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Patient non-adherence: an interpretative phenomenological analysis

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Abstract

Purpose – While interpretative phenomenological analysis (IPA) has been used in health psychology research, it has so far not been applied to seek deeper insights into the patients' experiences about treatment. The purpose of this paper is to address this gap by using IPA to understand patient non-adherence.

Design/methodology/approach – In total, 18 patients with chronic conditions seeking healthcare services in Goa and Karnataka, India, were selected by using the snowball sampling method. In-depth interviews were conducted face to face. A semi-structured questionnaire developed by the researchers was used to collect the data. IPA was used to explore the themes to predict patient non-adherence.

Findings – The study results indicate that economic factors, health system related factors, social factors and psychological factors impact patient non-adherence. Patient non-adherence includes medication non-adherence and lifestyle modification non-adherence.

Research limitations/implications – Being cross sectional in design, the results may not be as appropriate as the results derived from a longitudinal study given that non-adherence occurs over time.

Practical implications – Patient non-adherence is a global health issue. Multidisciplinary approach to enhance patient adherence to treatment should form part of public healthcare policy.

Social implications – Exploring the factors influencing patient non-adherence will help the health-care industry stakeholders to reduce healthcare cost and improve patient's quality of life.

Originality/value – Although there is extensive quantitative research on the prevalence of non-adherence, qualitative research is limited. This paper addresses this gap by using IPA to understand patient non-adherence and its factors and dimensions.

Keywords Chronic conditions, Interpretative phenomenological analysis, Patient non-adherence

Paper type Research paper

Introduction

Chronic diseases require lifelong treatment and managing chronic diseases is complex, as it demands adherence to medications and lifestyle modifications for a sustained time or a life span. On – off adherence to chronic disease medication and lifestyle modification can be referred to as "patient non-adherence". There is substantial evidence about non-adherence to chronic disease treatment such as:

(1) human immunodeficiency virus (Naidoo *et al.*, 2013; Mbuagbaw *et al.*, 2012; Sarna *et al.*, 2008; Horne *et al.*, 2004);

(2) cancer (Bhattacharya *et al.*, 2012; Kondryn *et al.*, 2011);

(3) hypertension (Al-Ramahi, 2015; Lemstra and Alsabbagh, 2014; Evans *et al.*, 2012);

(4) unipolar depression (Banerjee and Varma, 2013) and mental disorders (Sharma *et al.*, 2012);

(5) diabetes (Ahmad *et al.*, 2013; Mann *et al.*, 2009);

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(6) multiple sclerosis (Syed *et al.*, 2014); and

(7) non-adherence has been reported in developed and developing countries (World Health Organization, 2003).

Non-adherence rates (Schmid *et al.*, 2009; Vermeire *et al.*, 2001) indirectly points to its seriousness throughout the world. The National Institute for Health and Clinical Excellence (2009, p. 21) defines non-adherence as a hidden problem, which can be diagnosed and most are solvable. Non-adherence is a multifaceted problem that affects patients and their families, healthcare providers and managers, health insurance providers, pharmaceutical manufacturers, employers and the government (American Pharmacist Association, 2013; National Institute for Health and Clinical Excellence, 2009; National Council on Patient Information and Education, 2007; World Health Organization, 2003). Murray and Valkova (2013) note that non-adherence-related complications are more expensive to treat. Given the potential health and other related chronic diseases non-adherence-related consequences, if addressed efficiently and effectively, will significantly benefit society (World Health Organization, 2003).

Aims

Addressing non-adherence should begin by exploring patient perspectives (National Institute for Health and Clinical Excellence, 2009). It is important to evaluate minutely, why patients are non-adherent to chronic disease treatment. Despite the positive association between adherence and health outcome, some patients remain non-adherent. There is no single reason attributable to non-adherence, i.e., there are many factors. Recent research demonstrates the need for high-quality studies to identify the psychosocial predictors leading to non-adherence (Zwikkar *et al.*, 2014; Arias-Llorente *et al.*, 2012). While previous research laid more emphasis on quantifying non-adherence, we use the interpretative phenomenological analysis (IPA), a qualitative approach, to identify patient non-adherence determinants. Our study is relevant in a world that is experiencing rising chronic diseases and non-adherence.

Method

Analysis

In a quantitative study conducted by the researchers at a primary health centre in Karnataka, India, patients with chronic conditions were more non-adherent to treatment than acute patients (Mekoth and Dalvi, 2015). Unlike other services, healthcare customers use services only when they are unwell, hence the patient's experience and behaviour ought to be different from other service customers. Therefore, the analytical unit we select is a patient with a chronic condition.

Sample

We used a cross-sectional study design. Patients seeking treatment in different health facilities in Goa and Karnataka, India, and willing to participate in the interview were selected. Each participant's oral consent was sought. The snowball sampling method was used and the chronic disease groups, from which 18 patients were sampled, required medications and lifestyle modifications.

Data collection

We used a semi-structured questionnaire to elicit chronic patients' experiences and perceptions about their treatment and non-adherent behaviour:

(1) Please tell me your personal details.

(2) Please tell me about your sickness.

(3) Please describe your treatment.

(4) What was the doctor's advice?

(5) Do you adhere/not adhere to the doctor's advice?

(6) If not, then why are you not adhering to your doctor's advice? Are there any special reasons?

IPA: an overview

Harris (2012) stated that a qualitative approach is a prerequisite to a quantitative study. When the research topic is complex, qualitative approaches such as phenomenology, grounded theory, discourse and conversation analysis, ethnography and IPA are useful. IPA explains how we make sense about personal experiences (Smith, 2010; Chapman and Smith, 2002). It is a useful research tool to describe human experiences (Biggerstaff and Thompson, 2008; Larkin *et al.*, 2006; Fade, 2004). The researcher tries to understand the participant's world and to describe what it is like. IPA has been successfully used in health psychology studies. Smith and Osborn (2007) explored patients' experiences with chronic back pain. Griffiths (2009) researched parent and child's perspectives towards childhood cancer. Harris (2012) attempted to learn about adoptive mothers' feelings. Gambling and Long (2012) studied young women's experiences after surgery and recovery. Blore (2011) investigated the positive psychological change in a person following a road traffic accident. Nunn (2009) examined the relationship between eating disorder and the self. Ryninks *et al.* (2014) studied mothers' experience – their contacts with stillborn infants. Denovan and Macaskill (2013) evaluated the relationship between stress and coping in first year undergraduates. It was the research lacunae in non-adherence that motivated these researchers to undertake qualitative studies. Our work is aimed at exploring the factors affecting non-adherence to medication and lifestyle modifications among patients with chronic conditions. IPA is relevant to the research objectives, as it allows us to explore participant experience and its inherent meaning. Our results may provide additional evidence about non-adherence structure and determinants, which will help healthcare professionals to understand the root causes of non-adherent behaviours.

Data collection

By prior appointment and after informed consent, each participant was interviewed at his/her residence. The researcher explained the purpose of the study. Some participants did not wish to disclose their identity; hence, each patient was number coded. Questions were asked in Marathi, Konkani or English. Each interview lasted 60-75 minutes. With prior permission, narratives were audio recorded and converted into transcripts in English by the researchers.

Data analysis

The IPA outlined by Smith (2010) and Pietkiewicz and Smith (2012) was modified to derive the explanatory framework. Each transcript prepared from the patient's narratives was read several times. Whilst non-adherence determinants may vary among patients, we grouped viewpoints to understand the issues raised by participants and to draw annotations from the transcripts. The left margin in each transcript was used to write annotations drawn from the study's scope. This procedure was repeated for all transcripts. Participant views and researcher interpretations were analysed (Pietkiewicz and Smith, 2012). Annotations were studied thoroughly, outlining the meaning inherent in the participant's experience. Looking at the connecting themes, frequency distributions were calculated. On the basis of frequencies, broad and subordinate themes were established, which were grouped to explore

non-adherence determinants and dimensions. Patient quotations were extracted from the transcripts – relevant annotations and patient quotations are given in Tables I-V and sample characteristics appear in Table VI.

Results

Sample characteristics

Interviews were conducted with 18 patients, of which 61.1 per cent were male. The age of the respondents ranged from 25 years to 78 years, averaging 52.6 years. Respondents were

Annotations drawn	Patient's quotation
Unaffordability Free service Frustration Long waiting hours Treatment non-adherence Dissatisfaction with staff quality Medication non-adherence Inconvenience Lacks external support Work-related problems	I take diabetes and high blood pressure treatments. I cannot afford private treatment. Poor no […] At this Government hospital, since everything is free, on Fridays, what a crowd […] Waiting area gets flooded with people. It is frustrating. I spend four to five hours here. I wish to stop treatment but what to do? Helpless […] But everything is free. Nurses shout and scream. Cannot expect respect I do not take medication while travelling and if there is work tension Sometimes, I am tempted to eat sweets, rice and salty food. Wife yells […]. [Laughs] Doctor says be tension free. Not possible. I have two sons, employed but alcoholic, not supporting the family. Although I am old, but cannot leave the job, family is dependent on me. My fate […] what to tell?

Table I. Patient quotations with annotations (diabetes)

Annotations drawn	Patient's quotation
Long waiting time Frustration Dissatisfaction with staff quality Expensive healthcare Discontinued treatment Medication non-adherence Lacks external support	My family doctor suspected a heart problem. He sent me to another doctor. My god there […]. wait, wait and wait […] to meet the doctor. After long time, he came. He did not even talk to me for five minutes. No personal touch. Staff did not treat me as a human being. Some concern for old […] On the day of operation, we spent a lot. Fortunately, I had taken out an insurance policy. Full amount was not reimbursed. I discontinued that treatment, because of staff attitude and money. Disgusting. Post operation, I bought the medicine but did not take. At this age, I have to do all house-keeping work as my daughter-in-law died

Table II. Patient quotations with annotations (cardiovascular disease)

Annotations drawn	Patient's quotation
Social stigma Long duration treatment Dissatisfaction with staff quality Medication non- adherence Inconvenience Lacks external support Unaffordability Discontinued the treatment	I have many health related problems, but I am strong ha […] I get my husband's pension that is why I am independent. Future who knows? Last year, I had chronic chest pain and cough. Due to tuberculosis, avoided social contacts, giving excuse of sickness. After one year's treatment, now I am ok […] Actual doctor should tell what will happen if you do not take medicines in time. They are not bothered. I suffer from arthritis and other problems also. To be healthy, for arthritis and dermatological problems, I take more doses than prescribed. I always keep the stock of medicine because my house is in a village far away from here. It is very inconvenient to visit the doctor. I do not do tests in time. Problems […] whom to tell? Some treatments I have discontinued. I have kept the prescriptions. I bring the medicine from the pharmacy, avoid going to the doctor

Table III. Patient quotations with annotations (arthritis and dermatological problem)

Annotations drawn	Patient's quotes
Non-professional health service Regimen difficulty Lifestyle non-adherence to diet Unaffordability Medicines are costly Medication non-adherence Work-related problems	I always consult a doctor who is practicing at my village. People say he is not a doctor. I am not bothered. We get good outcome with his medicines. There is credit facility also. Doctor told me smoking and consuming alcohol is not good for health. This even I know. My bad habits are creating problems at home, so I want to control alcohol consumption but I will not give up smoking. I am illiterate; I do not understand what doctor told me about my medicines. I cannot change my food habits. Do not smoke, no alcohol, no good food, then how to survive? At present, I am feeling OK. Going to city means, I will have to pay for transport, food, doctor's fees, tests and buying medicines. Therefore, I am postponing going to city doctor. Today my son- in law brought me here. Tests and x-rays done. Doctor told my son-in-law something. I came to know something is seriously wrong. I get temporary relief with medicines. Medicines are very costly; therefore, we buy only four or five tablets. I was working on daily wages. If I am unable to work fast, employer shouts. My family is facing lot of financial problems because of my sickness

Table IV.
Patient quotations with annotations (lung cancer)

Annotations drawn	Patient's quotes
Fed up of sickness No caretaker Lacks social support Frustration Unaffordability Medication non-adherence Work-related problems Lifestyle non-adherence to exercise Social stigma Treatment non-adherence	I am fed up of this sickness. For years, I am doing home remedies as well as I take medication from local doctor, but of no use. I feel nobody is taking care of me. Doctor does not even listen to me; I do not take his medicine. Since neighbours were enquiring, mummy stopped my treatment. Now, we go to Bambolim hospital. Sometimes I am hospitalized. I consult many doctors. I have no money to buy medicine. I avoid taking medicine because I feel sleepy the entire day and I have to do housekeeping work. Otherwise mummy shouts. I do not want to take treatment. Doctor told to do yoga. Such difficult, my god. I do not remember those exercises. Even if I try something, body pains. I am completely alright […]. you see […] I am alright no, but my mother feels I am sick. I do not want others to know about my sickness. I do not follow the doctor's instructions. I go for spiritual healing

Table V.
Patient quotations with annotations (bipolar disorder)

Patient no.	Gender	Age (years)	Health-related problem	Sickness duration (years)
1.	Male	62	Diabetes	15
2.	Female	78	Cardiovascular disease	1
3.	Female	50	Cancer	2
4.	Female	69	Arthritis and dermatological problem	7
5.	Male	54	Diabetes, liver problem and piles	5
6.	Male	30	Chronic back and stomach pain	1
7.	Male	35	Alcoholic liver disease	1
8.	Female	25	Acquired immunodeficiency syndrome	1
9.	Male	29	Epilepsy	4
10.	Male	58	Depression disorders	4
11.	Male	55	Cardiovascular disease and piles	4
12.	Male	50	Diabetes	3
13.	Female	60	Chronic obstructive pulmonary disease	5
14.	Male	70	Cancer	2
15.	Male	60	Lung cancer	4
16.	Female	65	Arthritis	5
17.	Female	43	Bipolar disorder	4
18.	Male	48	Chronic renal failure	1

Table VI.
Sample characteristics

being treated for: diabetes (three participants), cardiovascular disease (two), cancer (three); arthritis (two), chronic back and stomach pain, acquired immunodeficiency syndrome, epilepsy, depression, bipolar disorder, chronic renal failure, alcoholic liver disease and chronic obstructive pulmonary disease (one each), representing 12 chronic conditions (Table VI). Sickness duration ranged from 1 to 15 years. The frequency tabulation and broad and subordinate themes generated are summarized in Tables VII and VIII, respectively.

Subordinate themes, such as "free service" and "non-professional health services" were not considered relevant to our study. "Work-related problems" was renamed "work compulsion". "Skip medicine dose", "forgot to take medicines" and "not filling prescription in time" formed "medication non-adherence". "Non-adherence to 'diet", "exercise regime" and "rest" formed "lifestyle modifications non-adherence". Qualitative data were used to explicate 11 broad and nine subordinate themes, which were clustered to explore non-adherence factors and dimensions. Factors influencing patient non-adherence were multidimensional, in eight dimensions: "work compulsion", "unaffordability", "dissatisfaction with staff quality", "poor external support", "frustration", "inconvenience", "social stigma" and "regimen difficulty". "Patient non-adherence" was found to be bidimensional: "medication and lifestyle modification non-adherence". Patient non-adherence factors are summarized in Tables IX and X.

Discussion

A major challenge to healthcare the world over is the growing prevalence and deaths due to chronic diseases. This worrisome phenomenon can be attributed to several factors, the gravest among them being patient non-adherence. As stated by NICE (2009), the first step to understanding and dealing with the non-adherence issue is exploring patients' perspectives before motivating them to comply with treatment and care. The Pharma (2011) report

Table VII. Broad themes relating to patient non-adherence

Sr. No.	Broad themes	Frequency
1.	Lifestyle modification non-adherence	15
2.	Work-related problems	13
3.	Medication non-adherence	19
4.	Unaffordability	10
5.	Dissatisfaction with staff quality	8
6.	Treatment non-adherence	8
7.	Lack of external support	9
8.	Frustration	7
9.	Inconvenience	5
10.	Social stigma	4
11.	Regimen difficulty	4

Table VIII. Subordinate themes relating to patient non-adherence

Sr. No.	Subordinate themes	Frequency
1.	Lifestyle non-adherence to diet	8
2.	Lifestyle non-adherence to exercise	5
3.	No care taker	3
4.	No filling prescription in time	2
5.	Free service	2
6.	Expensive healthcare	2
7.	Nonprofessional health services	2
8.	Lifestyle non-adherence to rest	2
9.	Long waiting hours	2

Table IX.
Factors influencing patient non-adherence (broad and subordinate themes)

Sr. No.	Factors
1.	Work compulsions
2.	Unaffordability
	Expensive healthcare
3.	Dissatisfaction with staff quality
4.	No external support
	No caretaker
5.	Frustration
	Long waiting hours
6.	Inconvenience
7.	Social stigma
8.	Regimen difficulty

Table X.
Dimensions-patient non-adherence (broad and subordinate themes)

Sr. No.	Dimensions
1.	Medication non-adherence
	No filling prescription in time
2.	Lifestyle non-adherence
	Lifestyle non-adherence to diet
	Lifestyle non-adherence to exercise
	Lifestyle non-adherence to rest

demonstrated that qualitative insights into adherence are lacking. Our results have shown patient non-adherence nature and structure. Medication non-adherence is defined as a deviation from the medication regimen advised by the healthcare professional. We found that medication non-adherence includes not administering the medicine, administering a different dosage, administering at a different time. Lifestyle modification non-adherence is not following exercise, diet and rest regimen as advised by the healthcare professional.

Our results indicate that non-adherent behaviour in chronic conditions is caused by many factors: "work compulsion"; "unaffordability (economic factors)"; "dissatisfaction with service quality"; "inconvenience (health system related factors)"; "social stigma"; "lacks external support (social factors)" and "frustration"; and "regimen difficulty (psychological factors)". The study results are like a cystic fibrosis study in Spain (Arias-Llorente *et al.*, 2012).

The working population find it difficult to adhere to treatment due to work pressures. Being the sole breadwinner compels him/her to work against advice to the contrary due to the financial constraints/inadequate savings, i.e., patients find healthcare services, adopting lifestyle modifications and transportation unaffordable.

Patients feel that healthcare professionals are not sensitive to their information and emotional needs. Information about treatment and non-adherence dangers provided to the patient is inadequate due to the seller's market in India, i.e., power still favours healthcare professionals. Dissatisfaction with the service quality affects loyalty and in turn leads to treatment discontinuity.

Debilitated patients require help to follow exercise, diet and timely medication administration. Negative health outcomes and poor external support lead to frustration, which subsequently influence non-adherence. If social stigma is associated with disease, then patients want to keep it private and show high predilection towards treatment adherence to facilitate speedy recovery. When the treatment regimen is complex, confusion persists and non-adherence increases. Normally, lifestyle modifications are difficult and patients find it inconvenient to adopt the changes.

Practical and social implications

Along with economic and health system related factors, psychosocial issues emerged as a strong non-adherence predictor. Behaviour research, if shifted to a multidisciplinary approach, may predict a chronic patient's non-adherent behaviour. Patient non-adherence is not yet viewed as an important element in public health policy. Any step towards recognizing and preventing non-adherence will have substantial benefits to the patient and healthcare stakeholders. Exploring patient non-adherence – its nature, structure and factors – can enhance adherence and reduce healthcare costs. Overall, healthcare should be reoriented to address the challenges posed by rising chronic disease rates and preventing treatment non-adherence. Adherence to treatment will increase positive health outcomes (World Health Organization, 2002), improve the patient's quality of life and reduce the burden on the healthcare systems.

Conclusions

We identify patient non-adherence factors and dimensions. The conceptual framework derived from our study shows that patient non-adherent behaviour results from: economic, health system related, social; and psychological factors. It indicates what influence the decision to not adhere includes medication and lifestyle modification non-adherence. We demonstrate that patient non-adherence is prevalent and multiple factors predict it. Hence, a multidisciplinary approach incorporating patient-centred care is required to improve adherence among patients with chronic conditions who are at the risk.

Limitations

Our results may not always be relevant, i.e., data were provided from a longitudinal study (given that non-adherence occurs over time). Furthermore, data were collected using a qualitative approach; hence, there may be selection and response bias, which may have a bearing on theme accuracy exploration. We adopted the snowball sampling method, which may limit the study's scope and generalization.

Recommendations

Our results should provide a base for further research into patient non-adherence. We highlight the factors affecting patient non-adherence through IPA, which may prove insightful to researchers who are assisting and enhancing patient compliant behaviour. One more area in which IPA can create a positive impact is investigating healthcare service provider experiences through control group trials among patients.

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