

Gaining Insight into Patients' Experience of Adherence to Hypertensive Treatment

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ABSTRACT

Hypertension is one of the major risk factors for coronary heart disease and the most important factor for cerebrovascular diseases. Adherence to treatment is a fundamental pre-requisite for therapeutic benefit in hypertensive patients. Adherence is a complex behavioural process that is strongly influenced by the way in which patients live, as well as the psychological and social support system. **Aim:** To understand and conceptualize the experience of people on long-term antihypertensive treatment **Method:** Qualitative analysis using semi-structured interviews with ten hypertensive patients from the medical clinic of Kuala Lumpur General Hospital. **Results:** Although the participants were aware of having high blood pressure they declined receiving any treatment at the early stage of the disease. Fear of death and disease complications are reinforcements for participants to adhere to medication. They perceived the label of "hypertension" will affect their self-identity and social role. Positive thinking regarding medication assists participants to adhere to treatment. Conversely, participants who perceived medication negatively also adhere to a medication regime, as adherence behaviour satisfies the family. Participants justified modifying their regimen or taking Complementary and Alternative Medicine (CAM) as they believe know the their body best. However, participants wished to obtain more information regarding hypertension and its treatment from the doctors. **Conclusion:** In finding the fine balance between stepping in and holding back treatment and care, health professionals need to know their clients in context. This balance can only be achieved by establishing processes of negotiation within an ongoing therapeutic relationship.

Keywords: Hypertension, adherence

INTRODUCTION

High blood pressure is a significant public health problem in many industrialized countries.^[1] The Third Malaysia National Health and Morbidity Survey showed that the prevalence of hypertension was 32.2% among Malaysian residents aged 18 years and above. The incidence of stroke increases nearly threefold in patients with borderline hypertension and eightfold among those with definite hypertension. Overall cardiovascular risk increases by two to threefold.^[2] In addition, poorly controlled blood pressure represents an important economic burden to a country.^[3] In Malaysia, about RM215.9 million was spent on antihypertensive medications alone in 2005.^[4] Despite the availability of effective treatment, less than 25% of patients being treated for hypertension achieve optimum blood pressure. Non-adherence has been identified as the main cause of failure to control hypertension. The rate of adherence to treatment in the community is far from optimal, being only 8.2%.^[2]

Adherence is defined as the extent to which a person's behaviour in taking medication, following diet and executing lifestyle changes correspond with agreed recommendations from a health care provider.^[3,5,6] The original term used to describe behaviour in following treatment was "compliance". However, at the WHO Adherence meeting in June 2001, participants concluded a preference for the term "adherence" rather than "compliance" as "adherence" recognizes the central role of the patient in the treatment process.^[3,5,6]

Why qualitative research?

The use of a qualitative research approach in this study is founded on two reasons. First, qualitative methods are often used when the object of study is some form of social process, meaning or experience that needs to be understood and explained in a rounded way. Also a qualitative inquiry facilitates the exploration and description of social processes through nuance, complexity and detail.^[7] Second, quantitative studies have shown a gap in understanding health beliefs and behaviour in following treatment, especially the inability to answer 'Why' and 'How' questions. In addition, quantitative researchers are detached from the participants during data collection, which results in the failure to observe

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the behaviour of following the treatment in everyday life. Conversely, qualitative research is suitable for exploring the subtleties and personal meaning that inhere to living with a chronic illness such as hypertension.

Research design

Because of the communal nature of human beings, people understand the world around them through interpreting their activities together. Similarly, hypertensive patients like other ordinary patients, live in a social world that is constructed by people. In everyday interaction with others, adherence behaviour can never be static; rather it is a dynamic, complex process and is not a one-off decision. This is because it is influenced by patients continually interacting and evaluating their experience of illness and their prescribed treatment in everyday life. In other words, adherence behaviour largely depends on how patients construct meaning in hypertension and its treatment with their social life. Therefore, the only way a researcher can understand the social processes and experiences of illness is through interacting face to face with patients.

MATERIALS AND METHODS

Participants

The researcher selected participants from the medical clinic of Kuala Lumpur Hospital, Malaysia. A purposive sampling technique was used initially, followed by theoretical sampling. The participants were selected by a physician and later contacted by telephone to confirm their willingness to participate in the study.

The inclusion criteria for the participants are as below:

- has been diagnosed with hypertension and has been on medication for at least one year
- the main diagnosis is hypertension
- patient has been discharged from hospital
- clinically stable

In this study, data reaches saturation when a sample of ten participants has been interviewed. They consist of five males and five females with ages ranging from 40-56 years. Ethnic groups represented included Malay, Chinese and Indian.

Data collection

Before the interviews, telephone calls were made a week before the appointment as a reminder. All interviews were tape-recorded except for two participants who refused to be recorded. In these two interviews the researcher took notes of important statements. During the interviewing process, probes were asked where necessary to expand upon and clarify the participants' responses (refer to figure 1). Each interview lasted about an hour and each respondent was scheduled for three sessions on different dates. The interviews were conducted at the respective respondent's home. The interviews were transcribed and analyzed as soon as possible after each interview to guard against inaccurate interpretation of the data.^[26] This action helped the researcher to determine the theoretical shape and recognize the saturation. On completion of the interview, participants were briefed and were thanked for participating. Each participant received a small gift for his or her participation.

Main research question:

Can you tell me your experience of adhering to hypertensive treatment?

Sub interview questions

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| 1. How did you find out you have high blood pressure? | 8. Could you describe how your family members influence you in taking medication? |
| 2. How did the diagnosis of high blood pressure impact on you? | 9. What other method you use to maintain normal blood pressure? |
| 3. What did you do with the medication after you left the clinic after consultation? | 10. Why do you think the method you mention is effective? |
| 4. What would happen if you ignore the medication prescribed by doctor? | 11. Tell me what everyday routine task you do will help you in maintaining good health? |
| 5. In what way, you agree/disagree doctor have told you about high blood pressure? | 12. How will the routine task make you feel healthy? |
| 6. Why you can't/can accept 'high blood pressure' label on you? | 13. How is your relationship with the doctor during consultation? |
| 7. What do you think about the prescribed medication? | 14. What do you expect most from the doctor? |

Figure 1. Research question

Data Analysis

Nvivo 7, a computer package, was used to aid with the organization of qualitative data. Each interview was transcribed and analysed by using the constant comparison method. Constant comparison steps involve the process of coding and categorizing. Coding requires the use of concept, which places labels on the discrete happening, events and other instances of phenomena. Although events or happenings might be discrete elements, the fact that they share common characteristics or related meaning enables them to be grouped. This was followed by the construction of categories, where a more abstract notion was used for the grouping of concepts.^[8] The final presentation is organised around well developed and ordered themes.

Ethical Consideration

The researcher obtained the ethical approval from the Universiti Putra Malaysia ethical committee.

Trustworthiness of the study

Three steps were used in improving the credibility of the study. Credibility can be justified in terms of prolonged engagement, member debriefing and member checking.^[9] The researcher spent about 12 months interacting with the participants. This was inclusive of first meeting, home visits and interviews conducted on different dates, and the meeting for data validation. Member debriefing was carried out with co-researchers periodically. Member checking was done with participant validation conducted in an informal interview environment. The interpretation from the researcher elicited recognition from the participants as being applicable and relevant to their situation. This is to ensure that the individual participant's perception is identified and clarified. To enhance dependability, an audit trail was used to maintain the detailed record of how data was collected.

RESULTS

In the process of analysis, the researcher compared concepts and not individuals or cases. What is required in conceptualizing is not how many individuals exhibit a particular concept but rather how often the concept emerges and what it looks like.^[10] Seven themes emerged after the data was theoretically compared and saturated. These are identified as awareness versus denial, fear of death and disease complications as reinforcements, acceptance and self identity, cognitive consistency and dissonance, knowing how to survive by self controlling regimen, effect of pets on psychological wellbeing and information needs from doctor. Each formulated theme is discussed below, followed by a few examples from participants outlining their experience.

Awareness versus denial

Naturally, individuals are motivated to live in a meaningful and structured world. Given this motive, people are seldom content to be passive observers of events. They try to explain and become actively involved in understanding the events they observe. The participants recalled the day they were diagnosed with hypertension. They re-examined their experience when they first became aware of having high blood pressure and how they dealt with it. Some of the participants attributed genetic and inherited risk of hypertension as the main causes. One of the reasons for them not seeking health advice is because they experienced no obvious symptoms.

"I have a very strong family history of hypertension. Not my mother side, my father side, very strong... and all are big size in body. 2 died because of heart attack. All of my 10 sibling 9 of them have hypertension including me. Only one may not have, the youngest one. She is working in a construction firm. I found out when I was 20 something during a medical check-up. I knew something was wrong when checking me for 3 times... I was young then and didn't do anything to it- Not seeing any doctor and not taking any medication. I was healthy and not having any headache or illness. I like outdoor activities and active then... until I reach 30 something, it was one time I went for medical check up again, my blood pressure was 200/100. My family members and colleagues advised me to take medication before something bad happen. I was very reluctant because I still feel I am okay..."

Some participants perceived that high blood pressure results from temper, being hostile and getting angry. When participants were first diagnosed as having "hypertension", they denied the fact and refused to take medication. They wanted to challenge and maintain their original self – a person without hypertension.

"I understand my personality, my neighbours said I am emotional, at home when I shouted at my children due to small matter, my wife sometime even asked me to see doctor to heal my hot temper. Once I get angry, I can feel that my headache get worse and I can feel blood shoot up to my brain. This continues... There is one week I had headache

non-stop, even with panadol, I still feel not well like usual. I knew something is wrong... Then I went to see a doctor nearby my house... He told me I got high blood pressure, which is dangerous and need to take medication to heal it. I was shock and don't believe it... when I reach home, I threw all the medication. I am not that serious like what he thought! I know all because I have bad temper..."

Fear of death and disease complications as reinforcements to adherence

However, participants rationalize their reaction to the diagnosis and make connections between life events and having hypertension. At middle age, individuals have a growing awareness of one's own mortality.^[11] Fear of death and complications of hypertension such as stroke and coronary heart disease make them think about taking medication if they want to think about a meaningful life. Although death is considered a threat, it provides a motivation and positive force for participants to adhere to the prescribed regimen.

"I seen my neighbour died because of stroke, it all happened within a day, when he arrived hospital, the doctor cannot do anything already. His wife told the doctor his husband seldom take medication. When I visited him in hospital, he already unconscious... I was very sad and cannot accept his sudden demise. he looked healthy to me before he died and we had a chat the night before also... you know hypertension can kill me like that also..."

"You know one of the problem of hypertension is it will cause kidney not working. It is important that I don't want any diseases from hypertension. I want to live longer to see my grandchildren grow up. So, I have no choice but to take medication."

The disclosure indicates that the fear of death and disease complications prompted health seeking behaviour. Obviously, an individual's health seeking behaviour is influenced by his culture, experience, knowledge and perceived threat of disease.

Acceptance and self-identity

Taking medication is considered as recognition of having an illness. If people do not accept their illness, they are unlikely to accept its treatment.^[12] Acceptance is a strong statement in studies of chronic diseases.^[13] When hypertensive patients deny that they have high blood pressure or distance themselves from it, they usually downplay its significance claiming that "they are carrying on with life as usual" or that "they did not take the preventive strategies as this involved a change of self-identity and acceptance of the chronicity of the condition".

"I don't want to lose my good friends, they like drinking, we meet because we have many things to share. Normally we will drink during talking, 4 of us is come to about 5 bottles of Carlsberg or Guinness Stout. I don't think that is a lot, if I can't drink that small amount, I might as well die; life is just meaningless where you can't even enjoy occasionally with friends. I don't want because of my illness that makes me without friends... I can't do it, it is not me, I will become sicker..."

However, participants who have a family history of hypertension appear more receptive to the diagnosis and are more able to follow what has been prescribed.

"I always accompany my mum to clinic for follow up when I was a schoolgirl. I listened every explanation from the doctor about my mum high blood pressure. My mum take medication since the first day she diagnosed as a hypertensive patient. However, when I left her for work, she has few episodes of stroke due to skip medication that ends up with disability. I know the consequences of not taking medication. I understand what a hypertensive patient needs – take medication. How dare I stop it? My mum experience is enough for me!"

Perception of medication influence adherence behaviour

Participants exhibit different strategies in taking medication. The perception of medication plays a role in adherence behaviour. Instead of reservation about antihypertensives, they change their thinking by accepting medication as a tonic for daily consumption.

"To take or not to take medication is up to your own thinking, if you think the medication is bad for you, then you will not take it, like me, I take the medication because I think it like some sort of tonic that can make me healthier every day. So far I never think more than that, you know tonic, which you must take regularly. So, if I take it, I will become healthy!"

In contrast, there are participants who perceive that western medication is harmful and not natural but they take it regularly because of the expectations of family members. They say that the pressure to take it is exerted by their loved ones. In this instance, the participants' behaviour in taking antihypertensives is not consistent with their thinking.

"My wife will remind me to take medication everyday. To prevent me from forgotten to take, they bought me a medication box with 7 compartments and written 7 days a week. They will check it or fill up for me. I told you I don't believe in western medicine because it is not natural and have side effects, but what is important is they are happy. My wife and my children are happy if I take medication as what they want. As long as my family members are happy, I will just follow what they asked to take. I feel better like that rather make them unhappy. You know, they are very important to me, if they are happy, I am happy too."

Knowing how to survive by self-regulating regimen

After a few years of taking antihypertensives, participants start to feel despondent. Out of the ten participants, nine thought of minimizing the dosage, self-regulating it or taking Complementary and Alternative Medicine (CAM). Some thought of "taking a break". This is because they believe that only the person who is taking the medication knows the optimum regimen and strategies to use it. Some are convinced that CAM will reduce blood pressure. The motivation for using CAM is to stop toxicity and the side-effects of western medicine.

"What can I do some more besides taking medication every day? I already don't have choices. It makes me feel tired and sickening. Sometime I reduce the doses according to my body and my mood especially when I feel relax and not working. I am not doing it every day, when I feel that I don't need medication on that particular day, I will just stop it. Don't worry, I know my body well..."

"You can't take medicine for whole life if you aware of the side effects. If I have a choice, I'll choose to take less. Some of my friends have the same view like me. I tried some traditional herbs from a well-known herbalist recommended from my friends. It really works and my blood pressure came down. The best thing is I didn't feel tired and coughing like before. Unfortunately it was expensive. I can't afford to take in long period."

Effects of pets on psychological wellbeing

Participants do use non-pharmacological management for stress management such as regular exercise and social coping strategies by seeking supportive companions. They use non-pharmacological methods such as keeping a pet to maintain blood pressure. There are studies^[14,15,16,17] reporting that an animal companion can facilitate human health and quality of life. The development of a reciprocal attachment in human-animal bond can be interpreted as a friendly, affectionate, companionable interaction. Some participants highlighted that pets provide companionship and pleasurable activity, facilitate exercise and play, provide something to care for, are a source of consistency, are a comfort to touch and pleasurable to watch.

"Because of "Oscar" I have to bring him out twice a day. He make me walk and sweat, He is as if know I need to exercise every morning and evening, he will just bark at me to go out if I forget to bring him out. I feel one of the medications for my high blood pressure is just by sitting close to Oscar and give him food. When he looks at me, I feel very calm when petting and playing with him."

Information needs from doctor

The participants expected the doctor to give them more information about hypertension and medication use. Unfortunately, they had little chance to talk to the doctor because of the doctor's busy schedule. In addition, they felt uncomfortable when the doctor kept asking the same question at every consultation. They wanted the doctor to listen to their feelings and experiences when taking antihypertensives.

"Taking medication or not", this is the usual statement as opening conversation. I will always say "yes". Then when I want to ask more about the medication and my blood pressure problem, how its work on my high blood pressure and is it safe to take in a long period, or can I take any other medication? The nurse already called another patient. Where got chance to talk to them?"

DISCUSSION

The themes developed symbolize a process of adaptation and accommodation over time with hypertension and its treatment in a local context. Most participants considered their illness heredity, as hypertensive patients' children

tend to have higher blood pressure than aged matched children of non-hypertensive parents. Although, this may result from shared environmental influences – high salt or alcohol intake, sedentary lifestyle – there is a large genetic component.^[18]

When initially labelled hypertensive, some participants demonstrated “active denial” by ignoring or refusing medication. Although aware, those suffering asymptomatic hypertension refute being ill. The diagnosis of hypertension is difficult for participants because the sudden “crisis” from its emergence is a turning point and time of acute distress.^[19] However, the distress serves as a useful developmental transition and forces participants to seriously re-examine themselves. An individual’s health seeking behaviour is influenced by – personal experience; ability to control the situation; and a feeling that “the illness and the danger are thoroughly nasty and able to kill easily”.^[20] Similarly, participants expressed fear of the possibility of sudden death, stroke, heart attack or kidney failure if they ignored medical advice. The feeling of fear acts as a stressor and catalyst for adherence to treatment. Therefore, the complications of hypertension and lifestyle modifications should be conveyed by health professionals to patients who refuse treatment, as encouragement to adhere to antihypertensives.

Some patients describe how they accept the status of being hypertensive and the effects on their self-identity and social role. Some emphasized self-identity more than acceptance of abstaining from alcohol. Being with friends, drinking alcohol and performance of social roles outweigh the acceptance of the sick role of a hypertensive. Acceptance is conditional on the patient’s beliefs, values and personality. Participants from a hypertensive family are better at accepting or adhering to medication because of the parents’ experience. Therefore, adherence behaviour and the “self-care” lifestyle have been inculcated since young, as are the consequences of non-adherence. Consequently, hypertensive parents should educate their children concerning possible eventualities regarding risk factors and treatment.

Participants stated that a person’s thinking determines his actions. Therefore, thinking of the medication as a tonic will bolster one’s adherence behaviour and correct the patient’s distorted thinking concerning medication. Most negative thoughts that disturb a person are distorted and unrealistic.^[21] Identifying a patient’s thinking errors can play a major role in behavioural change therapy. Consequently, instilling positive thinking regarding medication assists patients to adhere to treatment.

Conversely, participants who perceive medication negatively may also adhere to a medication regime, if the adherence behaviour satisfies the family. Generally, psychological wellbeing is shaped by cultural beliefs concerning the person’s fundamental nature.^[22] Interpersonal harmony is fundamental in Asian thinking,^[23] and enriched by the feeling of connectedness with significant others.^[24] Similarly, in the Malaysian context, a patients’ family members or significant others play an important role in changing the behaviour of non-adherence, encouraging them to behave as if in favour of the medicine and adhering to its regimen. Hence, caregivers are important in influencing adherence behaviour and should be included when educating patients on medication use and lifestyle modification. A well-informed caregiver serves as an educator and reminder to the patient at home.

Participants continue their evaluation of the illness and prescribed medication after leaving the clinic. Participants justified modifying their regimen as they claim they know their body best. Besides the doctor, they sought information from friends/family concerning medication. Some considered complementary and alternative medicine (CAM) beneficial, and being natural, may not be toxic or have the side effects of western medication.^[25] However, CAM can be detrimental if used to replace effective, conventional treatment. Similarly, CAM may compromise efficacy by enhancing or delaying the effect and masking a correct diagnosis, thereby endangering lives.^[26] However, in a contextual perspective, patients should be encouraged to find their own level of treatment.^[27] If they take unauthorized or harmful CAM, they should be advised to stop.^[13] Patient non-adherence to medication is dangerous if not disclosed to health professionals.^[28] Thus, a “self regulating regimen” should be encouraged to allow patients to control and make decisions collaboratively with health professionals.

Keeping pets has been found to help reduce blood pressure among participants. The action of stroking an animal can cause transient decreases in blood pressure and heart rate,^[14,15,16,17]. The presence of a pet may lower autonomic responses to conditions of moderate stress and improve the psychological wellbeing of people. Mechanisms underlying the ability of pets to promote human health largely depend on the emotional ties between the pet and the owner.^[29] Some owners consider their pet to be a part of the family; these attachments can help improve psychological health. This bolsters physiological wellbeing by providing social support and creating the belief that they are loved, and belong to a network of mutual obligation. Pets are typically perceived as nonjudgmental, and are there in times of trouble when the master needs them, creating the impression of unconditional love, and dependability. Therefore, health professionals should be aware of a pet’s role in promoting optimal holistic health.

Adherence is a function of the doctor-patient relationship.^[30] Patients need information about their problem and treatment, and are not completely lacking in knowledge. People’s health seeking behaviour is influenced by inherited ideas, family and personal experience as well as alternative practitioners and the media.^[31] Moreover, information obtained changes with new experiences. Communication between doctors and patients needs to be improved to ensure adherence to medication.^[32] Without a primary basis for hypertension and its treatment, patients cannot rationalize the

treatment. This study's findings imply that patients expect the doctor to listen and devote time to solving illness related problems, not just diagnose and prescribe.

One of the limitations of this study is that the conceptualization of the experience of hypertensive patients' adherence to treatment is not applicable to other experiences of chronic illness. This should only be used to hypothesize and should not be treated as a developed theory. The implications for practice can be used in educating health professionals. Additionally, health professionals should involve the patient's family in planning and changing adherence behaviour and lifestyle modification. Notably, patients need information about their illnesses and treatment from doctors. How this translates into healthcare policy and practice, with the time constraints on consultation, requires further study. Finally, this research can continue into a larger sample with a different approach for the development of a theory concerning adherence.

CONCLUSION

It is difficult to understand how patients endure their chronic illness with stoicism unless we ourselves have journeyed into the depths of their experience. Even then, our experience is different from that of others, because it belongs to each one of us individually. This study adds to our understanding the experience of hypertensive patients who accommodate hypertensive treatment in their everyday life. Health professionals are aware that their clients already have strategies, knowledge and expertise at hand in living with hypertension. In finding the fine balance between stepping in and holding back treatment and care, health professionals need to know their clients in context. This balance can only be achieved by establishing processes of negotiation, with two-way communication within an ongoing therapeutic relationship that is mutually respectful of each other's expertise in dealing with hypertensive treatment. Such a relationship, which enhances the client's highly tuned knowledge of themselves, can make the adherence pathway a success.

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