

Online Versus Office Participation of Fibromyalgia Survey

Robert S. Katz¹, Sharon Ferbert², Alexandra Small³, Susan Shott¹

¹Rush University Medical Center, Chicago, IL; ²AFFTER, Chicago, IL; ³University of IL Medical School, Chicago, IL

ABSTRACT

INTRODUCTION: Utilizing online surveys may be an efficient method to acquire data concerning fibromyalgia syndrome (FMS) and other disorders. This study compared responses to a 40-question survey administered both on-line to people who described themselves as having FMS and to a separate group of FMS patients in a rheumatology office setting. To avoid confounding by gender or country, only data from U.S. women were analyzed.

METHODS: 540 respondents were included, 501 who identified themselves as having FMS in an online survey, and 39 pts in a rheumatology office practice who had been diagnosed with FMS according to ACR criteria and who completed a written version of the same survey in the clinic. The online survey was administered by AFFTER (Advocates for Fibromyalgia Funding, Treatment, Education and Research). We compared the responses to the online and written forms of the survey. The chi-square test of association and Mann-Whitney test were used to compare the online-survey and written-survey respondents.

RESULTS: Patients were predominately middle-aged (59% aged 36-55) and Caucasian (91%). There were no statistically significant differences between the online-survey and written-survey respondents with respect to age, age at FMS diagnosis, childhood abuse, pain threshold, pain location, difficulty exercising, or helpfulness of most coping strategies. However, online-survey respondents were significantly less likely than written-survey respondents to report difficulties with fibrofog (3% vs. 13%, $p = 0.012$) and memory problems (7% vs. 18%, $p = 0.018$). Online-survey respondents also had significantly higher ratings for pain experienced during an average week ($7.0 + 2.1$ vs. $6.0 + 1.9$, $p = 0.005$), fatigue experienced during an average week ($7.4 + 2.1$ vs. $6.8 + 1.8$, $p = 0.035$), and number of areas with pain or tenderness ($16.0 + 4.4$ vs. $11.0 + 4.5$, $p < 0.001$), as well as significantly worse (lower) ratings of how well they coped with FMS ($4.5 + 2.2$ vs. $5.6 + 1.9$, $p = 0.005$). In addition, online survey respondents reported seeing significantly more physicians before obtaining a diagnosis of FMS ($p = 0.013$), and were significantly less likely to have been diagnosed by a rheumatologist (47% vs. 89%, $p < 0.001$). Online-survey respondents were also significantly more likely to report that support groups helped them cope with FMS (29% vs. 5%, $p = 0.001$), and to state that their condition had worsened over the last few years (48% vs. 14%, $p < 0.001$).

CONCLUSIONS: Although a clinical diagnosis of FMS is more reliable when made by a rheumatologist in an office setting, an online approach can obtain larger numbers of patients. However, numerous statistically significant differences were found between the responses of online-survey and written-survey pts. Further research is needed to determine whether these differences are due to the different survey formats or to patient characteristics.

INTRODUCTION

Utilizing online surveys may be an efficient method to acquire data concerning fibromyalgia syndrome (FMS) and other disorders. This study compared responses to a 40-question survey administered both online to people who described themselves as having FMS and to a separate group of FMS patients in a rheumatology office setting. To avoid confounding by gender or country, only data from U.S. women were analyzed.

Many patients diagnosed with fibromyalgia seek additional information and care through participation in self-help groups, including fibromyalgia organizations and Internet groups. Online fibromyalgia support groups can make a valuable contribution in empowering patients. On the other hand, these patients may represent a subset of those with fibromyalgia, and may not be representative of FMS patients generally.

A study by Katz et al. in *Arthritis and Rheumatism* (2007) compared 1831 FMS patients diagnosed by their rheumatologists with 509 patients with fibromyalgia who self-referred for study participation. The results suggested that Internet participants with fibromyalgia had more symptoms and greater symptom severity, more depression and more psychiatric illness.

METHODS

540 respondents were included, 501 who identified themselves as having FMS in an online survey, and 39 patients in a rheumatology office practice who had been diagnosed with FMS according to ACR criteria and who completed a written version of the same survey in the clinic. The online survey was administered by AFFTER (Advocates for Fibromyalgia Funding, Treatment, Education and Research). We compared the responses to the online and written forms of the survey. The chi-square test of association and Mann-Whitney test were used to compare the online-survey and written-survey respondents.

RESULTS

Patients were predominately middle-aged (59% aged 36-55) and Caucasian (91%). There were no statistically significant differences between the online-survey and written-survey respondents with respect to age, age at FMS diagnosis, childhood abuse, pain threshold, pain location, difficulty exercising, or helpfulness of most coping strategies.

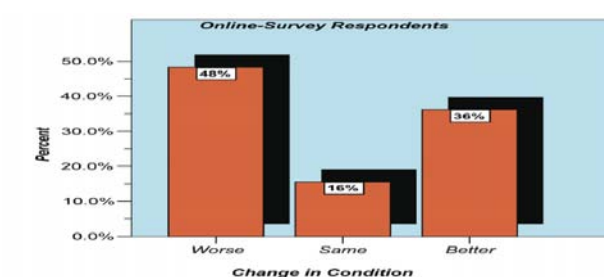
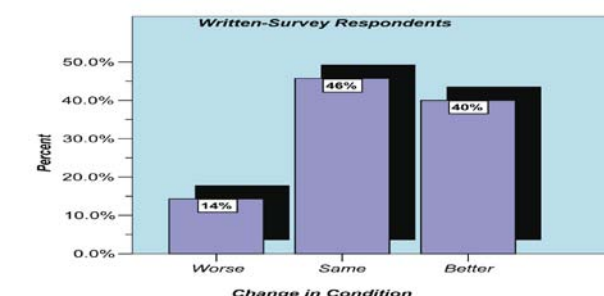
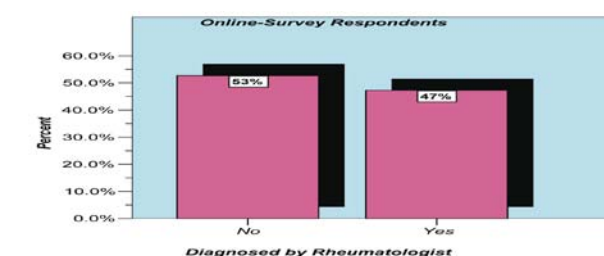
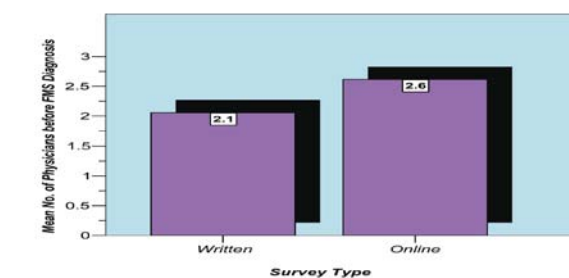
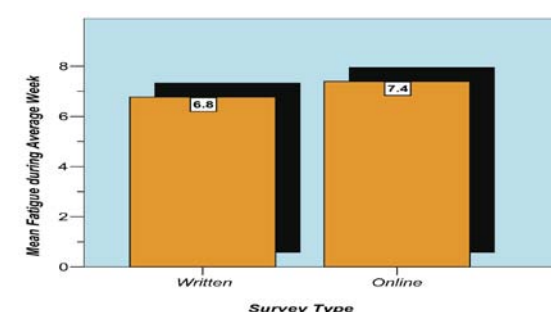
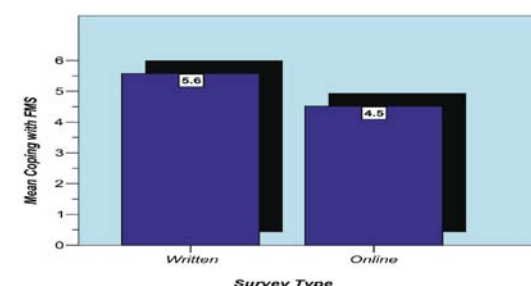
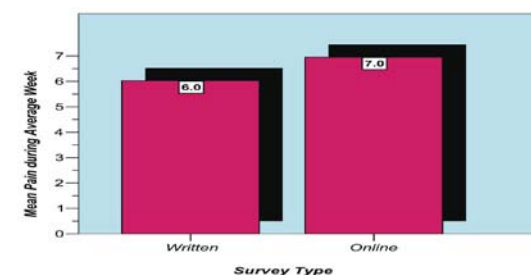
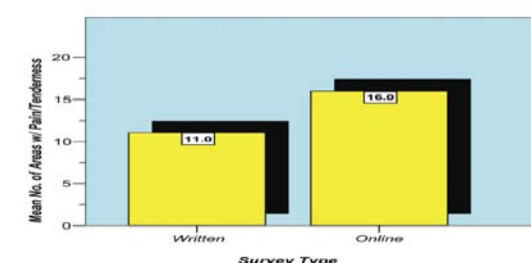
Online survey respondents also had significantly higher ratings for pain experienced during an average week ($7.0 + 2.1$ vs. $6.0 + 1.9$, $p = 0.005$), fatigue experienced during an average week ($7.4 + 2.1$ vs. $6.8 + 1.8$, $p = 0.035$), and number of areas with pain or tenderness ($16.0 + 4.4$ vs. $11.0 + 4.5$, $p < 0.001$), as well as significantly worse (lower) ratings of how well they coped with FMS ($4.5 + 2.2$ vs. $5.6 + 1.9$, $p = 0.005$). In addition, online survey respondents

reported seeing significantly more physicians before obtaining a diagnosis of FMS ($p = 0.013$), and were significantly less likely to have been diagnosed by a rheumatologist (47% vs. 89%, $p < 0.001$).

Online survey respondents were also significantly more likely to report that support groups helped them cope with FMS (29% vs. 5%, $p = 0.001$), and to state that their condition had worsened over the last few years (48% vs. 14%, $p < 0.001$).

Online survey respondents were significantly less likely than written-survey respondents to report difficulties with fibrofog (3% vs. 13%, $p = 0.012$) and memory problems (7% vs. 18%, $p = 0.018$).

ONLINE VERSUS OFFICE PARTICIPATION OF FIBROMYALGIA SURVEY



CONCLUSIONS

Statistically significant differences were found between the responses of online-survey and written-survey fibromyalgia patients. Further research is needed to determine whether these differences are due to the different survey formats or to patient characteristics.

Online fibromyalgia participants tended to report more pain and fatigue and have greater difficulty coping with their illness.