

Australia and New Zealand Inhibitors Workshop: meeting the challenges

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OBJECTIVES

Families with haemophilia and inhibitors often cannot relate to the experiences of other hemophilia families in developed countries, increasing their sense of isolation. The Australia and New Zealand Inhibitors Workshop was the first educational workshop in the region to focus specifically on the challenges faced by families with inhibitors.

The Inhibitors Workshop aimed to:

- 1) provide information and education about hemophilia and inhibitors;
- 2) provide a forum for the discussion of issues associated with living with hemophilia and inhibitors; and
- 3) develop a sense of community within the group in order to facilitate networking opportunities and mutual support.

METHODS

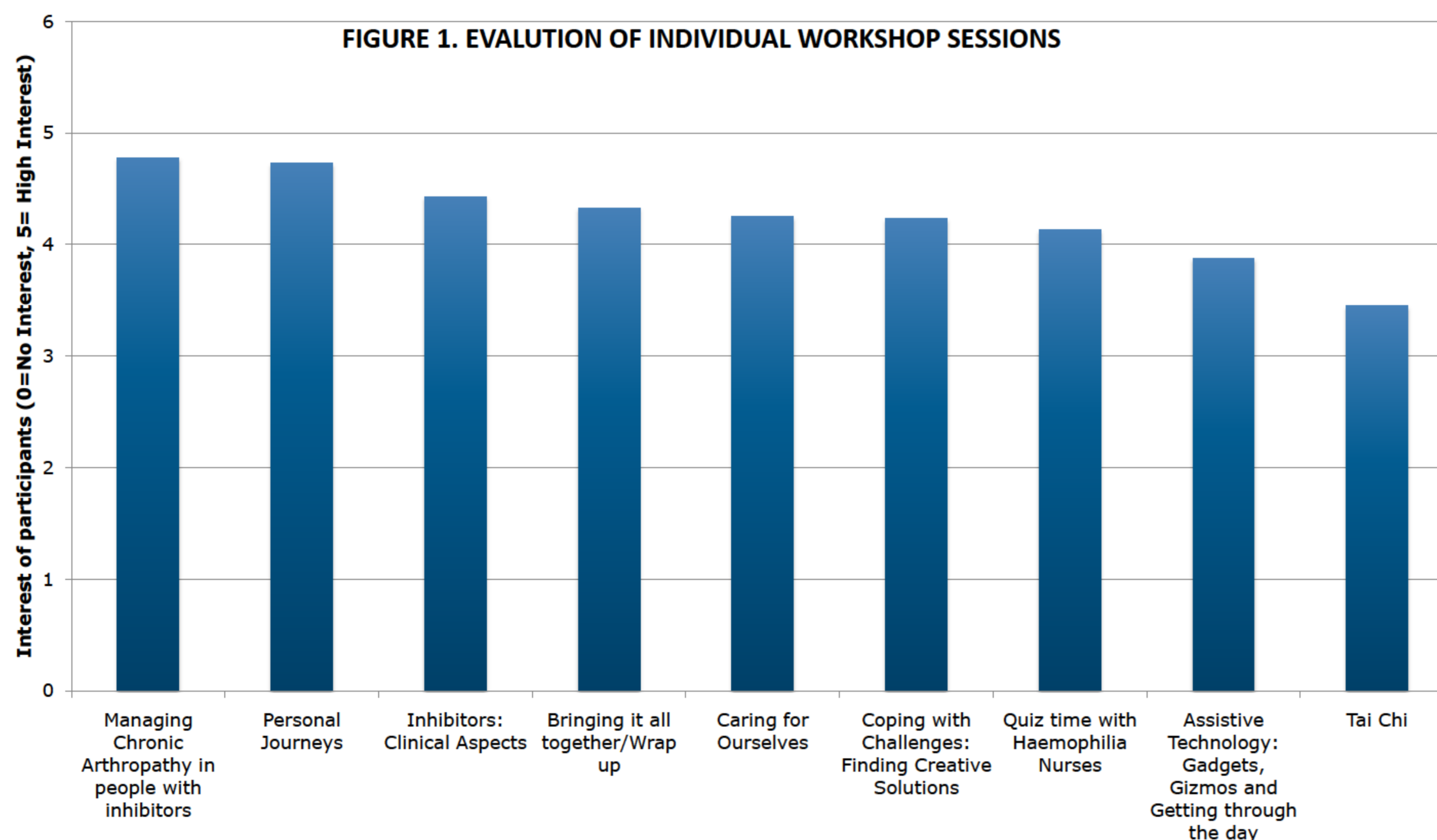
As numbers of inhibitor patients in Australia and New Zealand are low, a joint 3-day residential workshop was organized in Sydney in October 2011, drawing on the clinical expertise from both countries. The workshop was organized by the Haemophilia Foundation of New Zealand with support from the Haemophilia Foundation of Australia and a joint planning committee. Participants included parents of children with inhibitors and men with inhibitors of all ages, as well as a partner or support person.

The program encouraged participation, learning and fun and included information and education from a hematologist, physiotherapist and hemophilia nurses, models of health and wellness, and the challenges of living with inhibitors and strategies for meeting these. For discussions, participants were split into four groups: adults with inhibitors, young adults with inhibitors, parents of children with inhibitors and carers/partners.

RESULTS

The inhibitors educational workshop was the first ever Trans-Tasman event focused specifically on the challenges faced by families with inhibitors. In total 28 people participated in the workshop, including six adults with inhibitors, seven youth with inhibitors, nine parents of children with inhibitors and six carers/partners of people with inhibitors. The age of participants ranged from 19 to 69 years. Sixteen participants were from Australia and 12 from New Zealand.

Evaluations showed that 55% of respondents 'Strongly agreed' that the workshop was relevant to their needs, 41% respondents "Agreed" and one respondent did not answer this question. The majority, 81%, of respondents felt their understanding of haemophilia and inhibitors had 'Increased', 15% felt it 'Stayed the same' and one participant did not answer.



The participants' favourite parts of the workshop were: Education / learning (n=15), Meeting others with similar issues (n=14), Hearing personal stories (n=9), Interactive format of workshop/working together (n=8), Reducing sense of isolation/ connection (n=6), and the Physiotherapy session (n=4). The ranking of individual workshop sessions is shown in Figure 1, with 'Managing Chronic Arthropathy in people with inhibitors' ranking the highest followed by selected participants sharing their Personal Journeys.

Comments from participants on the workshop:

- "This is so what is needed for this community - a workshop and opportunity to connect with others with inhibitors. Thank you! Thank you!"
- "Well organised and catered to everyone's needs. A great way for likewise people to meet and feel involved when they rarely meet people with similar issues."
- "Gaining understanding, empathy, knowledge and forming new relationships with carers, haemophiliacs, health professionals has given me better support."

Disclosure: Haemophilia Foundation of New Zealand and Haemophilia Foundation Australia received an education grant from Novo Nordisk for the Workshop.



CONCLUSIONS

The top strategies for coping with the challenges of living with inhibitors were identified as:

- 1) becoming informed or educated;
- 2) getting connected to others with inhibitors; and
- 3) maintaining a good support network.

By the end of the workshop all participants reported having gained knowledge, and connected with others with inhibitors which will hopefully led to ongoing mutual support.

