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Development of a Tool to Measure Adherence to Treatment of Patients with Terminal and Chronic Diseases

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Abstract

The present work was designed to develop a tool to measure adherence to treatment of patients suffering from terminal and chronic diseases like HIV/AIDS, Diabetes, High Blood Pressure, Thyroid and Arthritis. Initially, literature related to the area explored to know about the adherence and its factors. Some factors were finalized to use to develop the tool. On the basis of these factors the dimensions of the tool determined, and items were developed. The initial form of questionnaire was devised a four point scale to response. Item analysis was done on a sample of patients suffering from terminal and chronic disease. The final version of the tool has 25 items having 13 positively scored and 12 inversely scored. By using appropriate statistics the psychometric properties of the test established. The Alfa co-efficient of the test is very high. The content validity was established and the construct validity established by factor analysis. Total 9 factors emerged in the present tool.

Keywords : Adherence, Terminal and Chronic

Introduction

Adherence to treatment is directly concern to the person's behavior towards the health care issues, have an important role in chronic diseases. The term 'treatment adherence' refers to the ability of the patient to develop and follow a plan of behavioral and attitudinal change that ultimately serves to empower him/her to improve health and self manage of a given illness(APHA, 2004). Treatment Action Campaign (2006) defines it as a word to describe taking drugs exactly as they are prescribed. It includes taking them at the right time and in the right doses. It helps to reduce the viral load and also help to prevent drug resistance. Skipping medications make it easier for drug resistance to develop. Icovics (1997) defined medication adherence as the percentage of prescribed doses taken. Poor adherence to treatment regimen is a long standing problem in many chronic health conditions (Smith et al, 2003).

It is very important to take medicine at the appropriate times. Melbourne et al (1999) noted that within a sub group of patients who took more than 90% of doses, there was significant dosing fluctuation 50% of patients during the first two months of treatment. Adherence is extremely influenced by the complicated regimen which is to be followed. Sethi A.K. and colleagues (2003) shown that it is need to take drug on time as take all or nothing. According to Treatment Action Campaign 2006, it is important to pay attention to dietary restrictions for different drug combinations; ignoring these can be like taking only half a dose. Missing one or two doses a week can have a big impact on the chances of successful treatment. It is important to consider the patient's daily schedule; patient tolerance of pill number, size and frequency; and any issues affecting absorption (Vermire et al 2001, Williams and Friedland 1997). Studies have shown that patients taking once daily regimens have higher rates of adherence than the patient taking twice daily dosing regimens (Nachega et al 2014). Simple, once-daily regimens, including those with low pill burden without a food requirement, and few side effects or toxicities, are associated with higher levels of adherence (Raboud et al, 2011; Nachega et al 2014). Some patients may selectively adhere to components of a regimen believed to have the fewest side effects. Side effects from medication including diarrhea, fatigue threats patient and affects adherence (Aids Info, 2011) and also associated with irregular medication intake or stopping medication altogether (Ayalu & Sibhatu, 2012).

The reason for non- adherence may often be found outside the individual responsibility of patients, solution may requires the provision of social support (IMM, 2013). In some cases the influence of the family members was so significant that relatives such as parents or husbands made treatment decisions (Roura et al, 2009). Past studies have demonstrated relation between supportive social systems and treatment adherence. (Gordillo et al, 1999; Catz et al, 2000) Soliciting help from family members may also improve adherence.

The most common reason given by patients for missing medication is "forgetting" (Conn et al, 1994; Dunbar-Jacob, 1996). It is indirectly caused by carelessness. Daily schedule issues (including a busy schedule, shift work or travel away from home) may cause of forgetting. Lacey et al (2009) found forgetfulness as a strong barrier to adherence to treatment. Dunbar- Jacob et al (2001) weighted schedule disruptions for missed dosing. Also medical co morbidity was associated with forgetfulness as a prominent cause of non-adherence (Barfod et al., 2006; Wu et al., 2008). Ayalon et al (2005) proposed that some investigators described forgetfulness as non intentional non-adherence and differentiated between the intentional, and non-adherence. The non intentional non-adherence was attributed to forgetfulness or difficulties keeping track of medication regimen, and it was associated with greater cognitive impairment, and is more common among the elderly than the intentional non-adherence (Barfod et al., 2006; Bulloch et al., 2006; Burra et al., 2007; Taj et al., 2008).Other research findings suggest that doctor patient's communication and health related beliefs of patients contribute to adherence (IMM, 2013). These findings suggest that educational efforts and improved physician patient communication may increase patient's adherence to medical therapies (Friedman et al, 2008). Consistent access to health care and medicines also appear to influence treatment adherence. The level of services, communication, and rapport between the pharmacist and patient often impact adherence and deserve further attention (Icovics et al, 1997). A patient provider relationship that enhances patient trust through non judgmental and supportive care and use of motivational strategies can positively influence medication adherence. Establishing a trusting patient provider relationship over time and maintaining good communication will help to improve adherence and long term outcomes (AIDS Info, 2014). Beside this, awareness emerged by appropriate knowledge helps in better way to improve adherence. Appropriate knowledge make understand the patients their disease exactly and its outcome. Education, government efforts and patient's own eagerness help to seek knowledge.

Patient readiness refers to the understanding of, motivation and commitment to their treatment plan. Before a prescription is written, it is important to establish the patient's readiness to accept the treatment plan offered. This involves educating the patient and engaging the patient in problem-solving in an effort to remove obstacles to treatment adherence. Mekonnen et al. (2010) found self assessment of the health status affects decision of patients to the adherence.Past research shown the positive association of self efficacy with adherence (Gifford et al, 2000; Catz et al, 2000; Safren et al,2001). The concept of self-efficacy is an integral component of self-regulation models (Merluzzi et al, 1997).

Aim of the Study

To develop a tool to measure Adherence to treatment in patients suffering from terminal and chronic diseases.

Method

Sample

The sample consisted of 100 male and female patients suffering from terminal and chronic diseases. Sample was drawn from ART centre and ICTC centre of B.R.D. Medical College, private clinics and the patients known personally. The age range of the participants was 20 to 50 years. The participants were residents of Gorakhpur and adjacent rural area.

Procedure

First of all the literature consisted of this area investigated to review the available research to measure Adherence to Treatment. Available questionnaires and other tools reviewed and some approaches were selected for further investigation. Approaches were deeply reviewed to know about theoretical dimensions related to adherence to treatment. Finally, Patients decision, Regimen, Carelessness, Doctor-Patient's communication, Appropriate Knowledge, social support, Right time, Side-effects, Motivation and commitment found as more effective dimension to adherence to treatment. 27 items were written in Hindi language according to these dimensions. An attempt was made to check the items with the help of faculty members of Department of Psychology and Department of Hindi language experts.

These 27 items were administrated on a sample of 100 participants. The participants made their responses on four point scale varying as Always (4), Often(3), Sometimes(2), Never(1). 13 items were positively worded and 14 were negatively worded. Item No.1, 2, 3, 5, 6, 7, 10, 12, 20, 22, 24, 26, 27, were positively worded and Item No 4,8,9,11, 13, 14,15,16,17,18,19,21,23,25,were negatively worded.

Further, Rapport was established to the patients and after describing the purpose of the study, their consent has been taken. The essential instructions were given. After completion, the scoring was made.

Analysis

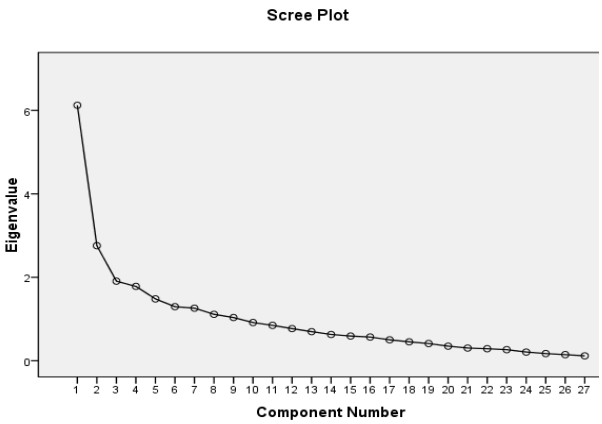
The Factor Structure

Obtained score was subjected to an inter item correlation. On the basis of the initial checking 2 (Item no.13 & 25) items that were not connected with other items were dropped. On the remaining 25 items a factor analysis was computed using principal component extraction method with Varimax rotation.

KMO Bartlett's test of sampling adequacy was found to be appropriate (0.67). The Bartlett's test of sphericity was significant [χ2 (351) =1.062, P<.01] Rotated factor structure yielded 9 components above the eigenvalue of 1. Rotation converged in14 iterations. Factor 1(variance – 11.95%) had 5 items, factor 2(variance –11.53%) had 5 items, factor 3(variance – 10.36%) had 5 items, factor 4(variance – 7.90%) had 3 items, factor 5(variance – 6.09%) had 2 items, factor 6(variance – 5.71%) had 2 items, factor 7(variance – 5.47%) had 1 items, factor 8(variance – 5.31%) had 1 items, factor 9(5.11) had 1 items.

Factor Loading Table

Item No.	Factor 1	Facto 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9
15	.604								
17	.718								
18	.738								
19	.698								
20	.560								
2		.801							
3		.718							
9		.589							
14		.531							
27		.764							
4			.606						
5			.611						
8			.551						
11			.709						
21			.626						
16				.598					
22				.740					
23				.802					
6					.784				
10					.683				
12						.884			
24						.452			
1							.893		
7								.853	
26									.784



Psychometric Properties

To establish psychometric properties, inter item correlation and Cronbach's alpha was computed. An attempt found Cronbach's alpha 0.64. Equal length Spearman Brown reliability was found to be fairly high (0.64). After all the calculation to validate the present to an exploratory factor analysis was done. Principal component method was used to factor extraction and orthogonal rotation was done to get final factor structure. Psychometrically adequate items in the factor analysis were accepted and psychometrically poor items were dropped in the final version of scale.

Discussion

Total nine factors were retained in the final version of the present scale. Total 69.43% variance explained by these nine factors. The factors are: Patients decision, Regimen, Carelessness, Doctor-Patient's communication, Appropriate Knowledge, social support, Right time, Side-effects, Motivation and commitment. The author has initially started assuming nine dimension of adherence. These dimensions were determined on the literature review that was available in this area. The final factors structure has also nine factors. So the prior determination of the initially nine factors by author is validated by the present factor structure.

First component is patient's decision that is related with patient's behavior to stop taking prescribe drugs with intention. Patient generally aware about the situation but still they discontinue to take drugs the given time and day. The second component is regimen which is related with the appropriate dose of

the prescribe drugs and it is about the patient's willingness to adherence. The regimen advised by the doctors.The third component Carelessness/ forgetfulness. This component is characterized by two different processes. The first process is non-intentional non-adherence and second is intentional non-adherence. The non intentional non-adherence is attributed to forgetfulness and the intentional non-adherence is attributed to Carelessness. The forth component is doctor- patient's Communication that is indicating the quality of communication process between Doctor and Patient**.** Fifth component is the appropriate knowledge about the whole situation consequence of the discontinuation of the drugs. The sixth component is related with the perceived social support. Family and friends support play an important role in the patient's life. Vigilant about time is the seventh component. This is related to take medicines at right time. Side-effects and motivation and commitment are eighth and ninth component.

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Factors and Items of Adherence to Treatment (ADT) Questionnaire

Item No.	Items	Loading
Factor 1: Patient's Decision		
1.	मैं डॉक्टर के बताये नुस्खे को बीच में ही छोड देता हूं ।	.604
2.	मैं कुछ ठीक हो जाने पर दवाईयॉ बीच में छोड देता हूं ।	.718
3.	मैं जानता हूँ कि दवाइयों को निर्धारित समय पर लेना आव"यक है फिर भी छोड देता हूं ।	.738
4.	मैं जब दवा लेने से बेहतर महसूस नहीं करता हूँ तो दवा लेना बन्द कर देता हूं।	.698
5.	मैं दवा समाप्त हो जाने पर जल्दी से जल्दी फिर प्राप्त करने की को"ि"ा करता हू।	.560
Factor 2: Regimen		
1.	मैं डॉक्टर द्वारा बताई गई निर्धारित मात्रा में ही दवा लेता हूँ।	.801
2.	मैं डॉक्टर के बताये नुस्खे का पालन करता हूँ।	.718
3.	मुझे दूसरों की उपस्थिति में दवा लेने में संकोच होता है।	.589
4.	मैं डॉक्टर द्वारा बताई गई दवाईयों की मात्रा बदल देता हूं।	.531
5.	मुझे डॉक्टर ने दवा खाने के तरीके के बारे में पूरी तरह से बताया है।	.764
Factor 3: Carelessness/forgetfulness		
1.	मैं समय से दवाई लेना भूल जाता हूँ।	.606
2.	मैं ठीक होने बाद भी डॉक्टर के बताये हुए दिनों तक दवाईयॉ लेना जारी रखता हूँ।	.611
3.	मैं दवा लेने में लापरवाह हूँ।	.551
4.	मैं डॉक्टर की बताई उपचार सम्बन्धी हिदायतों को नजर अन्दाज कर देता हूँ।	.709
5.	कार्य के दौरान अकेले में दवा लेनें का समय नहीं मिलने पर दवा नहीं खाता हूं।	.626
Factor 4: Doctor- Patient's Communication		
1.	मैं भूल जाता हूं कि डॉक्टर ने दवा किस प्रकार से खाने के लिए बताया था।	.598
2.	मुझे डॉक्टर ने बताया है कि दवा छोडने पर किस प्रकार का नुकसान होगा ।	.740
3.	मुझे लगता है कि डॉक्टर ने बहुत ज्यादा दवाएं लिखी हैं इसीलिए मैं दवा लेना छोड देता हूं।	.802

Factor 5: Appropriate Knowledge	
1. मैं जानता हूॅ कि दवाइयों को निर्धारित समय पर लेना आव"यक है।	.784
2. मुझे डॉक्टर ने बताया है कि दवा छोडने पर नुकसान होगा ।	.683
Factor 6: Social support	
1. मेरे परिवार के लोग समय से दवा लेने की याद दिलाते हैं।	.884
2. मेरे मित्र समय से दवाईयॉ लेने के लिए उत्साहित करते हैं।	.452
Factor 7: Vigilant about Time	
1. मैं दवाईयॉ समय पर लेता हूॅ।	.893
Factor 8: Side-effects	
2. दवा के साइड इफैक्ट की तकलीफ के बावजूद मैं दवा लेना जारी रखता हूॅ ।	.853
Factor 9: Motivation and commitment	
3. मैं दवा समाप्त होने के पहले ही आगे की दवाईयॉ ले लेता हूं।	.78