

The Process of Adapting to Life with HIV in Greece: A European Research Project

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Abstract

Introduction: This paper outlines a European collaborative research Project between the Nursing Departments of Bournemouth University, of Technological Educational Institute of Athens and of Technological Educational Institute of Crete, which explores the changes that Greek people with HIV experience in their life after diagnosis of HIV. It further attempts to identify how they adapt to those changes and what might help this process. The research network also involves "Andreas Syggros" Hospital of Athens.

Aim: The aim of this research Project is to explore the lived experience of adaptation for Greek individuals who have been diagnosed as having HIV.

Method: A qualitative interpretative phenomenological research design will be used to interpret experiences as described by the participants, and will also guide data collection and data analysis. Local procedures for gaining ethical approval will be followed.

Expected Results and Conclusion: The findings of the study will be used to test and strengthen the Perrett and Biley Negotiating Uncertainty Theory (PB-NUT) and to improve services ensuring they are patient-focused and therefore cost-effective. The Project will also present a theoretical understanding of adaptation to HIV that may assist health professionals in caring effectively for those with HIV and possibly other long term conditions. Finally, the Project will provide an opportunity to develop a solid research network among European and Greek Academic Institutions, regarding HIV and AIDS, with useful results for practice and policy.

Keywords: Adaptation; HIV/AIDS; Uncertainty; Greece; European project

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Introduction

The present Project is a joint research effort between three Academic Institutions in UK and Greece. It involves the Nursing Departments of Bournemouth University, of Technological Educational Institute of Athens and of Technological Educational Institute of Crete. The research network also involves "Andreas Syggros" Hospital of Athens.

This proposed Project aims to explore the physical and psychosocial changes that people with HIV experience in their life after diagnosis. It further attempts to discover how people with HIV adapt to those changes and which supportive strategies are used in the process of adaptation.

As a frequently asymptomatic infection, HIV will often appear 'silent' yet the serious nature of the infection and long-term progression to AIDS means living with HIV creates great uncertainty as patients do not know how or when physical symptoms might develop, change or deteriorate. The uncertainty experienced following diagnosis has been well documented in the literature [1]. Modes of HIV transmission such as unprotected sex or the sharing of intravenous injecting equipment have led to experiences of stigma and prejudice for those living with HIV. Significant social consequences have been evident for those with HIV, causing prejudice, fear, and ignorance. For people with HIV and their families, the uncertainty of physical illness alongside the development of AIDS can be compounded by social rejection, prejudice, and discrimination [1].

HIV was formally identified in 1981. During the 1980s, patients diagnosed with HIV were told to expect a significantly shortened life span; the prognosis was considered to be the equivalent to a fatal condition [2]. From 1996 onwards, when new antiretroviral treatment was introduced, people with HIV have been able to maintain a relatively good health and extended quality of life [3]. Today, those who are living with HIV are considered to have, and are treated as having, a chronic condition [2,4]. There is now estimated to be 34 million people around the globe living with HIV/AIDS, including 3.4 million [3 000 000-3 800 000] children less than 15 years. Although the majority of these people (22.9 million-around two thirds of the global total) live in developing countries, the western world has been significantly affected [5,6].

HIV in Greece

The population of Greece at the end of May 2011 reached almost 11 million [7]. According to the data of the Hellenic Centre for Disease Control and Prevention (H.C.D.C.P.) the cumulative number of people reported as having HIV in Greece (including those with AIDS) towards the end of 2011 was approximately 11,500. Of these 81.3% were male and 18.3% were female [8].

Greece experienced a substantial upwards shift in HIV epidemic after 2000. From 2000 to 2010, between 397 and 653 cases of HIV-1 infection was notified annually in Greece with 6% - 10% of them going on to develop AIDS. In 2011, 954 HIV infections were reported, which represented a 57% increase compared with 2010. The vast majority of those are men, who acquired HIV by sexual contact. In 2011, an HIV outbreak in the population of injecting drug users (IDUs) was observed in Greece. More specifically, the reported number of HIV infections among IDUs in 2011 (241) was approximately 15-fold greater than the corresponding figure in 2010 (15) [8]. According to HCDCP, there have been no changes in testing policy that could explain this increase [9]. In 2011, the reported HIV infections among IDUs represented almost 1/4 of the total number of registered HIV cases in Greece for that year, while in 2010 the corresponding percentage was only 2.5% [8]. A similar increase in cases amongst IDUs was reported in Eastern Europe, namely Romania [10]. The new epidemic seems to be spreading through transmission networks of different sizes, suggesting a limited number of sources, or high levels of transmission networking among the IDUs [11].

The high prevalence of HIV-1 infection among IDUs in Eastern Europe remains concerning [12]. Given the estimated large number of IDUs in the eastern part of Europe (range 20 202–25 171) who inject illicit drugs in Greece and the limited resources in the public sector because of the current financial situation in Greece, public health authorities face the potential of a rapidly growing HIV-1 epidemic in this vulnerable subset of the population and, possibly to the wider community, with dramatic medical, social and economic consequences [9,11,13].

Developing Understanding of How People Adapt to Life with HIV in Greece

Understanding a person's illness experience can help develop strategies to assist the person adapt to the physical, emotional, psychological and social changes they may experience. Research has identified that people are more likely to engage with services and follow treatment plans when they feel they are being

listened to and understood [14,15]. Within the field of HIV/AIDS, it is recognised that understanding illness and treatment beliefs can strongly influence medication adherence [16,17]. The overall healthcare experience can also be improved when health professionals have a deep understanding of the person's situation and are able to tailor care accordingly toward a more cost-effective delivery of health care [18,19].

During the 1980s and 1990s many research studies investigated how patients came to terms with an HIV diagnosis. Responses to living with HIV included issues such as the experience of stigma, fear and stress [20-24]. People with HIV are now living longer as a result of advances in treatment. Research is needed to keep up with the changes in disease presentation and extended life expectancy, examining how people cope and adapt to living with HIV today [25-27]. Models and theoretical frameworks that help us understand the chronic illness experience are now considered applicable to those with HIV. These include the chronic illness trajectory, the shifting perspectives model of chronic illness, illness appraisal research, and the "John Wayne" model of chronic disease [28-31]. The Perrett and Biley Negotiating Uncertainty Theory (PB-NUT) recently explored the adaptive processes of HIV patients in the UK, describing a process of constantly 'negotiating uncertainty' by movements between anticipating hopelessness and regaining optimism [32]. The results of this study need further development across cultures to strengthen the theory.

Studies exploring how people with chronic health conditions adapt as their life is shaped by their conditions have been conducted extensively at an international level. However no such studies have taken place in Greece [31,33,34]. It is essential to understand the adaptation of HIV patients in Greece taking into account the different HIV trends in Greece compared to other European countries, and cultural differences which may or may not influence the adaptive process.

Knowledge in the field of HIV is extremely important in order to provide quality of care and to understand the needs of people with HIV and improve the quality of life [35]. As the incidence of HIV positive people has increased recently in Greece and given the countries declining financial situation, it is imperative that money invested in health services is not wasted but meets the needs of those it serves. Such research will help uncover the adaptive issues of those with HIV in Greece, and can be used to improve services ensuring they are patient-focused, safe and therefore cost-effective.

Aim

The aim of this research project is to explore the lived experience of adaptation for Greek individuals who have been diagnosed as having HIV.

The research question will be "How do people adapt to being diagnosed as HIV positive?"

Method

A qualitative interpretative phenomenological research design will be used to interpret experiences as described by the participants, and will also guide data collection and data analysis. Interpretative phenomenological analysis (IPA) focuses on "lived experience" and explores the way that individuals ascribe *meaning*

to their experiences in their interactions with the environment [36]. IPA is based on naturalistic inquiry and uses small numbers of participants. It involves purposive homogeneous sampling, flexible interview schedules and verbatim transcript. Analysis requires systematic search for themes, and connections between themes and establishment of superordinate themes. The main aim of IPA is to capture rich accounts of the lived experience for the individual under investigation [36-38].

IPA as a method of research has begun to expand from social science and health psychology to other areas such as nursing, nutrition and public health [39]. Phenomenology seems to have similar rational with nursing philosophy as for both, understanding the unique human being is the target. Nursing concerns with human responses to illness and knowledge in nursing is closely related to understanding human experience within specific cultural and social contexts [40].

IPA has recently grown in popularity and has been successfully used to explore the impact of HIV on specific population groups such as HIV positive Black Africans living in the UK, and HIV-positive gay men in UK [41-43].

As IPA concerns with actual life cases and focuses on exploring how people give meaning to important experiences of their lives, the use of IPA approach to this study can be proved useful in order to inform the development of tailor-made strategies to support people with HIV. For example, studying the "*lived experience*" may provide specific information on the decision making process followed by the individual, the transition process from potential hopelessness to optimism and the adaptive stages that the individual experience. This information can be then used to inform counselling and education policies for people with HIV. It will be also used to test and strengthen the Perrett and Biley Negotiating Uncertainty Theory (PB-NUT) which has been generated in the UK [32]. This is the first attempt to develop such policies within the Greek context and to generate knowledge based on the lived experiences of the study participants.

Participant Selection

A purposive sampling technique will be used. The sample size, as previously noted, is traditionally small in IPA studies and is expected to be approximately 10 to 12 participants. Participants must be over 18 years of age, and must be Greek Nationals, born to Greek National parents. Participants will need to have been diagnosed with HIV at least two years previously in order to be able to recall any experiences of adaptation which may have been encountered.

Some basic clinical data will be collected through participants' medical records. These data will include the year(s) diagnosed with HIV, current CD4 count and current viral load. Information regarding current antiretroviral therapy will be gathered by chart review and patient interview. All data will be collected with the approval and signed consent of their medical lead and patient before the interview.

Participants must be able to read and write in Greek and to be capable of granting and willing to grant informed consent to participate in the study. Exclusion criteria include the inability to meet any one of the above criteria. Data collection will be ceased when category saturation has been achieved.

Recruitment

Volunteer recruitment will take place in STD clinic of "Andreas Syngros" hospital in Athens, where the majority of HIV testing, treatment and care for the local population takes place. Full permission will be gained from clinic staff to access the site. Posters and postcards advertising the study will be placed in the clinic waiting areas. Upon attending the clinic and completing their appointment, potential participants will be asked by an appropriate clinical representative if they would consider participating in the research study. If they agree, then the clinical representative will request a telephone number that can be passed onto a representative of the research team in order that an interview appointment can be made. In order to preserve any potential breaches of anonymity, careful arrangements for the return phone call will need to be agreed between the clinical representative and the potential participant. In addition, the researcher may be available to interview some participants on site (subject to work patterns, interview accommodation and administrative arrangements being suitable).

Ethical Issues

Local (Greek) procedures for gaining ethical approval will be followed. The research proposal, consent form, participant information sheet and risk assessment form will be submitted to the research ethics committees (or equivalent) at the participant Institutions, that is Technological Educational Institute of Athens, Technological Educational Institute of Crete and "Andreas Syggros" Hospital, of Athens.

Participants will be given and will be asked to read the participant information sheet, and will be asked to sign two copies of the consent form (for the participant and the researcher to keep), prior to the data collection phase. Anonymity will be emphasised and potential participants will be assured of confidentiality of their responses. To decode the transcription of the interviews, participants will be allocated a unique numerical identifier. Ethical considerations will be taken into account and voluntary participation to the study will be confirmed. Participants' rights to withdraw from the study at any time will be also stated.

Data Analysis

Data analysis will be carried out immediately after each interview according to the basic principles described by IPA [43]. All interviews will be tape-recorded and transcribed. Interpretative phenomenological analysis will take place according to Flowers: [42]

"a detailed, rigorous and systematic engagement with each participant's interview transcript, employing inductive and iterative processes of reading, exploring, coding, reflecting, interrogating, integrating and, eventually, thematising. The analyst aims to identify patterns of meaning (themes) in the participant's experiential claims and concerns...In IPA, the final analytic account aims to reflect the shared understandings of the experience in question..." (Flowers et al., page 1380) [42].

The researcher will keep self-reflective notes throughout the research project. These notes will be used after the interview, listening to tapes and reading copies, in order to gain a comprehensive understanding of the participant's experience. In the process of "open coding", categories and themes will be

identified to best capture the essential qualities of the interview. The researcher will make sense of connections between emerging themes, relating the identified themes into 'clusters' or concepts and producing tables that identify the main features and concerns reported by the participants.

The findings will be used to improve health professionals' understanding of the person's situation and to provide a high quality, tailor-made and cost-effective care according to people's needs. This will be achieved through dissemination of the findings (publication, conferences) and educational interventions such as seminars and workshops.

Discussion

An HIV positive diagnosis can cause an array of emotions and re-evaluation of priorities. Living with HIV can present unique challenges to relationships and the need to confront stigma and prejudice. Studies exploring adjustment to chronic conditions, such as HIV, have been numerous internationally but none have taken place in Greece [31-34]. The results of this study will document the experience of adapting to HIV by Greek individuals. HIV demographics are changing in Greece and this may impact the individuals' experience and perception of their diagnosis. It is also possible that the Greek culture and heritage may mean people with HIV in Greece undergo different adaptive experiences that those documented from other countries. It is hoped that this study will enhance our understanding of these issues. Moreover, in the field of HIV, knowledge and education is extremely important in order to provide quality of care, to understand the needs of people with HIV and to improve the quality of life [35]. As the incidence of HIV positive people has been increased recently in Greece [8], issues regarding adaptation to life after diagnosis and coping with uncertainty become of considerable importance.

The added value of this research Project lies on the following aspects:

- It will provide an opportunity to develop a solid research network among European and Greek Academic Institutions, regarding HIV and AIDS.
- It will enable health professionals to better understand the experience of adapting to HIV in Greece, and this will enable them to be better placed to help individuals' adapt.

Furthermore, the results of the study will be used to:

- Test, strengthen and further develop the Perrett and Biley Negotiating Uncertainty Theory (PB – NUT) [32], and see if such models could be applicable to Greece individuals.
- Extend other international work exploring the HIV experience and bring the first documented experience of Greek individuals.
- Disseminate new knowledge to other sites and countries which may have different cultural and social backgrounds.
- Provide opportunities for education for health professionals in Greece who are involved in HIV care. These opportunities will have the form of seminars and workshops that will be developed from the research findings. It is aimed these educational interventions to have an ongoing and systematic character and become useful tools for educating health care professionals in a regular basis.

Implications for Practice and/or Policy

This research Project will:

- Present a theoretical understanding of adaptation to HIV that can be used to assist nurses in caring for those with HIV, and possibly other long term conditions.
- Assist people with HIV by formulating and promoting strategies that enable positive adaptation.
- Support volunteer bodies, nurses and other health care professions to plan quality interventions that can maximise positive adaptation, wellness and quality of life.

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