

Health belief about adjuvant endocrine therapy in premenopausal breast cancer survivors: a qualitative study

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Objective: The aim of this study is to describe the connotations of health beliefs about adjuvant endocrine therapy (AET) in premenopausal breast cancer survivors in Northeast China and to explore the reasons underlying bad behaviours and influential factors of AET adherence and persistence.

Methods: Semi-structured interviews were conducted using a qualitative description research method with 30 premenopausal breast cancer survivors who had undergone surgery and AET for more than half a year. The researcher collected and coded the interview transcripts and extracted the concepts and themes.

Results: Two main categories of themes regarding the health beliefs of survivors who were undergoing AET were formed in the conceptual framework: connotations and modifiable factors. Subcategories of the first category included perceptions of the survivors regarding the risks and effects of recurrence or metastasis of breast cancer; the methods, benefits and barriers of AET; behavioural clues; and self-efficacy. Subcategories of the second category included religious belief, disposition, matrimony and other demographic factors as well as traditional Chinese female characteristics, gender role and other socio-cultural factors.

Conclusion: Demographic, socio-cultural and other factors play an important role in the health beliefs of breast cancer survivors. Health beliefs such as related knowledge of AET, related cognition of recurrence or metastasis of breast cancer directly affect adherence to and persistence with AET. Therefore, implementing interventions with respect to health beliefs may enhance adherence to AET.

Keywords: adherence, adjuvant endocrine therapy, breast neoplasm, health belief

Introduction

The incidence of breast cancer ranks first among women with malignant tumours in both developed and developing countries. The incidence and mortality of breast cancer are distinctly different between urban and rural areas, and the incidence increases rapidly with age after the age of 20, peaking approximately 55 years. The number of patients in China is expected to reach 2.5 million by 2021.^{1,2} Patients with oestrogen receptor-positive and/or progesterone receptor-positive tumours can improve survival by undergoing 5–10 years of standardized AET,³ which is an indispensable therapy for comprehensive treatment of breast cancer survivors. Although AET can bring a great deal of benefits to survivors, the overall level of adherence to AET among survivors is poor.⁴ On one hand, the adherence to AET in Mainland China is generally unsatisfactory; on the other hand, the number of young

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survivors is gradually increasing, and some of them have poor adherence due to the influence of medical treatment and social factors, etc. There is no scale that can directly measure the non-adherence or poor adherence of premenopausal survivors. This paper is based on the health belief model (HBM). Young female survivors were interviewed, and an in-depth analysis was carried out, taking a social psychology perspective, on the reasons for poor adherence by premenopausal survivors, to provide a basis for further study of adherence interventions.

Methods

Using a qualitative description method, this study explored the connotations of health beliefs of women with breast cancer (stage I–III) who either have or have not undergone AET for 1.5 year or more as well as the reasons for poor adherence behaviours. At the time of the interviews, none of the women had undergone menopause, and no recurrence or metastasis of tumour nor any mental illness or other severe illness were found in these survivors, who were thus able to respond correctly and answer questions independently.

Participants were selected by way of purposeful sampling and snowball sampling, and an overall observation was carried out during the interview for the collected sample data, supplemented with such important factors as age, place of residence, marital status and whether they had any children, so that the samples could represent a broad population of survivors. During the interview, when the interviewer heard repeated information and could not obtain any more new information, the data were deemed to be saturated, and no further information could be elicited from the sample.

In this research, a doctor-patient negotiation room was selected as the site for the interviews to ensure that only the researcher and the interviewee could be present during the interview. A semi-structured one-to-one interview method was used for an in-depth interview. (The interview outline is shown in Supplement 1). The interview for each interviewee lasted 30–60 mins. The interview recording data were transcribed verbatim within 72 hrs. Numbers were used to identify the interviewees in place of their real names. Nvivo11.0 software (QSR International, Melbourne, VIC, Australia) was used to import the text file into the software and analyse the text data. The theme of the interviews was extracted using content analysis methodology by way of three-grade coding. Grade 1 coding is the process of decomposing, comparing, conceptualizing and generalizing data.

Grade 2 coding is the process of discovering and identifying core categories. Grade 3 coding is axis coding, which is the process of associating categories.

Different survivors treated with AET have different beliefs about treatment, and this in turn affects survivors' adherence to treatment and the outcome of their illness. Through systematic and subjective qualitative research methods, we can deeply focus on beliefs about AET and related factors.

Results

A total of 30 participants were interviewed at this stage. The data were saturated when the 30th participant was being interviewed, as no new coding category appeared. Finally, the interview data were analysed. The average age of participants was 40.9 ± 8.09 years, and 2 of the interviewees failed to comply with their doctor's advice, having never taken tamoxifen. Approximately 73% of them received radiotherapy, and 86.7% of them received chemotherapy.

Cognitions and understanding regarding AET

A vague cognition concerning AET

Due to the influence of Chinese traditional culture, many family members of cancer survivors do not tell them the truth about their illness to avoid certain emotions. Doctors give health guidance to family members instead of survivors themselves to avoid the survivors coming into a direct contact with the doctor, so many survivors are not clear about their body and the treatment, and they cannot make clear judgements or seek correct solutions when side effects or other symptoms occur in the course of taking medicine.

Cognition concerning the benefits of AET

The benefits include the importance of treatment, economic benefits, and the effect of treatment, etc. Many interviewees said that they were not clear about these, for example, that the therapy can lower the probability of recurrence and tumour metastasis.

An interviewee (P7) who had never started treatment said, "The doctor told me to take the medicine, but I think the surgery went very well, and it is not necessary to take medicine, so I did not take it."

This false belief and lack of awareness of the importance of AET directly led to the survivor's non-adherence to treatment.

Obstacles to the use of AET

There are severe side effects when premenopausal survivors take tamoxifen. Therefore, many survivors choose to stop taking the medicine, to take the medicine discontinuously, to reduce the dose or cease taking the medication after the symptom is mitigated.

An interviewee (P11) thought that

The effect may not be so obvious, and the medicine can lead to serious side effects, such as uterine cancer, vaginal bleeding. I was frightened by these side effects, so I didn't dare to take the medicine.

Those who do not have children are worried about the effects of medicine on marital life and fertility, so they choose to stop taking the medicine without permission once the side effects appear after taking the medicine for a period of time.

Recognition of illness recurrence and metastasis

Cognition regarding the possibility and severity

Some survivors have a poor understanding of the severity of recurrence or metastasis, thinking that those would not happen to them, so they will not pay any more attention to them.

Cognition regarding influence and threat

Influence on themselves: Some survivors are unwilling to face the possibility of recurrence and are indifferent, helpless or resigned to their fate and the unknown progression of their illness, so they embrace no expectation for the effect of AET.

Influence on surrounding people: They think that recurrence will affect the feelings and lives of family members, which thus contributes to compliance.

Influence on social roles: Some survivors play important social roles and have a strong sense of social responsibility and that a recurrence of the illness would influence many others. Thus, these survivors show better adherence.

Behavioural clues for treatment

Although many survivors can perceive the possibility and severity of recurrence and metastasis and choose healthier behaviours, it is also necessary to activate the behavioural decision process with some stimulating factors, which are known as behavioural cues for treatment. These mainly include a desire to communicate effectively with medical caregivers in a timely and effective manner, a desire for

regular health information support, a longing for support from family members and friends, and a desire to return to their social roles, etc.

Timely and effective communication with medical caregivers

Due to the limitation of the communication mode, survivors could only visit the outpatient department to receive consultation or advice. In this case, most survivors could not find solutions in a timely manner after surgery. This may cause survivors to deal with treatment problems by themselves or to stop taking their medicine when confronted with problems. Therefore, more convenient and timely communication, multidisciplinary professional guidance and regular follow-up are required for the postoperative follow-up.

Regular information support

Many survivors hope to receive health support, including multiple forms of health information support and beneficial information with respect to medical care and life, etc. Traditionally, we could obtain this information from books, magazines, and the health education handbooks issued by hospitals, but such information tends to be less updated. Thus, apps such as mobile client are needed to give survivors new information and timely feedback.

Social support from family, friends and other survivors

A majority of survivors show poor mental resilience, and they need care and support from family and friends to gradually be restored to their normal psychological state. Particularly, when young women lose their breasts and their medicine has many side effects, their quality of life is severely affected. Such patients are more fragile and need to be cared for. Social support can have a great influence on the psychology of survivors. Survivors receiving more social support tend to be more willing to actively participate in treatment.

"My husband and two children are a motivation for me to live." (P23) "I can see some ward mates are very upset, so I would share my experience with them and tell them how I overcome difficulties and build up confidence." (P15)

Motivation to return to social roles

Returning to their normal roles in work or family as a mother or daughter also provides a great motivation for treatment. Since premenopausal survivors are still able to make a contribution to society, returning to work is also an important motivation for treatment.

Self-efficacy for AET

It mainly includes therapeutic confidence, motivation and self-management. As viewed from the perspective of social psychology, a positive psychological support can promote the active treatment for survivors and maintain adherence to treatment. In contrast, survivors with negative emotions tend to have unproductive attitudes towards treatment. AET requires five to ten years; thus, it is difficult for survivors to maintain a long-term positive and optimistic attitude. Therefore, a certain amount of motivation and stimulation is required to encourage survivors to maintain good long-term adherence, which requires us to develop suitable interventions to help them maintain a positive attitude.

I do not like to stay at home doing nothing. I feel good when going to work. As soon as I am in my office and see my colleagues, I don't feel different from them and, I feel that I am in a better condition.(P6)

Demographic factors underlying health beliefs

The influence of religious beliefs

Some survivors have religious beliefs such as Buddhism, Christianity, etc. By virtue of religious beliefs, they can change their minds and improve their beliefs about AET and thus actively follow their doctors' advice. Or, if they encounter obstacles in the course of treatment, they can change their disposition, shifting towards a positive direction, and remove obstacles, etc. They also feel that it helps a lot and makes many improvements:

I didn't believe in religion before, but now I believe in Christ under the guidance of my friends. I feel very calm in mind and go to church every week. Now I feel cheerful and like to communicate with others. (P12)

I believe in Buddhism, and I do not pay much attention to this (breast cancer). I didn't cry or scream as much as anyone else on the day I knew I was sick. I take death lightly, but I am not indifferent. I feel that everything I do in my life will be reversed in my next life. (P14)

The influence of character

Some survivors are so introverted or stubborn that they are poor at expressing themselves when encountering problems. They may also be too shy to ask others for help. Meanwhile, some survivors are vulnerable to the influence of others and cannot resolve their own problems, which

can easily cause psychological problems over a long period of time, thus affecting the treatment of their illness.

Influence of marital status

Some survivors are divorced, or their husbands left due to their illness. Being unattended and lacking care and help from a loved one may affect their mood and attitude towards receiving treatment. Some survivors have a good marital status, and their husbands remind them to take their medicine every day and care about them and give timely encouragement and comfort when they need it. In another part of my quantitative research, I found that the divorce rate is as high as 52% after surgery, and the incidence of depression and anxiety is high among divorced survivors.

My husband divorced me. We got divorced after surgery and chemotherapy. (With tears in her eyes) he may be afraid of my looks after chemotherapy, and I don't want to take care of myself any more (more tears appear, which she wipes off). (P30)

The influence of socio-cultural factors on health beliefs

Influence of traditional gender role stereotyping

Some interviewees believe that, as traditional women, their most important task is to carry on the ancestral line for their husbands. The influence of this traditional culture is deeply rooted in Chinese women, and the influence of this role is two-sided. First, even if they get ill, they still prioritize giving birth to a child over their own physical condition. Failing to have a child may affect marital stability, and female survivors have a strong sense of family responsibility. Some women think that having children is a woman's most fundamental need. Only by giving birth to a child can the life of a woman be perfect and without regret. This reflects the necessity of childbirth to women under the influence of traditional culture. Thus, for some survivors, even knowing that recurrence may be more likely if they do not receive therapy, they still give priority to childbearing instead of treatment, and they give priority to their husbands. Second, some survivors feel regret for not having children, so they actively engage in treatment and seek help from doctors to complete the treatment as soon as possible in order to have a child. This also promotes adherence behaviour.

I was so scared, so I didn't take it, because I haven't had a child yet. I'm afraid I would not have a baby if I took the

medicine. To be frank, I am already sick. If I am unable to have a child, I'm afraid my husband would divorce me. (P11)

What a pity it would be for a woman to have no child. It's imperfect for women. I will feel very sorry for my husband if I cannot give birth to a child for him, for I don't want to let him down. (P28)

Most of the survivors need to support their parents and children, so they bear a relatively heavy family burden. Survivors who are in the postoperative rehabilitation stage may face more difficulties than others, eg, they easily feel fatigued, whether physically or mentally, since they attach more importance to familial matters but neglect their own medication adherence.

Discussion

Starting from the perspective of psychosocial oncology, this research is based on health beliefs within a social cognitive model, with the hope of describing health beliefs about AET through descriptive qualitative methodology and exploring whether a health belief model can be expanded to conceptualize the adherence behaviour of breast cancer survivors. The social cognitive model can be used to explain survivors' beliefs about treatment, as these beliefs have an effect, to a large extent, on whether treatment will be interrupted, thus affecting survivors' adherence behaviour.⁵

In the research on the adherence of survivors, although people believe that there is a certain relationship between quality of life and adherence, most studies also indicate that side effects of medicine may affect survivors' adherence behaviour. However, there is no statistical correlation between adherence and quality of life in some studies.⁶ In the research on beliefs about medicines, many have adopted the Beliefs about Medicines Questionnaire (BMQ) to investigate medication status. This kind of questionnaire is a generic one, unable to evaluate the specificity of the treatment of a specific illness. Some studies only show that non-adherent patients simply believe that there are no more benefits from AET,⁷ revealing nothing of their perceptions and experiences during treatment.⁸ In these studies, conclusions are only reached from the perspective of the belief about medicines, but the reasons for nonconformity are not analysed from the perspective of the patients' overall cognition regarding the recovery of health. Pan Y et al⁹ used the BMQ to investigate factors that promote non-conformity among survivors. Beliefs about the necessity for long-term adherence to treatment,

the severity of expected side effects, and poor management of side effects were all related to non-adherence, which is consistent with the results of this research. Some studies use self-designed questionnaires to examine the risks and benefits associated with taking tamoxifen, but there is not yet a standardized questionnaire or evaluation scale for patients.¹⁰

The findings of this research show that religious beliefs have a certain influence on health beliefs. Survivors have religious beliefs that influence their faith in treatment, but they are positive influences that promote adherence behaviour during AET. The influence of religious beliefs may be related to social development.¹¹ The average age of premenopausal women is low, and they are quickly receptive to new things. In addition, there is another important reason that knowledge is being disseminated through multiple ways and at a faster speed in the modern society. As technology develops, interactions among companions makes it easier to spread new beliefs and cultures. This is especially true with regard to the way that religion spreads. There are more reasons for them to have a mutual influence, but it also suggests that we can spread health knowledge in new ways, which can increase the speed and scope of transmission.¹²

The impact on marital status is rarely seen in reports at home. This research suggests that spouses play a positive role in helping women with AET in the course of treatment. For example, they can provide psychological comfort to relieve survivors' anxiety and promote adherence behaviour.¹³

Among the factors influencing premenopausal and postmenopausal survivors, socio-cultural factors have a completely different influence. The average age of postmenopausal survivors is high, so their traditional female or maternal role can be rarely reflected in those survivors. Therefore, it is necessary to distinguish between the items of the beliefs about health questionnaire and the content of the intervention scheme. Thus, targeted and specific interventions can be achieved, and the effect of intervention will be different. In the literature reviews, survivors, whether at home or abroad, all show a need for procreation.¹⁴ Young women, especially for those who have never had a child, have a strong desire to give birth to children. This can motivate survivors to actively cooperate with doctors. Some survivors without children are focused on the idea of playing their traditional female role to the point that they would rather give up the chance of survival in order to give birth to a child for their husbands,

thinking that this would “fulfil their obligations as wives”. The reason for such survivors’ non-adherence is a fear that the side effects of AET will affect their future fertility. However, the fundamental reason is that they do not understand the roles and importance of AET and that its side effects are blindly exaggerated or misunderstood. The influence of this socio-cultural factor can also be interpreted through socio-cultural theories.

Among survivors who are in their convalescence after AET, those younger than 45 tend to experience potential long-term side effects, such as infertility, due to treatment. This can have a severe influence on their physiological and social psychological status during rehabilitation when the symptoms of infertility appear.¹⁵ In the United States, 10.9% of new cases of breast cancer every year are between 20 and 45 years of age, and infertility is common, even for survivors who received rehabilitation treatment many years prior.¹⁶ Thus, for survivors who are the right age for pregnancy and have a desire for pregnancy should communicate with their oncologists and obstetricians with regard to pregnancy-related issues. Timely advice from doctors is very important for survivors who will soon lose their ovarian protection, so they should determine the appropriate time to get pregnant after treatment. For such survivors, special illnesses and knowledge about pregnancy should also be considered when designing the intervention protocol.

Study limitations

This study is limited due to its small sample size and homogeneity in terms of ethnicity and a specific age range that limits the generalisability of the findings of this study to a broader population.

Conclusion

The health belief framework for premenopausal survivors treated with AET consists of the following aspects: related knowledge, cognitions concerning the benefits and obstacles to AET, cognitions pertaining to the threats from illness recurrence and metastasis, action cues for treatment, self-efficacy of survivors, etc.

Main factors influencing the health beliefs of premenopausal survivors are demographic and socio-cultural factors.

Through understanding the connotations of health beliefs and their influence on survivors treated with AET and taking the health belief model, which is type of social cognitive model, as a theoretical basis, a questionnaire that

can comprehensively assesses health beliefs was developed, and a scientific and feasible intervention protocol was formulated, noteworthy for its effective specificity.

Clinical implications

Based on the results of this study, a health belief mode framework for breast cancer survivors treated with AET is obtained. This framework can be used to develop a specific beliefs about health questionnaire, which would allow us to develop a comprehensive evaluation of survivors’ health beliefs about AET and create further interventions based in psycho-oncology aimed at survivors’ health beliefs. These could in turn help prolong the life span of survivors and improve their quality of life.

Ethics approval

The study protocol was approved by the Ethics Committee of the First Affiliated Hospital of China Medical University (protocol approval No.2016-5-2), all participants provided written informed consent and this study was conducted in accordance with the Declaration of Helsinki.

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Disclosure

The authors declare no conflicts of interest in this work.

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