How patients can design their own information leaflet! A quality improvement project on retinal vein occlusion.

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Introduction

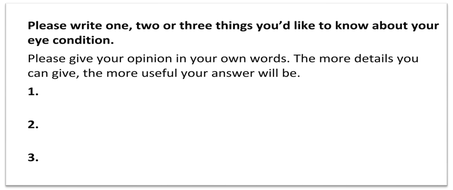
Retinal vein occlusion (RVO) is a common cause of sudden vision loss. Previous studies have shown there is a *misunderstanding about the condition* amongst patients (1). This misunderstanding affects quality of life, leading to increased anxieties about prognosis, available treatments and how this condition will affect activities of daily life such as the ability to work/ drive. This quality improvement project was designed to measure and improve patients understanding of RVO.

Method

A questionnaire was completed by patients receiving injections for RVO at the Macular Clinic in the Mater Hospital, Belfast. The questionnaire involved three knowledge-based questions, satisfaction scores based on current information they had been provided on RVO, and finally a free text section for any specific questions patients had. Thematic analysis was conducted on the free text, grouping questions under three main themes (prognosis, treatment logistics and self-help). These themes were used to write a new patient information leaflet, incorporating all the questions listed by patients. The new leaflet was distributed to patients and the same questionnaire was repeated.

Results

In the first cycle a total of 30 patients filled in the questionnaire (group 1), after the leaflet was introduced a further 18 patients filled in the questionnaire (group 2). In group 1, participants scored a mean of 56% in the 'knowledge' section of the questionnaire, which improved to 87% in group 2. In group 1 83% of participants had unanswered questions about RVO, however after the leaflet was distributed, this reduced to 33%. Overall satisfaction scores reported by patients were 78% in the group 1 and 76% in group 2.



Please write one, two or three things you'd like to know about your eye condition.

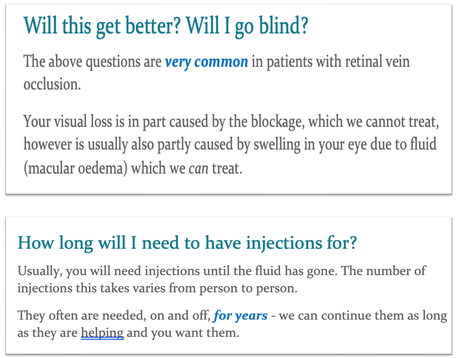
Please give your opinion in your own words. The more details you can give, the more useful your answer will be.

1.

2.

3.

Figure 1 showing an exert from the free text section of the questionnaire.



Will this get better? Will I go blind?

The above questions are ***very common*** in patients with retinal vein occlusion.

Your visual loss is in part caused by the blockage, which we cannot treat, however is usually also partly caused by swelling in your eye due to fluid (macular oedema) which we *can* treat.

How long will I need to have injections for?

Usually, you will need injections until the fluid has gone. The number of injections this takes varies from person to person.

They often are needed, on and off, ***for years*** - we can continue them as long as they are helping and you want them.

Figure 2 showing exerts from the new leaflet.

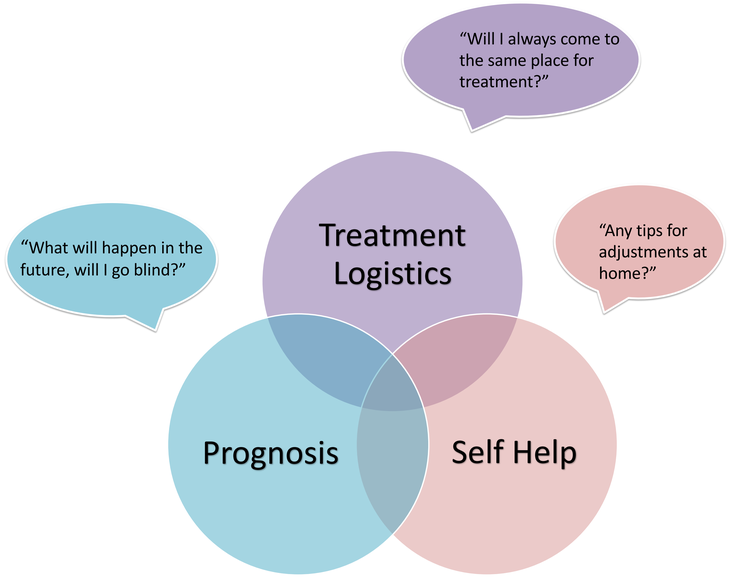


Figure 3 showing the three main 'themes' of questions identified in thematic analysis.

Discussion

The results show that the new questionnaire led to an *increase in patients' knowledge* on RVO. Furthermore, less patients had questions regarding their condition after reading the new leaflet suggesting that the leaflet had successfully *answered more of their questions or concerns*.

The most common question encountered in thematic analysis was related to prognosis, with the main concern being losing all sight or going blind. This finding correlates with other studies conducted on RVO (2).

Conclusions

This study concentrated on creating a patient centred information source drawing from patients' own thoughts/concerns.

The method employed is a simple and effective way to include patients in quality improvement and help empower them to become more involved in their care.

Future Directions

The methods employed in this quality improvement project could be adapted to any medical condition in any department. Creating information sources that meet our patients needs and empowers them to take ownership of their health care is vital.

Contact Information

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References

1. Monaghan MT, Steenson C, Williams MA. Re: Understanding quality of life impact in people with retinal vein occlusion: a qualitative inquiry. Clin Exp Optom. 2019 Sep;102(5):536. doi: 10.1111/cxo.12906. Epub 2019 Apr 24. PMID: 31018248; PMCID: PMC6767443.
2. Prem Senthil M, Khadka J, Gilhotra JS, Simon S, Fenwick EK, Lamoureux E, Pesudovs K. Understanding quality of life impact in people with retinal vein occlusion: a qualitative inquiry. Clin Exp Optom. 2019 Jul;102(4):406-411. doi: 10.1111/cxo.12875. Epub 2019 Jan 29. PMID: 30695815.

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