



## Information Needs of the Patients with Cervical Cancer

Qinghua Huang (Corresponding author)

The University of Sheffield

DG 10 Bartolome House, Winter Street, Sheffield, S3 7ND, UK

Tel: 44-75-1744-6298 E-mail: huanqinghua188@163.com

### Abstract

Cancer patients usually experience a long medical journey. In the process of event, relevant information for cancer patients plays important role in managing their disease. In order to improve healthcare quality for the patients with cervical cancer, this essay discusses the information needs of the patients from three aspects: the information needs at different stages of the patients' journey; relative merits and suitability of different methods for providing the information; and the considerations needed by the information providers when providing the information. The essay suggests that good practice in the provision of the information should give a comprehensive consideration, including technical, legal, policy and social issues.

**Keywords:** Information need, Patients' journey, Cervical cancer, Provision methods, Relative merits, Suitability, Information providers, Consideration

### 1. Introduction

Cervical cancer is a preventable malignant tumour resulting from infection with high-risk types of sexually transmitted human papillomaviruses (HPVs) (Vanslyke et al 2008). HPVs are a very common virus that can affect the cells of the cervix. When a woman's immune system is weakened due to smoking, poor diet, and other infection, such as HIV, the infection is possibly developed as cervical cancer. According to Williams et al (2006), "Each year, about 2,800 women in the UK are diagnosed with cervical cancer." In clinical medicine, cervical cancer can be classified in accordance with its types, stage and grade. The classification may give healthcare providers and patients a clear idea of how quickly it may develop, what is the most appropriate treatment, and how about the prognosis of a patient, and etc. At the early stage of the disease, the most common symptom of the patients with cervical cancer is abnormal bleeding, such as between periods or after intercourse. Often there is also a bed-smelling discharge, and discomfort during intercourse. This symptom or these symptoms, together with the results of the patient's physical examination for diagnosis and further tests, will help doctors to know which the best type of treatment is for every specific patient.

On the other hand, to let women know this information on cervical cancer through suitable method(s) is helpful for preventing, treating and managing the cancer of the cervix. Under the perspective of information studies, tailored healthcare information on clinical manifestation, diagnosis, treatment, and prognosis of the disease, may meet the patients' cognitive need, affective need and physiological need, including (1) provide reassurance and help to cope; (2) understand the processes and likely outcomes of possible tests and treatments; (3) assist in self care and identify self help groups; (4) identify suitable healthcare providers, learn about available services and sources of help; (5) gain a realistic idea of prognosis; (6) learn how to prevent further illness; (7) understand what is wrong; (Note 1) (8) act/respond quicker to health problems; (9) take more responsibility for their health make; (10) seek advice about how to tell children, (11) seek second opinions, and make sense of the stages of the disease; (12) interpret what health professionals have said; (13) tackle isolation; (14) help others understand. (Note 2) According to an investigation, vast majority of the patients with cervical cancer stated that having the information they wanted when they were preparing for treatment, would have reduced anxiety or stress, enhanced quality of life, improved treatment and minimized side effect (Toubassi et al 2007). Lack of the information may lead to increased anxiety and distress, may impact negatively on the patient's satisfaction and may influence a patient's treatment choices.

This essay discusses information needs of the patients with cervical cancer from the following three sides: (1) the information needs at different stage of the patients' journey; (2) relative merits and suitability of different methods for providing the information; and (3) the considerations needed by the information provider. It is hoped that the discussion of the three issues would be valuable in providing (healthcare) information for the patients not only in the prevention, diagnosis, treatment and management of the disease, but also in the protection of the patients' legitimate rights, for example, how the patients can properly accept proposed medical measure(s)?

## 2. Information Needs at Different Stage of the patients' Journey

Under clinical medicine, cervical cancer can be treated in a number of different ways and there may be different options depending upon a patient's conditions (the type, stage and grade of the cervical cancer, and etc.) (Note 3), and how it is affecting the patient. A study suggests that the patients at different stages of the tumour may have different needs of (healthcare) information (Ziebland et al 2004). Therefore, during whole periods of the disease, according to Mossman et al (1999), the patients (and their carers) often have a continuing need for information on the healthcare journey; although the type of information is probably change:

### 2.1 Before visiting her GP (usually the patient is at the stage 1 or 2 of the tumor)

Let us imaging **Scenario (1)**:

A 45 year-old woman notices that she has abnormal bleeding between periods, with a little bad-smelling vaginal discharge. She is worried and makes an appointment with her GP, who informs her do not worry but refers her to the local hospital.

What information might she require when she left her GP? At this point, the following information is usually needed by the patient: what is the possible meaning of these symptoms. What is cause of the problem? What procedures will be followed when going to hospital? Is there anything I can do myself to ameliorate the problem? Is it essential to have treatment for this problem? Where can I get more information about the problem?

### 2.2 During investigation

The patients need the information to seek reassurance that the doctor is doing the right tests, to prepare for the result(s), to improve the value of the consultation. After the diagnosis, the patients may collect the information about diagnosis, treatment, prognosis of the cancer, particularly, the information that is "difficult" to ask about directly, to seek second opinions, to seek advice about how to tell her family, to make sense of the stages of the disease, to interpret what health professionals have said, to tackle isolation.

### 2.3 When choosing treatment

The patients need the information about treatment options and side effects, alternative and/or complementary treatments, and the information that is included together with an honest assessment of whether the treatments are known to be effective(Coulter et al 1999). Before treatment, the patients need to find out what to take to hospital, how to identify and to prepare questions to ask the doctors, how to avoid the treatment risks. The patients want the information about the full range of treatment possibilities, including complementary therapies (Coulter et al 1999). Let us imaging **the scenario (2)**:

At the local hospital the consultant examines her with colposcopy and takes a biopsy. A week later she returns and is informed that she suffered from cervical cancer and will have to be removed by surgery, either trachelectomy (for the patients with an early stage of cervical cancer.) or hysterectomy. She may then have to undergo chemotherapy.

At this point, the patient may need following specific information: What is the best way to treat my cervical cancer? Do I have to have the treatment offered to me? What will happen if I don't have the treatment? Are there any financial costs to me? Are there any advantages to having the combination of treatments of surgery with chemotherapy? What can I do to speed recovery? What are the risks of the treatment(s)? Will the treatment(s) relieve the symptoms? What are the possible side effects? What effect will the treatment(s) have on my feelings and emotions? What effect will the treatment(s) have on my sex life? How can I prepare myself for the treatment?

### 2.4 Short term follow up

The patients may need information about side effects, reassurance about symptoms, advice about diet, complementary treatments, and advice on benefits and finances, to check that the treatment was optimal, perceived therapeutic benefits. Imaging **scenario (3)**:

The next month the patient accepts the surgical operation and is informed afterwards that the cancer had spread into the upper part of the vagina and tissues next to the cervix, where lymph nodes had to be removed. She undergoes chemotherapy (cisplatin) for six months and 3 months later the doctors informs her that there is no evidence that the cancer has spread.

At this point, the patient may need particularly the following information: what damage has been caused by the misdiagnosis and/or mistreatment? To what extent the medical error (or negligence) has damaged her physical body (fertility or my sex life)? What is the complaint procedure? What are the options for rehabilitation? What remedies for the wrong doing can be got?

### 2.5 Long term follow up

The patients need to share experience and advice, contact support groups and chat rooms, to campaign about the condition, to make anonymous inquiries (Ziebland et al 2004). It should be mentioned that the patients with stage 3 or 4 of cervical cancer, may want more information on how to prevent further spread of the tumor, its prognosis, and how to tell her children and husband.

Understanding the information needs of the patients at different stages of the disease may help information providers improving their information service. In practice, very few of the materials reviewed met all these needs adequately; particularly, the information about consequences of conditions and prevalence of the disease was often missing (Coulter et al 1999). Yet, the situation can be improved if the patients had been consulted about their information needs before the materials were developed.

In conclusion, “better information, better choices.” (Department of Health 2003) Providing the patients more information about how, when and where they receive treatment at different stages, has become one cornerstone of the government’s health strategy (Department of Health 2003).

### 3. Relative Merits and Suitability of Different Methods in Providing the Information

Healthcare information can be provided by four methods: (1) internet, (2) professional medical books and journals, (3) mass media, including booklets, leaflets, magazines and newspapers, audio visual like TV and radio Video/ tapes, electronic like CD-ROM, and etc, (4) clinician consultation or specialist advice. Every method, as stated as follows, has itself relative merits and suitability for the provision of the information:

“Information materials are no substitute for good verbal discussions, but consultations are usually short and plenty of evidence exists that patients do not receive the information they want and need. Leaflets and other materials can therefore play an important part in supplementing and reinforcing information provided by clinicians, but the information they contain must conform to the highest standards of scientific accuracy and must be tested for comprehensibility and relevance.”(Gardiner et al 1999).

This section respectively discusses the advantages and disadvantages of the four methods, and their suitability in offering the information for the patients with cervical cancer.

#### 3.1 The Relative Merits and Suitability of Internet Information

Internet based information may provide a versatile and all-inclusive source of information available to the majority of the patients in developed country or economy developed region (Helft et al 2005). The advantages of internet information are: (1) easy to access. A study on medical internet information suggests that the growth and wider availability of the internet have greatly increased access to health information (Eysenbach and Diepgen 1998). (2) Reduce the cost of healthcare information. (3) Increase of efficiency in producing and spread healthcare information. (4) Time-saving. (5) Internet can be used to provide tailored healthcare information for specific individual(s) by e-mail.

However, the disadvantages of internet healthcare information are also obvious: (1) the lack of accuracy. “Much of this material is inaccurate or misleading, but it is difficult for non-specialists to sort out the wheat from the chaff.”(Ziebland 2004). (2) The lack of reliability. Internet information may completely lack quality control at the stage of production. This may lead more easily to the lack of reliability. (3) The probability of misread. Publics lacking information skill train likely read a web page without seeing context pages or the “cover” page containing disclaimers and warnings. (4) Distortion by commercial interests. (5) Volatility. This means that the internet is too active and swiftly changing to be reviewed by a few such filtering services.

In short, access to the Internet varies widely across socioeconomic and age groups. At present, the Internet chiefly serves the working population and younger population better than those who have retired (Helft et al 2005). Nevertheless, this is changing as the retired population becomes increasingly computer literate. It is believed that the internet is a powerful resource of healthcare information if used correctly in the future (Hunter and Bridger 2004).

#### 3.2 The Relative Merits and Suitability of Professional Medical Book and Journal

Accuracy, reliability and professional are the advantages of the information provided by medical book and journal. But, under the eye of the patients, its main disadvantage is that “the Patients reading information intended for health professionals may misinterpret information, leading to false expectations about treatment options”(Helft et al 2005). In addition, the readability and accessibility of medical book and journal is also doubted. Thus, the suitability of medical books and journals is usually for the use of healthcare professionals.

#### 3.3 The Relative Merits of and suitability of Mass Media

Mass media information is thought to possess a number of advantages. The most outstanding advantage of mass media, such as video information, is that this information may be suitable for any persons, both able to read and unable to read. A study shows that women like seek healthcare information from a variety of mass media sources, including popular

medical books, women's magazines, and television program (Rees and Bath 2000). Another outstanding merit is that the information is usually vivid and acceptable. For example, the booklet may give general information about the diagnosis and treatment of cervical cancer, with simple, acceptable, readable and accurate language. Thus, the mass media is able to overcome the problem of people not understanding the data.

Healthcare information carried by mass media, however, is also viewed as having a number of disadvantages. One obvious shortcoming is that mass media cannot advise a patient (with cervical cancer) about the best treatment and prevention for the patient because this information can only come from the patient's own doctor, who knows full medical history of the patient. Another obvious shortcoming is that the mass media are not targeted and can be costly to use. The third shortcoming is once diagnosed the patients thought that mass media sources such as magazines were frightening and depressing owing to their often negative and sensationalized nature.

Given the relative merits of mass media, a survey shows that among older persons only 21.7% of patients preferred internet information and that 68.8% would rather be given a leaflet (Eysenbach and Diepgen 1998). It can be concluded that healthcare information provided by popular booklets and women's magazines are suitable for the patients who are able to read. Information leaflets, videotapes, and television program are still an important source of information favoured by all patients (Rees and Bath 2000).

### *3.4 The Relative Merits and Suitability of Clinicians' Consultation*

Clinicians' consultation or advice may provide tailored and detailed healthcare information by taking account of individual circumstances. For this reason, the healthcare information for the patients with cervical cancer is reliable, accurate, relevant, safe and acceptable. This is the most outstanding strength of clinicians' consultation that is different from the information of internet, professional medical publications and mass media. A survey finds out that "rather than refer to written materials, many people prefer to rely on the guidance of trusted communicators, such as physicians." (Hunter and Bridger 2004).

However, it is usually the most expensive and time consumed because it usually is offered one by one and face to face. Further, patient focus groups have reported considerable dissatisfaction with their experiences of communication with health professionals. A survey found that "most had wanted much more information about their condition and treatment than they had been given. Many did not feel they had been offered any choices about their treatment, and some had not realized that there were other options." (Toubassi 2007). Therefore, in order to enhance the clinical effectiveness of cervical cancer, the GP, particularly, gynecologists should value the communication with the patients. This is because clinicians' consultation or advice is regarded by the patients as the most valuable information, which is suitable for every patient.

To sum up, every method has its relative merits and applicable scope. Information providers should notice these.

## **4. The considerations needed by the information provider**

Healthcare Information is a relatively cheap intervention that could and should be part of standard care (Mossman 1999). According to the Patients' Charter (1991), patients are entitled to be given information on: (1) detailed information on local health services, including quality standards and maximum waiting times. (2) Services they have arranged. Health authorities must provide a clear explanation of any treatment proposed, including any risks and any alternatives, for the patients decide whether or not agree to the treatment. (3) Common diseases, conditions and treatments. (4) How to complain about NHS services. (5) How to maintain and improve patient own health.

The quality of healthcare information on cervical cancer for the (potential) patients should be considered because, firstly, good quality of the information can bring the patients take an active part in decisions about their health care; secondly, misinformation could be a matter of life or death (Eysenbach and Diepgen 1998).

According to Gardiner et al (1999), the following criteria can be used for the judgment of the information quality: (1) Accessibility; (2) acceptability; (3) readability; (4) comprehensibility; (5) presentation; (6) accuracy and reliability; (7) sources and strength of evidence; (8) reference to sources of further information; (9) credibility of authors, publishers, and sponsors; (10) relevance; (11) utility.

According to these criteria, the following healthcare information on cervical cancer may be judged as unqualified (Eysenbach and Diepgen 1998): (1) the information adopting the paternalistic view that patients cannot cope with bad news and must be kept ignorant of medical uncertainties; (2) the information in which the patients are seen as ignorant children in need of instruction and reassurance, rather than as experts in their own needs and preferences; (3) the information that benefits of proposed or adopted medical measures are emphasized, their risks and side effects are glossed over; (4) the information contained in patient information leaflets is inaccurate or misleading. (5) The information that lacks quantitative statement about recovery time and outcome probabilities.

**In order to improve the quality of the information, the following issues should be considered when providing (healthcare) information for the patients (Note 4):**

#### *4.1 Considerations for Keeping Patients Informed About Treatment and Care*

4.1.1 The information about diagnosis, treatment and care should be presented in a form that is acceptable and useful to support treatment decisions, and given in stages and be reinforced over time.

4.1.2 The information should be tailored to the needs, circumstances and wishes of every specific patient.

4.1.3 Information should be based on the current available. The evidence base of the healthcare information and the involvement of readers in the production of the material base should be considered.”(Shepperd 1999)

4.1.4 Health care providers should be prepared to share information with the patients that supports and promotes informed decision making about HPV testing and vaccines and their complementary roles in cervical cancer screening and prevention.(Vanslyke et al 2008)

4.1.5 The patients should be viewed as active rather than passive recipients of the information. The information should be offered to promote informed choice and shared decision-making.

4.1.6 To improve cancer screening practices, NPs need to address minority women’s beliefs about cervical cancer and provide information and services in a culturally sensitive manner at an appropriate level of learning (Ackerson and Gretebeck 2007).

4.1.7 In order that women’s information needs are met, more accurate and balanced representations of medical and psychosocial HPV information should be provided in patient information leaflets(Hall et al 2008).

#### *4.2 Considerations for Healthcare Information Communication with the Patients*

4.2.1 The patients should always be given the opportunity and time to ask questions about what they are told, to seek clarification and to ask for more information.

4.2.2 The patients should receive a copy of any letter written about their care or treatment by one healthcare professional to another, and must be given such information as enables them to participate in their care.

4.2.3 Before embarking on any procedure, patients should be given an explanation of what is going to happen and; after the procedure the patients should have the opportunity to review what has happened.

4.2.4 Healthcare information providers should avoid giving a specific patient conflicting advice and information. For the aim, professionals that are responsible for the care of any particular patient must communicate effectively with each other.

#### *4.3 Considerations for Feedback from the Patients*

4.3.1 The Patients must be given the opportunity to pass on views on the service which they have received. Formal, systematic structured surveys of the patients’ experience of their care (not merely satisfaction surveys) should be routinely conducted.

4.3.2 Information for the patients with cervical cancer should be nationally relevant and produced by an experienced organization and should have been tested on the patients for its appropriateness. For those patients who will die from their disease, the information on quality of life must be a priority since survival is unattainable; for those who will recover; it makes sense that they do so without unnecessary psychological sequelae from information deprivation (Mossman 1999).

4.3.3 Hospitals must have systems which ensure that the patients know where and to whom to go when they need further information or explanation.

#### *4.4 Considerations for Responding to the Patients When Things Go Wrong*

4.4.1 the following information need for the patients should be considered”: (1) the patients are entitled to receive an acknowledgement, an explanation and an apology. (2) Healthcare providers must explain fully and promptly to the patients what has happened and the likely long- and short- term effects.

4.4.2 Complaints should be dealt with swiftly and thoroughly, keeping the patients informed. An independent advocacy service should be established to assist the patients with specific information needed.

4.4.3 There should be an urgent review of the system for providing compensation information to those who suffer harm arising out of medical care.

### **5. Conclusion**

When providing information for the patients with cervical cancer, besides the patients’ conditions and relevant medical knowledge should be considered, the relevant provisions on offering healthcare information in “Good Medical Practice” established by the General Medical Council, and the recommendations regarding information communication provided by the “Final Report of Bristol Inquiry” should be followed.

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## Notes

- (1) The 1-7 needs of information are original from Coulter. A., Entwistle. V. and Gilbert, D. (1999), "Sharing decisions with patients: is the information good enough?" 318 *BMJ*318-322.
- (2) The 8-14 needs of information are reported by Toubassi. D., Hime. D, Winton. L. S. and *et al.* (2007), "The informational needs of newly diagnosed cervical cancer patients who will be receiving combined chemoradiation treatment", 21(4) *Journal of Cancer Education* 263-268.
- (3) Under medicine, cervical cancer can be classified into 1-4 stages.
- (4) The following section is written by taking "the Final Report of Bristol inquiry" as a reference besides otherwise citing. 27 November, 2007 found at [http://www.bristol-inquiry.org.uk/final\\_report/htm](http://www.bristol-inquiry.org.uk/final_report/htm)