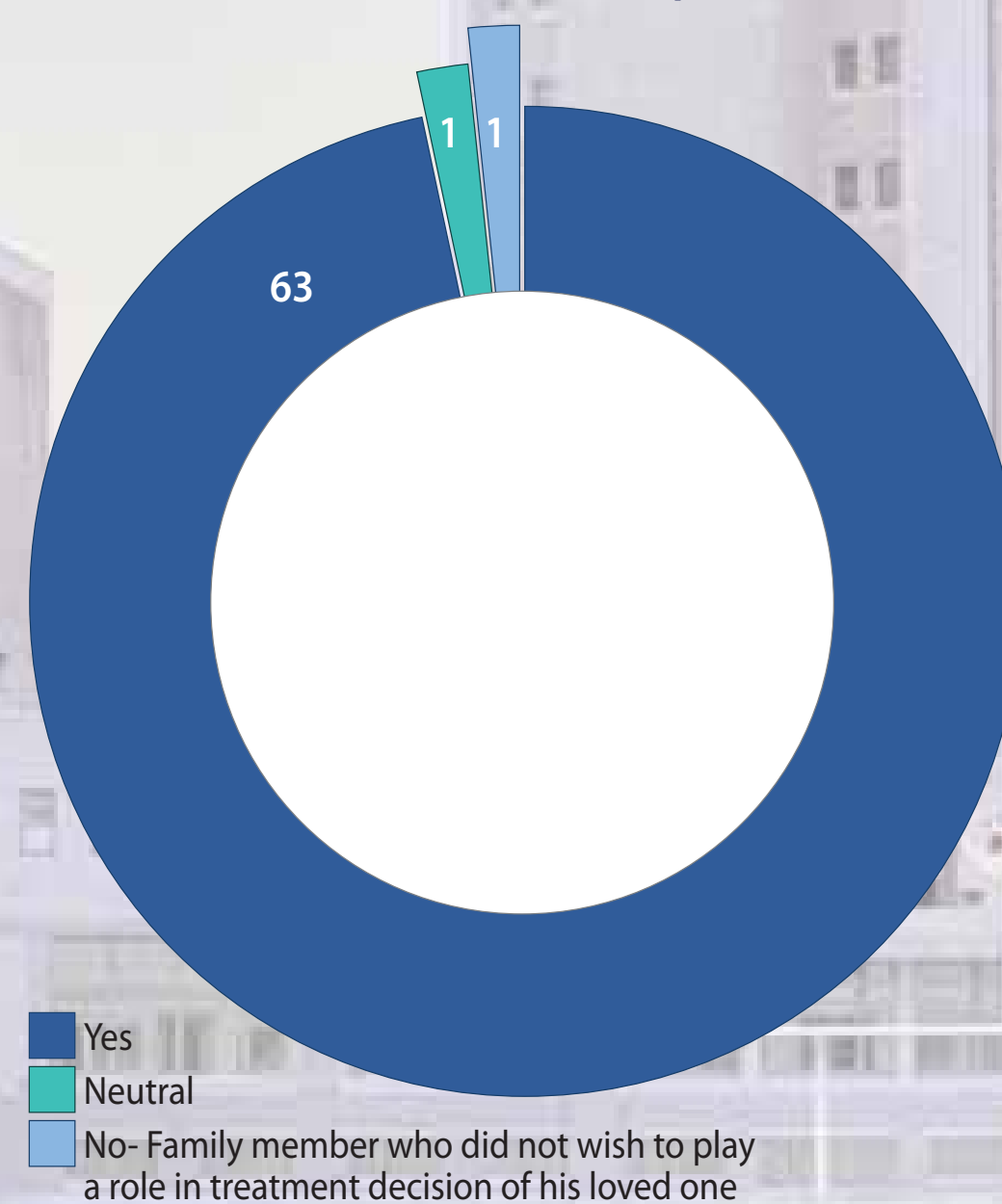
Results

What Attendees Liked Most About The Sessions



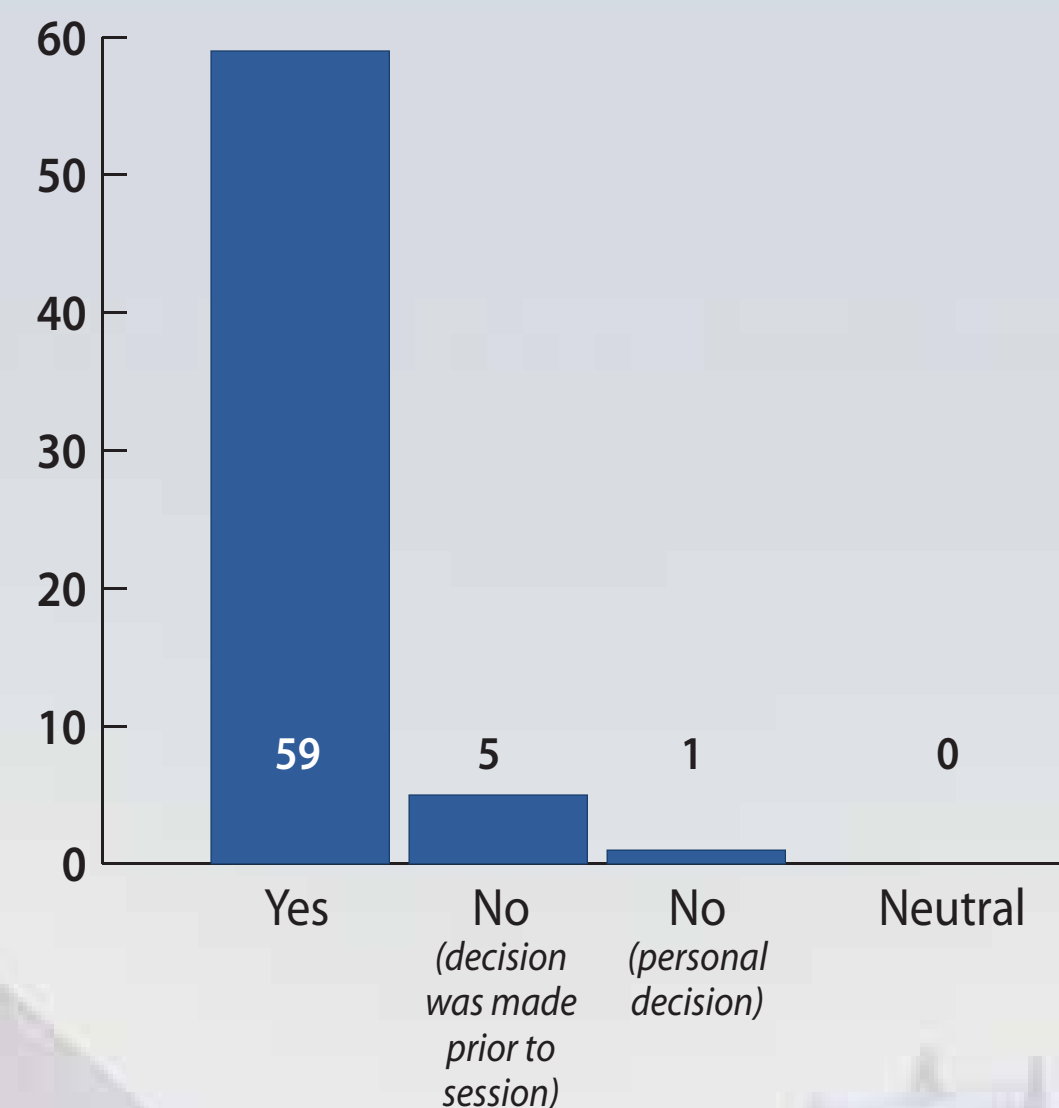
"Wonderful feeling of support" ~ Patient attendee

Was the Session Helpful



"A clear picture of the whole process" ~ Patient attendee

Did The Session Help Attendees Make A Treatment Decision



"Will help me assist my friend in making her decision" ~ Friend of patient

Secondary Outcomes

Peer Support

Informal support groups were established at the sessions.

Time Efficiency

MS practitioners have seen a reduction in the time needed to answer questions about alemtuzumab in the outpatient clinic, as the sessions provide a protected and welcoming learning environment for patients and families.

Shared Decision Making

Most patients expressed feeling that they play a role in the decision making process and wish to be involved. Many family members expressed a desire to support their loved ones.

Increased Confidence in Decision Making Ability

Receiving clear and concise information increased patient confidence in making a decision.

Discussion

- ▶ Patient and family survey responses validated that a collaborative patient-provider partnership approach that fosters participative shared-decision making and group learning can lead to positive outcomes and enhance the patient and family experience of care during the MS treatment initiation process
- ▶ Patients attending the sessions reported feeling well supported by the team and having a better understanding of the therapy
- ▶ Family members also reported increased knowledge of the treatment and a desire to support their loved one in making a treatment choice
- ▶ The sessions thus highlight the benefits of a comprehensive team approach that focuses on empowerment and patient involvement in the management of chronic illness (Halper, 1997)
- ▶ Alternatively, a small number of patients had differing expectations of the session content, thus a written outline clarifying the expectations of a teaching program should be provided to attendees before each session.

Future Directions

- ▶ Future directions include a need to:
 - (1) further evaluate the factors impacting treatment decision-making, so that practitioners may better support patients and families,
 - (2) expand the group teaching model to other MS therapies and health promotion issues for this clientele,
 - (3) address the family members' need for information on how to best support their loved ones in the context of medication initiation.

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