

How do Patients and Caregivers Access Scientific Literature?

Danielle Sheard,^a Julie Greenfield,^b Ruth Le Fevre,^c Aimée Hall,^a Annabel Griffiths,^a Maria Haughton^a

^aCostello Medical, Cambridge, UK; ^bAtaxia UK, London, UK; ^cCostello Medical, Singapore

Objective

- To investigate how rare disease patients and their caregivers acquire information about their disease and whether lay summaries aimed at non-technical readers are available, accessible and/or useful.

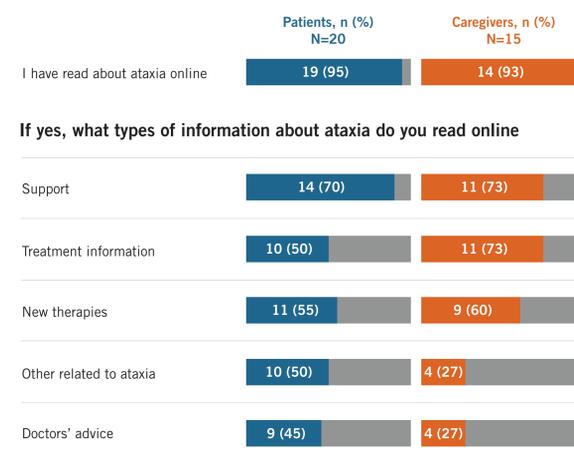
Background

- Rare disease patients are often faced with a lack of readily available information from their primary healthcare provider, which means they seek information independently.¹
- These patients are typically adept at navigating scientific literature and can provide valuable insights on how publications can be best tailored to meet their needs.
- Lay summaries are short, non-technical overviews, which can be made available alongside peer-reviewed publications. These summaries are primarily intended to engage patients and the wider public, with a view to increasing access to, and comprehensibility of, the scientific literature.²
- It remains unclear which types of scientific information are most preferred by patients and their caregivers and, in particular, how useful lay summaries really are for their intended audience.

Methods

- A survey was designed for ataxia patients and caregivers, and was completed by attendees during the Ataxia UK 2018 Conference (6-Oct-2018; Derby, UK).

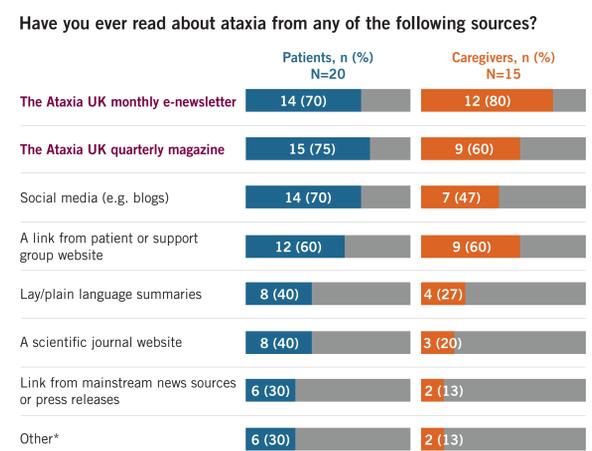
Figure 1 | Types of information accessed online



* Respondents were able to clarify their 'Other' responses in a free text box. Other sources of information for patients included: Google, Wikipedia, ataxia social media account, local experts. Other sources of information for caregivers included Ataxia blog, patient forum, links in the ataxia UK website and HealthUnlocked.

- The survey consisted of 10 questions, which asked respondents about their connection to ataxia, how they access scientific information, their experience of lay summaries and their opinion on two publications developed by the charity Ataxia UK: their monthly e-newsletter and quarterly magazine.
- Data from the survey were in categorical form (respondents could choose from a list of pre-defined options) or presented as agree/disagree statements; these were summarised using descriptive statistics.

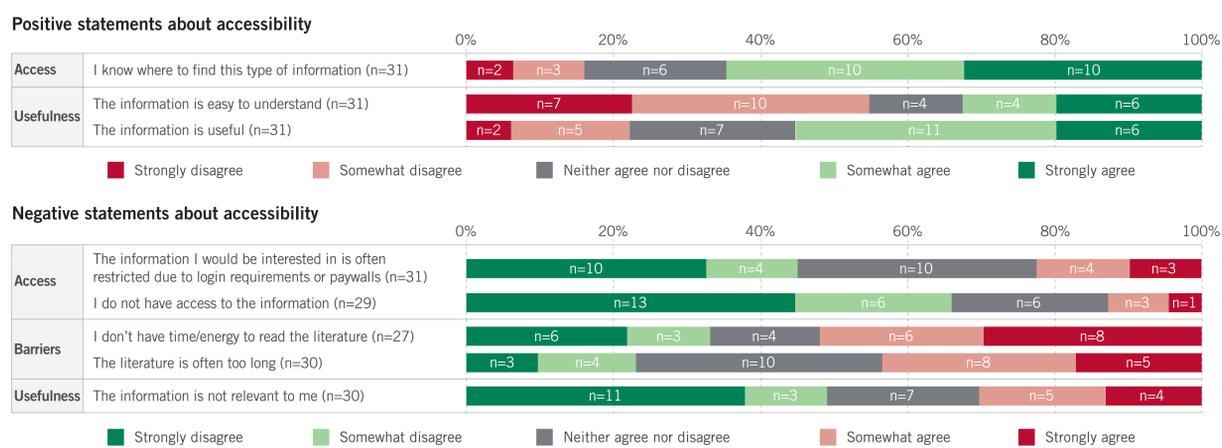
Figure 2 | Sources of ataxia information



Results

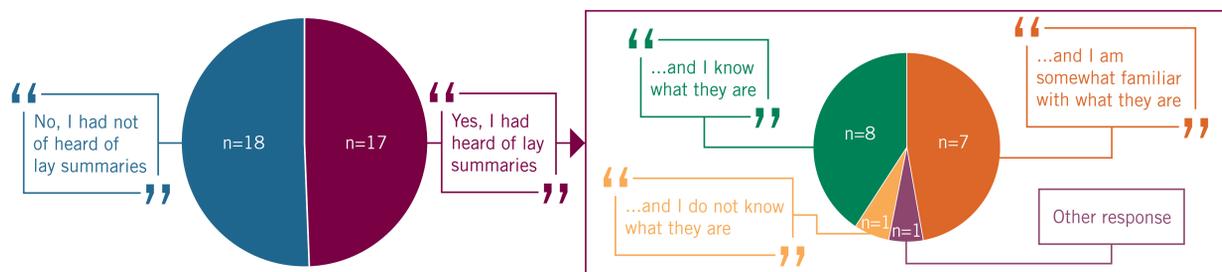
- Of 35 survey responses, 20 (57%) were from patients with ataxia and 15 (43%) were from caregivers of patients with ataxia.
- The majority of respondents (33/35, 94%) had read about ataxia online. Patients most frequently sought information relating to "support", while caregivers most often accessed information on "support" or "treatment information" (Figure 1).
- The Ataxia UK publications were the most-used sources of ataxia information (as highlighted in Figure 2), whilst only 8/20 (40%) of patients and 3/15 (20%) of caregivers had read about ataxia on scientific journal websites.
- Two-thirds (20/31, 65%) of all respondents knew where to find ataxia scientific literature and only 14% (4/29) felt they did not have access to the information (Figure 3). However, only 10/31 (32%) found the literature easy to understand, and other issues included lack of time/energy to read the literature (14/27, 52%) and overly lengthy content (13/30, 43%).
- Half of the respondents had heard of lay summaries (17/35, 49%) and, of these, the majority (15/17, 88%) were familiar with what lay summaries are (Figure 4). However, only 8/20 (40%) of patients and 4/15 (27%) of caregivers had read about ataxia in lay/plain language summaries (Figure 2). Overall, verbatim statements received from patients and caregivers regarding lay summaries were positive and indicated that easy to read, understandable summaries are "important", "useful", and "empowering" for patients.

Figure 3 | Accessibility of scientific literature available for ataxia



It was not compulsory for patients/caregivers to respond to all statements. Percentages are shown as a fraction of respondents answering each specific statement.

Figure 4 | Role of lay summaries



Respondents could choose from the pre-defined statements above when answering this question.

Abstract

Objective

Accessible scientific literature may help patients manage their health conditions. However, access to journal article lay summaries can be restricted. For rare diseases, scientific publications can be difficult to access and lay summaries are uncommon. Our objective was to corroborate this with rare disease patients/caregivers, and identify whether scientific literature accessibility is important to them.

Research Design and Methods

We designed a survey for ataxia patients/caregivers to investigate the accessibility and availability of online ataxia information. This survey was conducted at the Ataxia UK 2018 Conference (6-Oct-2018; Derby, UK). Descriptive statistics were calculated.

Results

The 35 valid survey responses included 20/35 (57%) from patients with ataxia and 15/35 (43%) caregivers. Most (33/35, 94%) read about ataxia online; the Ataxia UK monthly e-newsletter was the most-used media (26/35, 74%), while 31% (11/35) used scientific journal websites. Two-thirds (20/31, 65%) of respondents knew where to find ataxia scientific literature; only 14% (4/29) felt they did not have access to the information. Half the respondents had heard of lay summaries (17/35, 49%) and, of these, the majority (15/17, 88%) were familiar with what lay summaries are. Only 10/31 (32%) found the literature easy to understand. Other issues included lack of time/energy (14/27, 52%) and lengthy content (13/30, 43%).

Conclusions

Contrary to expectations, most ataxia patients/caregivers thought relevant scientific literature was accessible, although these conference attendees may be more informed than the general ataxia population. Even so, online information accessibility challenges included lack of time/energy, excessive length, and difficulties understanding content. Lay summaries could play a valuable role in improving the communication of scientific literature to patients, including dissemination via relevant charities.

Conclusions

- Most respondents thought that scientific literature was accessible, but several challenges to accessibility were identified; these included a lack of time/energy to read the literature, excessive literature length, and difficulties in understanding content.
- Publications produced by Ataxia UK were often used, which highlights the role that patient groups can play in disseminating information.
- Generally, respondents were familiar with lay summaries and felt positively about the role these can play in empowering patients. However, few patients or caregivers had read about ataxia in such summaries, suggesting that there is a need for additional materials of this kind.
- This sample is likely to represent individuals who are more engaged than the wider ataxia population. Further research is needed to understand how representative these results are both in terms of ataxia and rare diseases generally.

References

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Author Contributions

Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: DS, JG, RLF, AH, AG, MH; Drafting of the publication, or revising it critically for important intellectual content: DS, JG, RLF, AH, AG, MH; Final approval of the publication: DS, JG, RLF, AH, AG, MH.

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