

# Evaluation of N. Z. Endometriosis Foundation's Patient-Partnering program

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"One-on one was great. Afterwards I requested an overview of the appointment which was typed up for me" [Undiagnosed 13 yrs]

"...not being alone, and being believed" [Undiagnosed 16 yrs]

"Being able to discuss things with someone who had answers and who was understanding of the disease. Previously I had only dealt with male doctors" [Undiagnosed 13 yrs]

## Aim

This study aimed to assess the quality and value of the New Zealand Endometriosis Foundation's (NZEF) patient partnering program as it is being operationalised in MidCentral DHB. It was designed to gauge the effectiveness of the program in informing, empowering, and improving the quality of life of these women with endometriosis. This is a retrospective study which may also be used to improve the program.

## Method

When assessing new health programs it has been found that triangulating qualitative and quantitative data from the same participants enhances each of the data sources (Kidd & Parshall, 2000). This assessment consists of:

- ❖ **quantitative questionnaire** based on NZEF materials and deliverables in the program

- ❖ **open ended qualitative questions** included in the questionnaire to provide the respondents with space to exercise their own voice (Emad, 2006) and to contribute thoughts outside of the issues considered by NZEF and the researcher (McGowan et al, 2007). These responses were analysed for common themes and will provide an addendum to the questionnaire analysis as well as leading into the focus group.

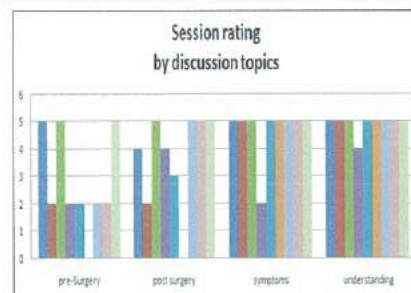
- ❖ **focus group** to provide a deeper investigation into the value derived from the program by giving the women a platform to communicate their experiences in the program as part of the endometriosis community. Questionnaires were mailed from NZEF to 30 women signed up for the program.

## Results

### Patient Advisory Sessions

These personal sessions received praise from all participants, indicating how important it was to these women to be listened to, to be understood, and to gain understanding.

"Someone who understood my pain and [the] many doctor visits leading to no help. I got real answers in easy to understand language" [symptoms for 18 years, diagnosed in 2006].



The item rankings are graphed to indicate 5 as most helpful, 1 as least helpful.

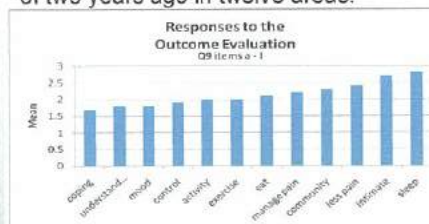
Gaining insight into their symptoms and talking with someone who was knowledgeable and empathetic (understanding) was rated as most important by the majority of respondents.

### Information Pack

This was rated highly for providing information on endometriosis symptoms (mean 1.55) and understanding of endometriosis as a disease (mean 1.64). Information on diet and nutrition was rated next most useful, followed by treatment options.

### Outcome Evaluation

Respondents were asked to rate their current health/comfort status now compared with their remembered status of two years ago in twelve areas.



Mean responses to each of the items in Question 9, graded from most positive (1.7) to least positive (2.8). A 4 point Likert scale was used.

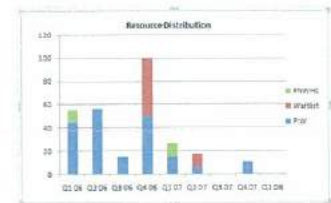
Using Factor Analysis, two components were generated from the twelve questions in this section.

Outward Life		Q.	Inner Life		Q.
eat	0.93	9a	control	0.92	9e
mood	0.92	9k	coping	0.92	9c
exercise	0.91	9d	less pain	0.83	9a
activity	0.86	9i	understand self	0.66	9f
community	0.85	9j			
intimate	0.77	9l			
manage pain	0.69	9b			
sleep	0.63	9g			

## New Zealand Endometriosis Foundation Partnering Program

The program consists of:

- ❖ an information / resource pack
- ❖ 0800 help line
- ❖ one-on-one patient advisory clinics
- ❖ seminars for patients and medical staff



"...there is also a growing awareness that this component of the "best practice" model is current gold standard treatment... we really want to know patient outcome and satisfaction: that they feel supported, informed and empowered." Deborah Bush, NZEF 21.4.2008 email excerpt.

## Conclusion

The eleven women surveyed represent a wide age range (16 – 42 years) and life story but are united in their experience in the program. Their various and unique needs have been met, an outcome that was possible through the individualised nature of the program.

The personal counselling sessions were rated most highly and the information pack added value with a smorgasbord of information which the women valued differently, depending on their situation and requirements. Overall, the women felt their quality of life with endometriosis had improved over their time in the program.

These results, while instructive, must be treated with caution due to the nature of the study which was a single sample at one point in time. A follow-up focus group is expected to add further understanding on the value of this program to these women.

## Acknowledgements

Thanks to NZEF and MidCentral DHB for consenting to this research. My gratitude for the women who took the time to complete the questionnaire.

Kidd, P. S., & Parshall, M. B. (2000). Getting the Focus and the Group: Enhancing Analytical Rigor in Focus Group Research. *Qualitative Health Research, 10*, 293-308. Emad, M. C. (2006). At WITSENDO: Communal embodiment through storytelling in women's experiences with endometriosis. *Women's Studies International Forum 29* (2006) 197-207. McGowan, L., Luke, K., Creed, F. & Chew-Graham, C. A. (2007). How do you explain a pain that can't be seen? The narratives of women with chronic pelvic pain and their disengagement with the diagnostic cycle. *British Journal of Health Psychology, 12*(2), 261-274.