

## **Information To Support Choice**

### **The Information Needs of Women Undergoing Hysterectomy**

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**Report produced from the research undertaken for the Masters Degree in Information Studies at Loughborough University. The dissertation is titled "Hysteria, its not funny on HRT".**

The Patients Charter enshrines the right to receive information about any health conditions and medical procedures that are proposed. This should include information on any risks associated with the treatment and any alternatives available. It also requires that healthcare professionals ensure that it is all clearly explained before the treatment takes place.

It appears, though, that the information that is available to women about hysterectomy, its' alternatives and the consequences is not given in any great detail. Hysterectomy is one of the most common surgical procedures for women in Britain today. Statistics indicate that by the age of 75, one in five women will have had their womb removed. Doctors and medical staff may not always have the time or the facilities to give enough detail and many women find it difficult to talk about because of its emotional, as well as physical, implications.

In addition to the above there is also a lack of easily understood information on the most frequently prescribed drug for these women, Hormone Replacement Therapy. Many women who undergo a hysterectomy are prescribed this type of drug, particularly if they had their operation before they would naturally have gone through the menopause, because healthcare professionals recognise the threat to their long term health without it. However, many women are only aware of the headlines that surround the topic and it is becoming increasingly controversial. It would be foolish not to acknowledge that there are considerations that all women must take into account before they embark on long-term drug therapy, but these should be considered before the operation even takes place and must be understood by the woman undergoing the surgery. Unless the surgery is life saving, and that is rarely the case with hysterectomy, all implications should be considered before treatment. This of course is only possible if there is adequate unbiased information available to women from the outset, preferably from their GP's surgery.

In order to consider the types of information that women receive currently and would like to be given, a questionnaire was devised and sent out five groups of women. They were drawn from two GP surgeries, the [Women's Health](#) organisation, Here's Health magazine and some who contacted the researcher personally. The data was analysed and considered and two information resources for women were produced; a web site and a pocket guide.

The web site that has accompanied the study can be found by directing your browser to: <http://www.hysterectomy-association.org.uk/index.html> Although there is little use of the Internet at present, there is evidence that it is growing rapidly and one of the most prolific areas already supported by the Internet is health information. The site is being maintained following the conclusion of the study and will form a major part of The Hysterectomy Association, now being started as a result of requests from women taking part in this study.

Both methods of communication have pro's and con's. The web site provides instant publication world-wide, is free to the user and requires no sponsorship, however the audience it reaches at

present is limited, particularly in the UK. The booklet can reach more women but will rely on sponsorship or self publication and there will be some cost to the user.

On the whole the women from the two surgeries involved in the study received more information, found it easier to understand and were able to discuss their surgery with their GP whenever they needed, to a greater degree, far more than women in any other group. They also appeared to be happier with the information they had received as they felt better prepared for the operation than their counterparts. Although the types of information that they received was similar to other groups fewer of them reported that they had not received any information, in fact two women reported that they had moved to one of the surgeries because of its reputation for providing good care. The women also reported they received more information from their GP although there was no apparent difference in when they received the information. They were also less likely to feel the need to use additional sources of information.

According to John Studd<sup>1</sup>, currently only 12-16% of those women (in the UK) that can take HRT (for any reason, including hysterectomy) do so. Of the women that completed the questionnaire 62% said they were currently taking a form of HRT. This simple illustration implies that women who have a hysterectomy seem more aware of the benefits of the drug than other groups of women who may be taking it simply to relieve menopause symptoms only.

Interestingly, receiving information about the menopause did not greatly influence the number of women taking the drug. On the whole, women that used additional information sources were more likely to take HRT than not. It may be possible to go on to make the assumption that having access to numerous sources of information increases a woman's feelings of ease with HRT and together with the knowledge of the risks helps them to make informed choices. Those women that had not had any information about HRT or used fewer sources of additional information did not record the same usage. This would seem to indicate that they feel their need for quality information has not been met by the healthcare system. However, it is interesting to note that those women from the two surgeries used fewer alternative sources than any other group, perhaps because they felt more confident with the information they had received at the outset.

Overall, the question of whether a 'good' GP makes a difference and whether the types and amounts of information have an effect on patients use of HRT has produced some interesting answers. The data suggests that where a patient considers a GP to be providing the information she requires, she records better care in general and will use fewer sources of additional information compared to other groups. However, when considering whether receipt of information plays a role in patient compliance with HRT, it appears that women receiving any amount of information from a healthcare professional will be more inclined to take the drug, than those that hadn't and if they then feel they have not received enough information they will then seek out other sources of information to support their decision.

There appears to be no doubt that women feel they are not being given enough information about either their hysterectomy or Hormone Replacement Therapy. Even where women said that they had received information about particular subjects, they were a minority in almost every case and there appears to be no standard practice followed within the NHS.

The majority of the women that completed questionnaires also made additional comments about their treatment. Whilst there were a minority (mainly from the surgeries) that said they were happy with the treatment and information they had received, the vast majority were not happy and two women said that they had changed to one of the two surgeries to receive better care. One respondent commented

“I was delighted to see that some research is being carried out on this important topic. It is still very neglected, and women are not being informed and suffer as a consequence”

She also went on to say “I am now much more assertive in asking questions and demanding information since the first op. Sadly, my second op. demonstrated that hospitals are not offering information on these topics and fellow patients were very uninformed.” This sentiment seems to be true across the majority of respondents.

The types of information that a patient receives from the medical professionals when they have a hysterectomy appears to depend to a great extent on the patient, the GP and the type of relationship that exists between the two. A patient that asks questions will, naturally, receive more information than a patient who accepts without question. As one patient said, whilst she did get information it was only after asking questions or presenting her own facts. There is considerable evidence that GP's and consultants are more than happy to answer any questions that a patient may have, but it is complicated further if a woman does not know what to ask about in the first place. There may also be a tendency on the part of the consultant to assume that if a woman doesn't ask questions then she has already been given the information she needs by her GP, and vice versa. The patient may well get caught in the middle with no way out and no knowledge that there is a way out.

However, some researchers have suggested that women don't ask questions because they don't want to take an active part in their health management and that the avoidance of information may be a coping strategy<sup>2</sup>. However, if a woman is not given time to think about what has been said she may not know what to say or how to ask for help. Even if women say that don't want to be given information at the outset, this is no reason for not giving it to them. Information is power, it gives a patient the power to make a choice for themselves, if they avoid the information as a coping strategy by ripping up the booklet, they have still made a choice to do that.

There is also an indisputable link between a woman's perception of what is “care” and the amount of information received. Those women that had said they were happy with their care reported better access to information from their GP and they also used fewer additional sources. Perhaps patients feel that “care” in the NHS is the feeling that there is someone that thinks of their welfare enough to give them information. It is not necessarily the information that they receive that is important but rather the act of giving. This correlation between the perception of care and information can be better understood when you consider the fact that those women that had received some information (any amount, in any format) actually recovered more quickly and had fewer post-operative problems than those women that had not been given any information at all and they were also more likely to go on to use HRT. This may simply be because a woman does not have any false expectations or understandings about her surgery and long term health there-after.

If there is a link between health after surgery and information, it may be agreed that it is in the best interests of the NHS to improve the standards of patient health information. Overall health costs could be reduced considerably; prevention being better, and cheaper, than cure. A typical scenario may be the woman who, twelve months after surgery, goes to her doctor saying she can't sleep and is often weepy, it is summer so she doesn't mention the sweating at night. If the GP, pressured as they are, doesn't connect these symptoms with her hysterectomy and suggests counselling or a course of anti-depressants (far fetched? - it does happen frequently) the costs to the NHS goes up. If a woman were aware of all the likely outcomes of her surgery at the outset, she would be better placed to recognise the symptoms and then take appropriate action.

The majority of women said that their preferred source of information was their GP. One woman commented “the GP should always have information but a library would be an ideal place to get information without bothering your GP”. However, identifying the correct point of delivery of information in the time leading up to a hysterectomy is crucial. As it is the consultant that will, more often than not, tell a woman she needs a hysterectomy perhaps this should be the right point of delivery rather than the GP. A woman’s GP can be used to provide additional information, support or help after she has read the literature already provided.

The surgery is, in the main, supposed to be elective. However once diagnosed and on the ‘conveyor belt’ towards surgery it is very difficult for a woman to get off and without adequate information about choices that is timely, appropriate and valid she may not feel able to. The process of hysterectomy becomes a process of submission not election, if there is no information given which enables choice.

It is important to remember again that the relationship a patient has with her GP is particularly important and those GP’s that took part in the study came highly recommended by their patients. One woman commented “My GP is most helpful on any matter discussed with him”. It would be very easy to assume that the lack of response from other GP’s indicates they may feel they are failing their patients. However, GP’s are under increasing pressure of time. They have to hold knowledge of many thousands of different conditions and treatments. They have increasingly larger lists and management responsibilities take them away from what they joined the profession to do. At the same time it appears that the majority of information women receive about hysterectomy and HRT comes from mass media sources. This factor, in addition to being a possible provider of misinformation, may also actually increase stress and anxiety. Misinformation can only be refuted when ‘good’ information has already been received, it is essential then that both patients and GP’s are supported by having access to standard information that is easy to understand and distribute.

At the outset of this study, I had assumed that any findings about a patients need for information could be applied across the range of conditions found in health care. However, at this point I have to say I do not think it can. Women feel very strongly about hysterectomy, the comments I have had from women taking part confirm this. Perhaps the depth of feeling is associated with the fact that this surgery cuts to the very heart of what being a woman is all about.

(Linda Newall, 1998).

## **REFERENCES**

1. Khastgir, G. and J. Studd. Hysterectomy and HRT. in press.
2. Scriven. A. Information Needs of Hysterectomy Patients. Nursing Standard, 9(7). 1994.