Readiness in HIV Treatment Adherence: A Matter of Confidence. An Exploratory Study[§]

Helene Sylvain[*,1] and Philippe Delmas[2]

[1]*Nursing Department, Universite du Quebec a Rimouski, Quebec, Canada*

[2]*Research Service, Hôtel-Dieu de Paris, France*

Abstract: Adherence to treatment is recognized as the essence of a successful HIV combination therapy. Optimal adherence implies a readiness to begin the treatment on the part of the patient. A better understanding of the "readiness phenomenon" will become an asset for optimizing HIV treatment. However, few studies have focused on understanding the process underlying the choice to adhere. The aim of this study is to understand the readiness process that leads to adhering to the HIV treatment, from both patient and professional perspectives. Twenty-seven in-depth interviews, with a qualitative exploratory design, were the source of our data. Participants were recruited in two hospitals in Paris. Throughout the data-collection process, analysed data were supplied to all participants and the research team, thus allowing for shared constructions. Four themes, interrelated with a constitutive pattern, emerged from the data we collected. Being ready to begin and adhere to treatment is a matter of confidence in oneself, as well as in relatives, in the treatment and in the health professional team. These themes are not constant and unvarying; instead, they constitute a picture moving across time and life events. Results of this study show that adherence that goes beyond "complying with" the medical instructions, but depends on how much of an active role the patient plays in the choice to adhere.

Keywords: Readiness HIV treatment adherence qualitative study.

INTRODUCTION

Although the adoption of Highly Active Anti-Retroviral Therapy (HAART) as the standard of care for people living with HIV/AIDS has contributed significantly to reducing HIV-related morbidity and mortality [1-3], living with HIV remains a constant challenge. As well as facing the problems related to chronic disease, the patient must manage a complex and changing treatment regimen and adhere to it. It has been well documented that near-perfect HIV medication adherence (i.e., at least 95% of the medication) is required for optimal viral suppression [4-6]. There is a strong linear relationship between adherence and a reduction in HIV viral load and limited adherence has been linked with acquisition of HIV-drug-resistant mutations [4, 7]. Despite this incentive, substantial numbers of HIV-positive individuals are currently failing treatment because of non-adherence.

Several factors have been found to influence patient adherence [8]: age [9, 10], duration of treatment [7, 11], drug or alcohol problems [12], psychiatric disorders [6], interaction between patients and care providers [13], social support [14], confidence in antiretroviral treatment [15] and "readiness" for treatment [16-19]. Readiness is defined as, "A conscious awareness, on the part of an individual, based on free will, that he has considered and determined that a particular behaviour change (i.e., taking his anti-HIV medication as prescribed) will be beneficial." [20, p.2]. We now recognize that the treatment should be arranged and available but commencement delayed until, as the individual is 'ready' to adhere to it [21, 22]. Optimal adherence thus entails a 'readiness' on the part of the patient to start and stick to the treatment [23]. Health professionals are therefore challenged to develop evaluation and intervention approaches that focus on adherence to treatment. A better understanding of the "readiness phenomenon" should be an asset in optimizing the quality of interventions.

Although one particular study by Enriquez and colleagues demonstrates that readiness is a key factor in successful adherence to antiretroviral treatment [17], readiness is a phenomenon that has not been a major discussion point in the field of HIV/AIDS [24, 25]. Few studies have examined the relation between readiness and adherence to HIV treatment, nor tried to understand the process that leads to becoming adherent [19]. As far as we know, no studies based on both patients' and professionals' perspectives have been conducted in a French-speaking country. The aim of this qualitative study is to examine and describe the readiness process for taking up complete adherence to HIV treatment, from both patient and professional points of view.

MATERIALS AND METHODS

We chose a qualitative exploratory design to examine the readiness process as a human experience and to perform it from a hermeneutic constructivist perspective [26, 27]. Participants were recruited from the external clinics of the

*Address correspondence to this author at the Nursing Department, Universite du Quebec a Rimouski, 300 des Ursulines, Rimouski, Quebec, G5L3A1, Canada; Tel: (418) 723-1986, Ext. 1812; Fax: (418) 724-1450; E-mail: helene_sylvain@uqar.ca

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Infectious Diseases Departments of two hospitals in Paris, France. To understand variation in the readiness process better, we classified prospective participants in three groups. We started with beginners (beginning treatment in the next three months) and adherents (viral load under 50 copies and self-administered questionnaire) and we added non-adherent patients (viral load over 50 copies and showing non-observance recognized by medical team) subsequently during the research process. Clinical research nurses working in these departments asked patients they interacted with to participate. They were screened using two criteria to determine eligibility: viral load under 50 copies and compliance rate over 95%, as determined by a self-administered questionnaire [28]. Professionals who had having at least two years clinical experience, were also recruited from these two departments.

Procedures

The research team was composed of professionals from the two hospitals. The team was composed of the two principal investigators, two research collaborators and seven clinic collaborators (six nurses and a physician). We used qualitative research techniques for preparing the interview guide, for developing interviewers skills and the for analysis process. We continued using these techniques to perform individual and collective coding for the first five interviews. This generated a second form of validation to increase rigor in the analytic process.

Interviews were carried out over an eight-month period by four members of the research team. To avoid potential biases, we made certain that interviewers had not previously known the participants in a clinical context. An ethics certificate (CER-38-95) was issued by the Research Ethics Committee of the first author's university. Following an explanation of the study, its purpose and the participants' rights with regard to the project. We obtained written consent from those willing to participate.

Data were collected in semi-structured interviews with individuals. Each interview began with a written questionnaire for socio-demographic data, and for information about prescribed HIV medication. To ensure unity in all interviews, we developed two interview guides (one for each group). These were validated by the research team. The interviews included questions about patients' individual history, in terms of adherence to treatment and about professionals' experience with adherence issues. As well, there were questions about the readiness phenomenon itself, as it is experienced (patients) or observed (professionals). With the exception of the first interview, validation questions were added by anonymously introducing other participants' responses, in addition to introducing the themes emerging from the analysis in progress. This is recommended by Guba and Lincoln [26]. Interviews were recorded on audiotape and were transcribed by doctoral sociolinguistics students. At mid-analysis, we organized a meeting attended by the transcribers and the research team. This was very useful for reducing misinterpretations of the taped interviews among the interviewers and transcribers.

Analysis began with each interview transcript [29] being read by each member of the research team. A synthesis of each interview was then written after the transcript was read. This enabled us to identify emergent themes for thematic analysis, which involved establishing units of information (unitizing) and classifying them into categories (categorizing) [30]. To help manage, shape and make sense of unstructured information, we used NVivo© qualitative analysis software to support the analytic process.

FINDINGS

Participants

Twenty-seven individuals, patients and professionals, agreed to participate by means of interviews, which lasted an average of 45 minutes. Most participants were male (88%) and most professionals were female (66%). Mean age of patients was 43 years, ranging from 30 to 59 years. Patients had been receiving HIV treatment for an average of 12.2 years. Professionals included physicians, nurses and a psychologist. All of them work in Infectious Diseases departments. They had an average of 14 years of clinical experience with HIV patients within range of 5-25 years, (see Table **1**).

Table 1. Characteristics of Study Participants (N=27)

Groups	N	Mean Years (Range)
Patients	**18**	
Adhering	10	
Male/female	8/2	
Age		49 (30-79)
Time since diagnosis		13 (2-20)
Duration of treatment		12 (2-19)
Non-adhering	5	
Male/female	5/0	
Age		39 (30-59)
Time since diagnosis		15 (12-20)
Duration of treatment		13 (12-15)
Beginning	3	
Male/female	3/0	
Age		42 (30-59)
Time since diagnosis		2 (1-3)
Professionals	**9**	
Medical doctor	3/0	
Nurse	0/5	
Psychologist	0/1	
Clinical experience with HIV		14 (5-25)

Stakeholders' Contribution

Prior to exploring the shared construction, which was drawn from a consensus of all partners in this study, a brief description of each group's contribution is here presented.

Patient Group

Eighteen patients participated in this study. After ten interviews with high-adherence patients, we found certain regularity in the data related to the process of becoming ready to join. Using purposive sampling, we continued recruitment to understand whether this process was the same when it was actually under way. To do this, we met people who were preparing for the start of treatment (beginner's group). We also met with patients who were identified as being non-adhering so that we could focus on similarities and differences in the emerging themes and see whether, depending on where the person was in the course of in his treatment, this made a difference.

Major themes revealed with the first group of adhering participants (ad) included the fact that readiness varies over the course of treatment. In fact, at the start of treatment, members of the adhering group reported needing little reflection because, for them, "It was a question of life or death" (ad1). However, in the course of treatment, some participants reported that there were variations in their own readiness over time. "There are 24 pills a day to take. At first it's alright but sometimes you get fed up… but you tell yourself that if you want to get better you have to take them, if not you're going to go under. If you want results, you have to fight; you can't just let yourself go." (ad8)

Thus, readiness come to be seen as a long-term process that fluctuates over time and, depending on events, continues to be present beyond the beginning of treatment. For all adhering patients interviewed, their relationship with the healthcare professional was crucial for maintaining the determination to continue treatment: "I think that what also matters a lot is the confidence we have in the medical personnel." *(*ad7) While the training received and the follow-up are very important, how the professional relates to patient is just as important, particularly her or his skill in listening to the patient. Support from family and friends is another factor commonly discussed by this group. "I live with someone and he is also ill…so when it's difficult we keep up each-other's spirit." (ad3)

All interviews with this group reflect their active participation. Most of these individuals are professionally and socially committed, often to the cause of AIDS. They have a will to take active charge of their health: "When all is said and done, you have to take hold of yourself, you have to have enough character and personality to fight back." (ad2) Moreover, seeing positive results encourages them to continue treatment: "As long as results are good, and for the moment they are… if I stop, I risk getting worse, so it's not in my interest to stop. (ad1) This group of participants led us to realize that readiness is not necessarily a forerunner to adherence over time, but that it can constitute an essential factor for beginning, continuing or going back to treatment adherence.

As mentioned above, for balance in the project we met with three people who had not yet started treatment. For those participants, the only important thing at that point was to start receiving treatment. In fact, for the participants who were just beginning treatment (beg) whom we interviewed, making the decision to start did not require lengthy reflection: "There is no point in wasting time thinking… it has to be done… it has to, that's all there is to it… there is no room for reflection." (beg1)

All the beginning, participants said they felt lucky to be receiving treatment and they placed great hope in their treatment. Sometimes this hope was excessive: "What I want is to be totally cured by this medication." (beg3) The major factor helping them start was the confidence they have in the treatment itself, as well as in the doctor and the medical team: "When someone gives me advice, if it comes from a person like a doctor or a teacher, I take the advice." (beg2) Participants talked about means of preparing themselves, such as finding information by reading, searching the internet or by contacting support associations. Some participants rehearse the situation as a way of preparing for it: "I pretend I already have to take the medication." (beg3)

For the beginning participants, being ready to start the treatment is a very personal feeling, experienced inwardly, and that does not require much thinking. However, all these participants agree on two major points: one must prepare by acquiring adequate information, and confidence in the doctor is essential. They know that this therapy is not easy. At this time, they know what the side-effects are, but have not experienced them.

Five participants whose medical records identified them as non-adhering (nonad) were added in the course of the project. We did this to get a better understanding of the readiness process over the longer term, as well as to examine similarities and differences in relation to the other groups. Individuals do not say that they 'do not adhere to treatment'; usually they state something about 'making a great effort and that it is difficult over a long term.' All members spoke about the occurrence of side-effects: "Five times, no more, I had to stop for a bit, one or two days, three at the most, because I really had very bad headaches" (nonad2). Constraints associated with taking the medication were often mentioned; however, it is not the constraint itself that is referred to, but the way in which it is experienced and the difficulty of assimilating it into everyday life. In addition, isolation and the wish to keep having the disease a secret were factors reported by all members of this group: "Anyway, since I get along on my own pretty well in general, I am a bit alone in my everyday life." (nonad2) Confidence in the health professional is a theme discussed by all the members of this group. The interviews revealed that the heaviness of the treatment was a burden that participants were not always willing to carry, but that they continued to have great confidence in their physicians and their treatment.

Professional Group

Interviews with caregivers in the professional group (prof) provided an additional perspective on the subject. Although they came from different disciplines, this nine-person group worked with the same clientele and shared a common vision of adherence. In fact, they spoke of the importance of working in a multidisciplinary team and they recognized the advantages associated with this. "Group spirit is very, very important in ambulatory care." (prof9) They all mentioned the important role of a relationship of confidence between the professional and the patient in promoting and sustaining the decision to become adherent: "We expect

them to have confidence in their doctor, which is a fundamental rule of the doctor/patient relationship." (prof8)

According to most members of the professional group we interviewed, having a profile as an active patient is very beneficial. The patient is presumably ready to adhere to the treatment when he takes an interest in it: "Once he becomes interested in his treatment, when it was explained to him, when he asked questions and has understood the treatment, how it works, what are the possible side-effects… I think this can be considered the thread that lets us suppose that he will adhere to the treatment." (prof3) On this matter the professionals and the adhering group are in full agreement.

In addition, professionals consider ample preparation of the patient to be necessary for achieving good follow-up: "It's a patient who has been prepared… rather than being given a treatment without psychological preparation…" (prof1) The individual's support system is also a factor considered by most professionals to be influential in treatment adherence. Conversely, concealment and isolation are significant impediments. " Like the other groups, the professionals viewed the adherence process as varying over time, and that being 'ready' not only applies before the start of treatment, but throughout its duration: "It would be very foolish to think that it's acquired once and for all… everyone needs a little constant motivation to keep going." (prof1)

Shared Construction

We identified some regularities and common themes among the different groups in the data analysis. Analysis of the findings reveals a major pattern built around confidence. We found 'confidence' to be the only theme discussed by all participants, in every interview of the study. Confidence is the one characteristic that is essential to readiness. So, being ready to take charge of one's health and treatment is a matter of confidence in oneself (as an actor), in relatives (social support), in the treatment (efficacy) and, most of all, in the health professional team. No themes are fixed forever; they constitute a moving picture across time and life events.

DISCUSSION

The findings support other work that has explored the points of view of individuals living with HIV with regard to readiness. The only review of literature on readiness, as related to HIV treatment, shows that fear of side-effects, the shock of learning the diagnosis and lack of confidence in the physician and the medical team are the three major obstacles to overcome in achieving readiness [31]. The small number of beginning participants in our study did not make it possible for us to investigate the fear of side-effects. However, it is possible that confidence in the medical team, a theme that we were able to identify clearly, enabled patients to overcome this particular fear using information they believed to be reliable. The importance of knowledge, as well as of the support of friends and family, has been well documented in intervention studies [32]. This study is based on a way of taking charge of one's health that corresponds rather closely to what participants report in this study.

In addition, it is interesting to note that the results of this study are in agreement with those presented by Enriquez and his colleagues about events that trigger readiness [33]. In this study, trigger events are described as change in either health status or in personal life status, such as disease progression due to non-adherence or the birth of a new family member [31]. The trigger, or change agent, causes individuals to re-evaluate their lifestyles and produces a realization that behaviour changes are essential to continuing to live [33]. After the trigger event, a process with five components takes place: changing attitudes toward HIV medication, finding the right health providers, creating the right support system, getting control of life and having goals. Specifically, relationships with the health professional seem to be a critical factor [25], as it is in our study. At the start of HAART, patients report that the most important external resource is their physician (80%), followed by the family (39%) and then by the nurse, at 26.5%. Another study has shown similar results for the doctor/patient relationship at the start of therapy [34]. The same is true for the quality of the patient/nurse relation, which is recognized as being one of the main contributors to patient satisfaction, as well as being key to the choice of adopting positive long-term health behaviour [35]. This becomes very relevant in a context where a disease becomes chronic, as is the case with HIV/AIDS. The development of adherence consultation has been described by Valentini [36].

Finally, a person's commitment to his treatment seems to be an essential factor in readiness process. This factor was stressed by patients and professionals alike. A number of studies substantiate these results; one study in particular bears on the notion of taking control and examines the hardy personality in an adherence context [37]. Other research has focused on this phenomenon through the concept of empowerment, which goes beyond personality traits and takes into account the psycho-social context of the person living with HIV [38, 39], as does the Transtheoretical model (TTM) where readiness is a part of the process of deciding to maximize treatment adherence [40]. Three characteristics place adherence in an empowerment perspective: self-help behaviour, caregiver-patient cooperation and an active role in one's own treatment [41]. In a chronic disease context, it therefore is important to consider the person as an actor in his or her own life and to reinforce his or her personal potential. This illustrates the contribution made by intervention studies using these theoretical foundations [31].

CONCLUSION

This research enabled us to integrate the perspectives of both professionals and patients in the same project. We used inter-group validation to arrive at a consensual construction that takes into account the different perspectives. This gives emphasis to the role of confidence as the central factor in the process of becoming ready to take charge of one's health. Factors, such as the relationship with the health professional, social support and the self-confidence have also been shown to be important as triggers for readiness. It would be interesting to pursue this orientation in future research to develop and evaluate appropriate interventions.

It should be noted that participating patients were interviewed in a hospital environment, and therefore benefited, in a professional context, from the availability of additional support, making them less isolated than individuals might be in the community. This is a limitation of this qualitative study [42]. In a qualitative research

project, generalization of results is not required [43]; instead, the research focuses on the human experience by recognizing the possibility that it might also be shared with, for instance, other populations living with HIV or other chronic diseases associated with treatment adherence [44].

Finally, it is important to mention that there is little experience in nursing research in France. This project may be seen as a contribution to the development of a team research culture in Nursing, as described elsewhere [45].

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