Showing we care – insight into professionals, patients and carers to understand lived experience, information needs, and likelihood to engage with support services

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Beating Macular Disease
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Background

Macular disease has a significant impact on the lives of patients and their carers. We wanted to increase our understanding of the needs of people affected by macular disease and ensure we can reach everyone who could benefit from our help. A significant focus of this research was to gain insights from those people who have a lower awareness of and engagement with low vision support organisations.

Methodology

We carried out a programme of research with a combined audience of 413 people. We surveyed eye care professionals (ECPs) to understand their perceptions of the information gap for patients and the impact of the planned new care pathways. We then surveyed patients with age-related macular degeneration (AMD) and diabetic macular oedema (DMO), as well as carers of people with macular disease. This was to understand their lived experiences, information and support needs, and likelihood to engage with support services.

Results

Lived experience

- Diagnosis can have a huge impact on patients. With the main emotions felt being shock, fear, and anxiety.
- Despite patients reporting a high emotional impact of a diagnosis, only 30% of ECPs believe emotional support to be a key need for patients.



Information and support needs

Patient and Carers value the following types of information and support the most:
- Practical tools and techniques for vision
- Peer support from someone with macular disease
- General information or education (websites or leaflets).

Professionals most likely to give information on:
- General support, help and advice
- General information or education (e.g. leaflets)
- Peer support.

- In general, ECPs are providing the right information to patients. However, patients would appreciate receiving more information on practical low vision tools and techniques.



Likelihood to engage with support services



58% of patients stated there have been times when additional support and information would have been useful.

50% of patients and carers said they would like regular contact/support from someone with experience of macular disease.

66% of carers did not receive any support for themselves.

Discussion

In order for support services and ECPs to provide the best care for patients with macular disease and their carers, it is important to understand what support patients and carers would like to receive. This is especially vital for those not currently receiving support, where we need to understand the barriers to receiving support and whether they have the need and willingness to engage with available support services.

One key finding relates to the lived experience and impact of diagnosis for those with macular disease, which shows a clear need for improved emotional support. We are able to see that support from those with experience of macular disease, who can relate to that lived experience, is a key need for these patients and something that they would be keen to engage with.

Another key area of need relates to information and provision of practical tools and techniques to aid vision for better daily living.

Conclusion

Over half of the patients surveyed who had not interacted with low vision support services stated that there were times that they needed support. Half of all patients also said they would like regular peer support.

There is therefore a need and interest in low vision support services which is evidently unmet in many patients.

It is essential for support services and eye care professionals to work together to ensure all patients are aware of the information and services available to them.