International Journal of Nursing Studies 51 (2014) 908–916

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

The dynamic process of adherence to a renal therapeutic regimen: Perspectives of patients undergoing continuous ambulatory peritoneal dialysis

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ARTICLE INFO

Article history:
Received 13 December 2012
Received in revised form 29 September 2013
Accepted 13 October 2013

Keywords:
Adherence
Continuous ambulatory peritoneal dialysis
Dynamic process
End-stage renal disease
Mixed methods research
Nursing
Renal therapeutic regimen

ABSTRACT

Background: The nature of end-stage renal disease and the need for continuous ambulatory peritoneal dialysis require patients to manage various aspects of the disease, its symptoms and treatment. After attending a training programme, patients are expected to adhere to the renal therapeutic regimen and manage their disease with the knowledge and skills learned. While patients are the stakeholders of their health and related behaviour, their perceptions of adherence and how they adhere to their renal therapeutic regimen remains unexplored.

Aims: To understand adherence from patients' perspectives and to describe changes in adherence to a therapeutic regimen among patients undergoing continuous ambulatory peritoneal dialysis.

Design: This study used a mixed methods design with two phases – a survey in phase I and semi-structured interviews in phase II. This paper presents phase II of the study.

Settings: The study was conducted at a renal unit of an acute hospital in Hong Kong.

Participants: Based on the phase I survey results, maximum variation sampling was employed to purposively recruit 36 participants of different genders (18 males, 18 females), ages (35–76 years), and lengths of dialysis experience (11–103 months) for the phase II interviews.

Methods: Data were collected by tape-recorded semi-structured interviews. Content analysis was employed to analyse the transcribed data. Data collection and analysis were conducted simultaneously.

Findings: Adherence was a dynamic process with three stages. At the stage of initial adherence, participants attempted to follow instructions but found that strict persistent adherence was impossible. After the first 2–6 months of dialysis, participants entered the stage of subsequent adherence, when they adopted selective adherence through experimenting, monitoring and making continuous adjustments. The stage of long-term adherence commenced after 3–5 years of dialysis, when participants were able to assimilate the modified therapeutic regimen into everyday life.

Conclusions: The process of adherence was dynamic as there were fluctuations at each stage of the participants' adherence. With reference to each stage identified, nursing interventions can be developed to help patients achieve smooth transition throughout all the stages.

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http://dx.doi.org/10.1016/j.ijnurstu.2013.10.012

What is already known about the topic?

- Educational programmes have been implemented to improve patients' adherence but the benefits are often short-lived.
- Only a few studies used a qualitative approach to explore adherence from patients' perspectives.
- A concept analysis of adherence indicates that adherence is a dynamic process, but the dynamic nature of adherence has not been explored.

What this paper adds

- This study explains adherence behaviours from the perspectives of patients treated with continuous ambulatory peritoneal dialysis.
- This is the first study to identify the three stages in the dynamic process of adherence to a renal therapeutic regimen.
- The process of adherence was dynamic as there were fluctuations at each stage of the participants' adherence.

1. Introduction

The nature of end-stage renal disease (ESRD) and the need for continuous ambulatory peritoneal dialysis (CAPD) require patients to manage various aspects of the disease, its symptoms and treatment. In Hong Kong, 8197 patients are on renal replacement therapy (RRT), with 3573 utilizing peritoneal dialysis (PD) (Ho et al., 2013). All new patients requiring RRT are prescribed PD in Hong Kong (Li and Szeto, 2008) because it provides survival advantage during the first few years of dialysis (Li and Chow, 2009). After implantation of the dialysis catheter, patients have to attend a structured CAPD training programme, which provides instructions on adherence to a four-component renal therapeutic regimen (dietary and fluid restrictions, and medication and dialysis prescriptions), blood pressure and body weight monitoring, and regular follow-up visits. After the training, patients are expected to adhere to the regimen and manage their disease, as their continuous adherence to the regimen is the key to successful management of ESRD and CAPD (Denhaerynck et al., 2007; Leggat et al., 1998).

The terms "compliance" and "adherence" have been used interchangeably in the literature (Bosworth et al., 2006; Hearnshaw and Lindenmeyer, 2006). "Compliance" was first introduced by Haynes (1979) to describe patients' "obedience" to recommendations of prescribed treatments, with the assumption that medical advice is good for patients and their rational behaviour is to follow the advice precisely (Roberson, 1992). However, the term has been criticized for its paternalistic undertone (Christensen, 2004) because noncompliance represents a lack of willingness to follow healthcare professionals' instructions, and is viewed as "disobedient" for which the patient is to blame (Bissell et al., 2004; Vermeire et al., 2001).

The World Health Organization (WHO) introduced the term "adherence" in 2001 based on the assumption that adherence implies patient agreement with the prescribed recommendations rather than passive obedience (WHO, 2001). Two years later, the WHO further defined adherence to a long-term therapy as "the extent to which a person's behaviour in taking medications, following a diet, and/or executing lifestyle changes corresponds with agreed recommendations from a healthcare provider" (WHO, 2003, p. 17). The introduction of this term reflects a paradigm shift towards the concept of an agreed behaviour (Vermeire et al., 2001). "Adherence" also implies increased patient autonomy in following a regimen believed to be beneficial (Bosworth et al., 2006).

However, healthcare professionals always link poor health outcomes to patients' inadequate adherence to the regimen (McCarthy et al., 2009) and implement educational interventions to induce lifestyle changes (Baraz et al., 2010; Barnett et al., 2007; Casey et al., 2002). Although some interventions are effective, the benefits are often short-lived. While knowledge is required for improved adherence, knowledge alone is insufficient in fostering long-term behavioural change (White, 2001). Due to the nature of the human body system (Kaveh and Kimmel, 2001), outcomes remain unpredictable even if patients can achieve strict adherence to a therapeutic regimen (Hearnshaw and Lindenmeyer, 2006).

Paradoxically, healthcare professionals usually regard adherence as top priority, while patients with chronic diseases always see symptom control, medical crisis prevention and quality-of-life maintenance as their priority (Vermeire et al., 2001).

Patients in Hong Kong may encounter additional difficulties in adhering to dietary restrictions because of the local Chinese custom of gathering at restaurants to maintain networks and social congeniality (Tam, 2001). In Chinese culture, food and social rituals at mealtimes have multiple layers of meaning, including life-giving nutrition, comfort, care, celebration and family ties (Wu and Barker, 2008). Patients are the stakeholders of their health and related behaviour. However, their perceptions of adherence and how they adhere to the regimen remains unexplored.

2. Background

Of the few qualitative studies that explored adherence from patients' perspectives, one was conducted in pharmacy by Lindberg and Lindberg (2008). They explored dialysis patients' obstacles in adhering to phosphate-binding medication and the measures patients took to overcome those obstacles. "Non-user-friendly drug compound, feeling of discomfort, forgetfulness, polypharmacy and patient ignorance" were identified as obstacles to adherence to phosphate binders (Lindberg and Lindberg, 2008, p. 571). To overcome these barriers, patients took the measures of "using a dispensing aid, consuming extra water and exercising routines". As patients with ESRD have to take multiple medications, it is necessary to examine whether they are non-adherent to phosphate binders alone or to the prescribed medications as a whole, and the rationale behind their decision-making.

Hagren et al. (2005) conducted a study on patients' experience of their life situation in relation to maintenance haemodialysis (HD). The participants described how HD encroached on their time and space, and how their life was