

Post Hysterectomy Experiences

A Survey By The Hysterectomy Association, UK

Introduction

Over the course of one week in July 2007 we asked women who were using The Hysterectomy Association website to complete a survey for us about their experiences post hysterectomy. The purpose of the survey was to identify any common themes or threads that could be used to indicate areas of future research into how a hysterectomy impacts on women's lives.

Limitations

First and foremost it is necessary to point out that this was very much a self selected group. The group with the largest number of responses, those aged under 50 who are, we believe, to be most likely age group to have access to the Internet, either at home or at work. As The Hysterectomy Association exists almost solely online, this was always going to be a significant factor in determining those who were able to take part. The questionnaire was hosted by Survey Monkey and required users to be connected to the Internet to complete it.

Although we asked where respondents came from, we didn't analyse this information. We also took no account of race, language, culture or educational ability. In addition, there were some symptom groups who had few respondents which may cast doubt on the validity of those results.

Despite these constraints however, lack of cohesive research across this entire subject area means that this survey becomes valid, if only for establishing that there is a need for more in-depth analysis and research in some of the areas covered. A more expansive survey is planned for launch in May 2008 and which will run for twelve months.

Results

We received 1639 responses from women, of which 1638 had already had a hysterectomy. Of these numbers, 43.8% of the respondents had their hysterectomy due to fibroids, 26.2% had their hysterectomy because of heavy bleeding, a further 18.3% had surgery due to endometriosis and 9.5% had a hysterectomy to remove or prevent some form of gynaecological cancer. Of the remaining respondents, hysterectomies were undertaken for a variety of other conditions, including pelvic inflammatory disease, post partum haemorrhage and prolapse. However, these figures were not statistically significant.

The majority of respondents had their surgery either six months prior to the survey, (49.4%) or within the previous 12 months (36.6%). Of the remainder, 11.5% had undergone surgery one to two years before the survey took place and 2.5% more than two years previously.

Our own anecdotal evidence has suggested that the vast majority of hysterectomies are performed on women between the ages of 30 and 50, and the results from the survey bear this assumption out: with 56.6% of respondents aged between 41 and 50, 22.6% aged between 31 and 40 and a further 17.2% aged between 51 and 60.

It was interesting to note that women had roughly a 50% chance of having their ovaries removed, with 54.2% having had both removed, 4.9% having just one removed and 40.8% conserving their ovaries. However 0.1% didn't know whether their ovaries had been removed or not.

24.6% of respondents were using oestrogen only hormone replacement therapy, 4.7% were using progesterone and a further 1.8% were using testosterone. However, 68.3% of respondents were not using hormone replacement therapy at all, although we see from further analysis of the results that this figure changes significantly depending on the reason for the hysterectomy and whether ovaries are removed or not.

We also asked respondents to rate their post operative experiences using very open questions. First of all, we asked whether their experience of sex had improved or not. Overall, 4.8% said that it was soon too tell whether their experience was better or worse, 9.2% said they didn't have a partner so weren't able to assess, 22.6% said it was better than before, 46.1% said it was the same as before and 17.3% said it was worse than before.

When asked to rate whether they felt happier and/or more positive since their hysterectomy, 31.5% of respondents rated themselves as much happier/more positive since having their surgery, 24.2% were somewhat happier since their operation and

28.4% said they felt much as they had before. However 10.6% said that they were slightly less happy or positive than before and only 5.4% were noted as being very unhappy or negative.

We also asked whether respondents had experienced any of a list of symptoms after their surgery had taken place. However, we didn't qualify whether these symptoms had been present BEFORE respondents hysterectomies and this does lead into question some of the results. Overall:-

- 26% of respondents reported a loss of sexual feeling
- 6.2% of respondents reported a loss of sexual function
- 39.8% of respondents reported mood changes/swings (although it is not clear whether these were seen as positive or negative)
- 27.3% of respondents reported depression. However a number also said that this was a condition that pre-dated their surgery
- 19.7% of respondents reported that they had experienced a urinary tract infection
- 20% of respondents reported that they had experienced a post operative infection other than a UTI
- 28.1% reported that they experienced a loss of feeling/numbness in the legs and/or abdomen
- 47.6% reported that they had experienced menopausal symptoms although again this wasn't clarified as occurring ONLY after their hysterectomy took place.
- 1.9% of respondents said that they had experienced prolapse of other organs
- 13.9% reported irritable bowel syndrome
- 16.7% reported that they experienced stress incontinence
- 2.1% of respondents reported damage to the urethra and/or bowel
- 0.8% of respondents said that they had experience prolapse of the vagina
- 24.1% of all respondents said that they had experienced back pain
- 6.6% experienced haematoma
- 0.8% experienced thrombosis

Whilst the figures above may look alarming, we did encourage our respondents to mark as many as were relevant to them and a number did comment that they had not experienced any side effects.

In addition to those side effects listed, the following were also noted by some women:- arthritis, headache/migraine, loss of bowel function, osteo-arthritis, constipation, hives, lymphodema, vertigo, pulmonary embolism, scar tissue, thrush, haemorrhage, PMS, cysts or adhesions, itching, breast tenderness, vaginal bleeding, bladder or bowel pain, cystitis, weight gain, blurred vision, granulation, arterial bleeding, groin pain, incisional hernia, C-Diff and MRSA, hip pain and anxiety.

Our final question asked respondents 'If You Had To Make The Choice Again, Would You Still Have A Hysterectomy?' An overwhelming 84.3% said that they would, 11% said they might and only 4.7% said no.

Discussion

Further analysis of the results demonstrated some interesting variations to the overall responses to questions though and do require some clarification and comment.

It is obvious really, that the age at which you have a hysterectomy, will be heavily influenced by the reason for which it has been recommended. Therefore 79.12% of those who said that the reason for their surgery was fibroids, over 96% of those having surgery was because of endometriosis and over 90% of those having surgery for heavy bleeding were all aged 50 and under. In addition, of those who had surgery due to endometriosis 44.2% were aged under 40.

The majority of women having one or both ovaries removed had surgery for either endometriosis or pelvic inflammatory disease (81.5% and 64.3% respectively). This figure is also reflected in the use of hormone replacement therapy, where the largest number of respondents to the survey who said that they used some form of HRT were those who had had endometriosis and pelvic inflammatory disease (57.8% and 50% respectively). It must be borne in mind though, that some of those women who had surgery due to endometriosis and/or pelvic inflammatory disease will be waiting up to 12 months before beginning any form of hormone replacement therapy.

Although the numbers of respondents weren't statistically valid, it became apparent that those women who had surgery because they had pelvic inflammatory disease, were those who marked higher adverse outcomes than any other group of respondents. In addition they were the ones least likely opt for a hysterectomy again if they had to make the decision a second time around.

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When age at hysterectomy was used as a filter, some of the figures were again very surprising. It appears that women are almost certain to have their ovaries removed if they are over the age of 51 when they have their hysterectomy. This is probably because they are the age group that is most likely to have their surgery because of diagnosed or suspected gynaecological cancers (80.1% of respondents who listed cancer as their reason for surgery were over the age of 51). In addition, they are the age group who said they were not using any form of hormone replacement therapy (oestrogen, progesterone or testosterone); this is probably because they were either already past their menopause before surgery took place or their cancer was oestrogen dependent.

The figures are no less startling when looking at experiences of sex post hysterectomy. Those who were aged under 30 were the group most likely to say that their sex life was the same or better than before (79.1%). In addition they were also the group that experienced the greatest happiness / positivity post hysterectomy, with 69.5% of their number saying that they were much or somewhat happier or more positive. Conversely though, they also had the greatest number to be slightly or very unhappy/negative (21.7%) only just beating those aged 51-60 at 21.4%, the group least happy with their sex life after hysterectomy.

It was very interesting to see that those who were aged between 41 and 50 were the group (847 responses in the survey), least likely to experience any of the side effects listed. Whilst those in the youngest age group were those who experienced the greatest number of other side effects and symptoms.

Conclusions:

To say that some of the results obtained from this very simple survey were surprising would be to downplay the impact they made. Whilst our own anecdotal evidence has always suggested that the vast majority of women were happy with the outcome of their surgery, we had not expected such large numbers to say that if they had to make the choice again, they would choose to have the same procedure.

There were a number of other elements that may be worthy of future research, including the very small number of women didn't know whether their ovaries had been removed or not. This seems to fall in line with our own anecdotal experiences of women getting in touch with the association to find out whether they can become pregnant now that they have had a hysterectomy.

Despite the limitations suggested at the beginning of this report, the figures may speak for themselves simply because there are so many large discrepancies, not least on the final question asking women whether they would make the same choice of surgery again if they had to. It may also be that those completing the survey who had their surgery more than 12 months previously may have ongoing health problems which would therefore be reflected in their responses and the survey results.

Finally, the results for the questions about overall happiness and feeling positive after the surgery must be placed against the huge number of negative web sites on the Internet, as well as the many personally harrowing stories of what has happened to individual women. This has served to create an impression that a hysterectomy is always a negative experience. However, what this survey does suggest is that most hysterectomy patients simply move on and put the experience behind them and never feel a need to tell people of their very positive outcome.

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