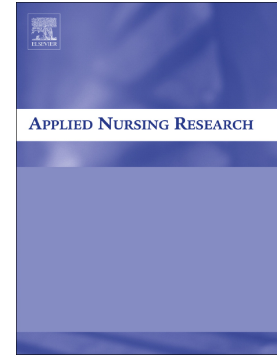


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“A journey towards acceptance”: The process of adapting to life with HIV in Greece. A qualitative study

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**Title: “A journey towards acceptance”: The Process of Adapting to Life with HIV in Greece. A Qualitative Study**

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**ABSTRACT**

**Aim:** To identify the experiences related to adaptation for people living with HIV in Greece and to explore different adaptation stages as well as their individual reactions.

**Background:** Receiving an HIV positive diagnosis leads to major changes in an individual's life and it can trigger an array of emotions including fear, despair and loss of control. As the profile of the disease has changed due to its transition into a chronic disease and extended life expectancy, adaptation to life and coping with uncertain events is of paramount importance.

**Method:** Interpretative phenomenological research design was used to guide data collection and analysis. A purposive sampling technique was used. Ethical procedures were taken into account and nine individuals who were diagnosed with HIV took part in the study using semi-structured interviews.

**Results:** Data analysis revealed the different stages of adaptation that the participants experienced after an HIV positive diagnosis. A superordinate theme identified as 'a journey towards acceptance' while five subthemes were formed, namely, 'Communicating the bad news, Conscious loneliness, Getting information, Receiving Support, and Moving on with hope'.

**Conclusion:** An HIV positive diagnosis can affect the very core of the individual as the essence of -self- is been targeted and in need of a reform. Education, empathy, family and social support can help the individual make small steps towards a greater journey, that of acceptance.

**Key words:** People living with HIV, Uncertainty, Adaptation, Lived experience, Qualitative study.

## INTRODUCTION

According to the World Health Organization (2017), 36.7 million people were reported as HIV positive at the end of 2016 whilst 1 million died from AIDS-related illnesses. The introduction of Highly Active Antiretroviral Therapy in 1996 changed the perception of HIV from a terminal condition to a chronic and more complex condition due to high drug costs, drug resistance, social stigma, medical complications, high prevalence of comorbidities and the complexity of prescribed medication (Paparello, Zeller, & While, 2014). Despite that, people living with HIV (PLWH) who can access treatment are able to experience a prolonged lifespan with a significantly positive quality of life (Colvin, 2011).

In Greece, a significant rise of HIV epidemic appeared after 2000. Within 10 years, an average of 525 cases of HIV-1 infection (HIV-2 is a less pathogenic type), the most widespread type worldwide while, were reported annually with 1/10th developing AIDS (Hellenic Centre for Disease Control and Prevention, 2011). In 2011 there was a 57% increase in HIV-1 cases in comparison to 2010 (European Centre for Disease Prevention and Control, 2012). The majority of the diagnosed individuals were men who acquired HIV by sexual intercourse. HIV diagnoses in injecting drug users (IDUs) were particularly prevalent during 2011 and 2012, mainly due to low levels of preventive services prior to the outbreak (European Centre for Disease Prevention and Control, 2012). In the period 2014-2018 the percentage of new diagnoses in persons who inject drugs (PWID) ranged from 12.35% in 2015 up to 16.85% in 2018 (National Public Health Organisation, 2018). The small increase of new PWID cases noted in 2018 could be attributed to activation programmes that carry out HIV testing in this specific population group (Hellenic Centre for Disease Control and Prevention, 2018). According to statistics released by the Hellenic National Public Health Organisation (EODY), a total of 473 new diagnoses of HIV were recorded from the start of 2019 to the end of October (National Public Health Organisation, 2019). Of these, 82.54% were in males and 22.41% were in females. The major cause of transmission of the newly HIV infected individuals was attributed to unprotected sexual intercourse, particularly amongst men who have sex with men (MSM). MSM attributed for the 41.86% of the reported HIV infections during 2019 followed by heterosexual infection (28.54%) and IDUs who accounted for 8.23% of cases (National Public Health Organisation, 2019).

As the profile of the disease has changed during the years, due to its transition into a chronic disease and extended life expectancy, (Richman et al., 2004; May et al., 2011; Mc Donald et al., 2015), more research is needed to reappraise the clinical disease management to chronic disease self-management and examine how individuals can cope and adapt to life after a positive diagnosis.

It is well reported in the literature that the multifactorial nature of the HIV infection and the slow progression to AIDS creates great uncertainty (Garcia et al., 2016; Ho, & Holloway, 2016; Kamen et al., 2016), as individuals are not aware of how or when various symptoms might develop, change or deteriorate. This emerging uncertainty severely affects PLWH and their carers at a social, professional, economic and personal level. HIV related research is particularly important in order to enable a deeper understanding on adaptation practices within the HIV field and improve the delivery of care and overall wellbeing for PLWH (Stavropoulou et al., 2011; Okpala et al., 2017).

Studies investigating the relationship between adaptation and chronic health conditions have been undertaken over the years at a global level (Yach et al., 2004; Nolte et al., 2008; Hay,

2010; Earnshaw et al., 2015). It is important to refer to the influential work of Mishel (1990), regarding the uncertainty theory in illness that illuminate how individuals recognise illness-related stimuli and how they structure meaning for those events. Uncertainty and adaptation to life for PLWH were examined in various studies since the HIV epidemic appeared, with an aim to highlight the effect that such a diagnosis and experience can have on a person's life. For example, redefining the meaning of HIV, setting new meanings for life that provide hope and optimism, gaining sense of control over life, stability, social and emotional support, were some of the adaptive tasks reported in early literature (Siegel, & Krauss, 1991; Schwarzer, Dunkel-Schetter, & Kemeny, 1994; Castro et al., 1998, Siegel, & Meyer, 1999). Moreover, information-seeking, development of decision-making skills, communication, positive behavioural changes and growth through changes in life since the HIV diagnosis, enable PLWH to make sense of their experiences and their condition (Crossley, 1999; Brashers et al., 2000; Brashers, Neidig, & Goldsmith, 2004; Dibb, & Kamalesh, 2011).

Furthermore, research on adaptation demonstrate that resilience, ageing and well-being was explored in adults who live with HIV as a factor that is associated with their physical and mental well-being; this relationship found to assist individuals with reducing uncertainty and improve their everyday activities (Emlet, Tozay, & Raveis, 2011; Chambers et al., 2014; McGowan et al., 2017; McGowan et al., 2018). The findings suggest that as people grow older, they develop resilience and a better coping strategy towards stress which derives from stigma, the illness and the fact that they age with HIV. The interventions used in order to improve resilience could be associated with improving mental and physical health, and a better adaptation towards the illness.

Uncertainty and adaptation to life with HIV were examined in the study of Perrett and Biley (2013), in the UK. From the results of the study, the formation of the Perrett and Biley Negotiating Uncertainty Theory (PB-NUT) was created. The different stages of transition and adaptation, following an HIV diagnosis were presented through (PB-NUT) (Perrett, & Biley, 2013). This theory suggests that adaptation to the uncertainties of being diagnosed with HIV is achieved by creating certainties whilst some uncertainties remain. Even though HIV can be asymptomatic, PLWH are considered to live with a long-term condition and in anticipation of developing various symptoms and side effects due to their treatment which will affect their daily life in an unknown way. But, feelings of hope and acceptance assist individuals to achieve positive outcomes. However, it was suggested that the results of Perrett and Biley study (2013), needed further development amongst cultures to strengthen the theory.

So far, no research efforts have been attempted in Greece regarding the experiences of adaptation for PLWH after an HIV positive diagnosis. The present study is the first attempt to examine HIV people's personal insights on the process of adapting to life with HIV in the Greek context and to generate knowledge based on the lived experiences of the people living with HIV. The findings of the present study can be used to further develop and strengthen the PB-NUT, by extending the knowledge on how PLWH in Greece adapt after HIV diagnosis. They may also inform the health care professionals about the adaptation processes that PLWH experience and develop thus, a conceptual framework in order to support effectively PLWH after HIV positive diagnosis.

In addition to that, adaptation processes and uncertainty in Greece may be affected by decreased support and stigma which are still prominent within the Greek social context (Kontomanolis et al., 2017; Daramilas, & Jaspal, 2016). Stigma, social isolation and discrimination experienced by people PLWH lead to significant physical, psychological, and

economical side effects. This became more prominent during the last years, as Greece confronted by a severe financial crisis that negatively affected the lives of PLWH as well as their HIV care (Daramilas, & Jaspal, 2016). Furthermore, findings from a study which explored the experiences of stigma and support as reported by participants in a network intervention to reduce HIV transmission in Greece, Ukraine and Illinois, revealed that both HIV-related stigma and social support in Greece may affect participants' willingness and ability to participate in network interventions and may lead to severely reduced opportunities, discrimination, and even rejection. (Williams et al., 2019). In this social context where stigma permeates and endanger the social structure, it becomes even more prominent to explore how PLWH adapt to life after an HIV positive diagnosis.

## METHODS

The aim of this study was to explore the lived experiences of adaptation for PLWH, after an HIV positive diagnosis. For this purpose, a qualitative methodological approach was used based on the principles of interpretative phenomenology (IP). IP is aligned with Heidegger's hermeneutic phenomenological approach, incorporating the ontological position of constructivism and an interpretive epistemology. Interpretative Phenomenological Analysis (IPA) focuses on the individual's personal insight and experience of a phenomenon or a life event, as well as the historical and cultural contexts of people in which they live (Creswell, 2014). IPA is often reported in the literature as the method which focuses on the exploration of the "significant experiences in people's lives" and is suitable when the researcher engages with complex issues (Smith, 2008; Smith et al., 2009, p.4).

As the issue in the present study was to explore the actual life cases and the lived experiences of people with HIV in Greece, a complex issue with social and psychological dimensions, the application of IPA was considered as the most appropriate research method.

Inclusion criteria in the study involved participants' age ( $\geq 18$  years old), who received a positive HIV diagnosis and did not have a diagnosis of AIDS. For the purposes of the study, participants had to be Greek nationals, in order to share common cultural values, and speak and understand the Greek language. A non-random purposive sampling strategy was used.

Participants were recruited by a clinical nurse in the Sexually Transmitted Diseases (STD) clinic of a large tertiary hospital in Athens, which is specialized in HIV and STD treatment. The access to the study site was approved by the head clinicians of the department. After completing their routine clinical follow-up visit potential participants were informed about the study and confirmed their willingness to participate in it. Following the appropriate communication arrangements, participants were interviewed once, in a private room provided from the STD clinic of the hospital, after their follow-up visit.

Semi-structured interviews were used for data collection. One interviewer was used for the interviews. The interviewer started the interview by asking one open ended question: "*How can you describe your experience after having the diagnosis?*" The participants were encouraged to freely discuss their experience and the open-ended interview questions were derived from the aims of the study. When appropriate, probes were made by the researcher in order to facilitate the interview process. The interviews lasted from 30 to 45 minutes. There were no problems encountered during the interviews process. Data collection was discontinued until saturation occurred, that is, when no new categories of explanation could

be identified (Sandelowski, 1995; Denscombe, 2014). Therefore, because of the nature of the research design and the consensus across views expressed, saturation was reached after 9 interviews.

A tape recorder was used during the data collection phase. Immediately after completion of each interview, verbatim transcription was carried out. The analysis of data was based on the principles of IPA and focused on the representation of the meaning of the participants' experiences and the identification of common themes and patterns as these reflected in the participants' own words (Moustakas, 1994; Smith et al., 2009). Self-reflective notes that were kept throughout the study, assisted the researcher to gain in-depth understanding of the participant's experience. A software for qualitative analysis was used (NVivo .10) in order to input and analyse the data. Data analysis using a software package is a dynamic process of moving from description to interpretation, enhancing the hermeneutic approach and ensuring the quality and validity of the interpretative process (John, & Johnson, 2000).

One of the challenges that the research team had to face was the challenge in translation from Greek into English, as the findings and data analysis of this research study would lead to an English publication. Therefore, the procedural steps of the data analysis were consisting of transcribing the data in Greek, reading and re-reading the transcripts to obtain a good understanding and feeling of the experience, and formulating meanings to clarify the hidden concepts. All data were imported over time into the software package in the Greek language and the analysis continued using the approach of description, use of language and use of concepts (Smith et al., 2009), which is a very common approach to IPA. Annotations in Greek were added in order to provide explanations for discovering deeper meanings. By using text search and word frequency queries the concepts and data were organized and the emergent themes were identified, compiled and validated within the original description. The process was repeated for each participant's data and fully integrated into the interpretative analysis. The translation from Greek into English occurred in the phase of the origination of themes, as firstly, they are considered as the most meaningful and important language parts in phenomenological research (Van Nes et al., 2010) and secondly, remaining in the Greek language as long as possible would minimize the limitations in analysis as well as the loss of the validity of the study. The researcher who was involved in the interview process operated as a translator in cooperation with another translator who was a native English speaker but who could also speak and understand Greek fluently. This collaboration in relation to translation was continued when the quotes of the participants needed to be translated in order to be included in the findings.

Trustworthiness of research findings was established by engaging with peer researchers to reduce research bias. During the data analysis phase, two peer researchers were invited to reach consensus on the emerging concepts and themes. In addition critical reflection was used to assess the research process and the techniques applied throughout the data collection and the data analysis phase.

Ethical approval was granted by the Scientific/Research Committee of the hospital (Ref.No.1667/28/06/12). A detailed research proposal including a consent form, a participant information sheet and a risk assessment were submitted to Committee before the commencement of the study. Issues of anonymity and confidentiality of responses were strictly preserved. Participants were fully informed about the nature and the aim of the research and signed the informed consent form before data collection phase. Voluntary participation was also stressed and participants were informed that they may withdraw from



the study at any time without any implication for their care. Access to the researcher was maintained for each participant throughout the stages of the research. A code name was allocated to each participant while transcribing and decoding the interview data for anonymity reasons.

## RESULTS

Nine Greek native individuals participated in the study, 8 male and 1 female. Their age ranged between 24 to 52 years old and they had knowingly been living with an HIV diagnosis for a minimum of three months. The demographic characteristics of the participants are listed in Table 1.

Code name	Age	HIV duration (years)	Employment	Marital status
Andrew	34	2	Private sector	Single
Chris	24	2	University student	Single
Denis	27	5	Private sector	Living with a partner
Gregory	38	0.3	Self-employed	Single
Hector	40	7	Private sector	Single
John	43	3.5	Public sector	Single
Nick	47	6	Private sector	Single
Peter	52	8	Retired	Single
Helen	33	2	Unemployed	Single

**Table 1: Participants' demographic characteristics**

All the participants were receiving antiretroviral medication for HIV. They all disclosed how they contracted the virus apart from the female one who was unaware of the way of transmission. Seven participants contacted the virus through sexual intercourse. In one participant the virus was transmitted through injecting drug use.

The data from this study reveals the different stages that participants underwent in order to adapt after an HIV diagnosis. A superordinate theme, namely '*a journey towards acceptance*' and five subthemes were identified (Table 2).

### ***Subtheme 1. Communicating the bad news***

It is important to understand that an HIV diagnosis can affect the psychological wellbeing as well as the overall quality of life (QOL) of the individuals. The way they were informed about the condition played a significant role towards understanding and helping those individuals process the overall situation.

Denis<sup>1</sup> says:

*The way the doctor informed me and my mother [about HIV], made me to accept it. I didn't lose [my mind].*

A similar situation is experienced by Hector who says:

<sup>1</sup> Code names were given to the participants for results presentation purposes.

*I was in a total shock. Then the psychologist [here] helped me understand that [HIV] is not a fatal disease, that I will keep living my life as it was, just a bit more careful. And I accepted it better.*

It seems that the way the participants informed, helped them to understand the situation better. On the contrary, Peter experiences a more disturbing scenario:

*At the beginning, as I said, it was very painful for me, I was saying that I would die tomorrow. [...] In the end I didn't die tomorrow and I am just fine (laughs). With medication, and since you don't die from HIV anymore....*

Finding out he is HIV positive led him to experience a lot of pain, however when he was informed about HIV the situation was improved dramatically that HIV is a chronic condition and not a fatal one anymore and he is trying to be “*just fine.*”

### ***Subtheme 2. Conscious loneliness***

We will begin the examination of a passage from Hector where we can identify a collective amount of information regarding his behaviour after receiving treatment—We are placing this example here since it demonstrates the overall behavioural pattern identified to the majority of the participants. Even though every single case is unique we believe that Hector represents strongly the feelings of each individual that has been identified to fit this category. Amongst the most prevalent feelings identified was that one of conscious loneliness:

*A few months after the commencement of my treatment, I entirely disappeared; that was my mistake; I wasn't even coming for my prescription, I had my own medication. During that time, I almost died from pneumonia, so I started the treatment I was receiving [for HIV], and thankfully my body was receptive [to the old HIV medication].*

*During Christmas I suffered from [a kind of] depression and I was trying to comprehend the idea of imminent death. I couldn't do anything. From the time you perceive it as such [that you are unable to do anything,] you are fine. [...]*

Loneliness became his emotional norm right after the HIV+ diagnosis. It is very important to understand that his two major actions a) distancing himself from everyone, and b) acquainting himself with the concept of dying were, in fact, proof that he wanted to live and they acted as his coping mechanisms in order to help himself, thus self-medicating.

It seems that his loneliness was developed unconsciously and led to thoughts about dying; after understanding his mistake he took action.

Similarly, Andrew says:

*I had to find an inner psychological equilibrium balance and then to talk to others and friends [...] You may have anxiety [regarding HIV] and not been aware about it, and out of the blue to be hit by the realisation [that you have HIV]. I tried to take it as calmly as I could. [...] I am a man of scale [...] you can't let the emotions run wild or else you will become crazy.*

We observe a similar reaction to loneliness as Hector but less severe. Andrew has accepted that he needs to find self-balance and to view his new state of life on his own way. Been able to recognise that anxiety [in relation to his condition] can be built without him realising it, and yet, been able to act prior of any emotional burst, suggest that loneliness, at this instance, is acting as a defensive, yet realisation tool towards transition.

A most depictive situation regarding the suggested stage of loneliness is portrayed by Peter: *I barricaded myself in the house, hugging the dog and for a week I didn't even set foot outside [of house]. I was feeling that I wanted to commit suicide.*

A similar pattern towards loneliness can be observed. His first reaction was to grieve. Grief is accompanied with loneliness. Both are time consuming and very personal moments. Peter wanted to grieve about his life, and as a result he chose to be lonely for a small period of time. At the same time he was aware that he wanted an attachment for support in order to alleviate the respondent's pain.

### **Subtheme 3. Getting information**

Some participants became aware that education or lack thereof affected the adaptive process. Furthermore, almost all participants suggested that information plays a pivotal role towards understanding HIV but most importantly preventing oneself from it.

Chris says:

*I had some knowledge [about the condition] since I was looking for information by myself, and through school via a sociologist [teacher] we received a very good briefing, so, it was a lot simpler, less shocking [to learn about the HIV+ diagnosis] [...],*

Having a prior knowledge for the condition as well as been aware and educated regarding the HIV, led Chris to a more accepting and less severe outcome about HIV+ diagnosis.

Peter seems to experience a similar situation with Chris after taking a different route:

*I didn't know anything. Nothing [at all]. I learned [about HIV+] from friends and from [an organisation about HIV] and life goes on. I am good now. Very good ... My panic didn't last long. Within a month I was [feeling] just fine with the [help from the] drugs and the help I was receiving from [the organisation about HIV]. I read a lot about [the HIV+]. The knowledge I received from the books [of the organisation] regarding HIV helped me a lot.*

Peter had no previous knowledge about the virus. This led to a difficult adjustment period. However, the participant stressed that a) the information he acquired from his friends regarding HIV and b) the education he received from the HIV organisation, played a key transitional role towards enabling Peter to feeling good.

Almost all of the participants suggested that there has to be education and information regarding HIV particularly from a young(er) age:

Andrew: *information should be available as well as individuals to help one another. [...] information that can reach everyone regardless.,*

Chris: *[...] it is fundamental a basic information to exist around prevention, but general information [regarding HIV] is important [...].,*

Denis: *information [regarding HIV] needs to be given to children at school. So that prevention taboo can be reduced, or prevention in general [to be promoted].*

John: *in the area of prevention something needs to happen, things are null in [sexual] protection. This may have caused an increase [to the HIV virus][...].,*

Nick: *something needs to happen in schools. I believe that children need to be informed since primary school. Another educational culture needs to be promoted. [...].,*

It is clear that they believe that information is a strong tool towards prevention and health safety. It is interesting that only a limited number of participants tried to educate themselves regarding the condition pre and post diagnosis.

#### ***Subtheme 4. Receiving Support***

Family, friends and society play a significant role towards transitioning to the new life. Participants shared their experience with ‘significant others’ something that made the HIV+ condition easier to process; Only one participant had support from the very beginning whilst all the others received it at some point during their journey.

Denis recognises that support is a vital factor regarding the situation. After a while he even stopped thinking about his condition since the support he was receiving led to such an outcome:

*My mother, my brother and two very good friends [are aware of my condition]. Thus, there is a very good circle that I can start discussing it but I don't [discuss it]. I have removed it from my mind but I do check it [the HIV condition] ....If something is bothering me, I will discuss it. But it's rare [something to be bothering me] to non-existent. [...] no one in my family were judgmental. They accepted it. Thankfully.*

From this passage we observe that immediate family members and the two closest friends were very accepting regarding Denis condition. The most important people around him [family and best friends] accepted his condition without any judgment something that led him to be grateful. Additionally, the way he expressed the word “*thankfully*”, it was as if, he was relieved from a heavy burden. For Denis adapting to the overall situation is an easier task than others, since he has the social support and the freedom to focus only on himself and not on social stigma.

Similarly, Andrew managed his HIV+ diagnosis way better since he had support. Having two other diagnosed friends and not feeling alone was impactful:

*Two friends of mine, the first one I know him a long time, they told me they both have HIV, and having lived with them [spending time with them] it came way better than just learning it previously [when I was alone, without having met those two friends].*

Here we observe Andrew feeling a relief that was able to have a support from his friends, and not dealing with this newly -found situation alone. Furthermore, not feeling any judgment regarding his condition was a strong motivational factor in order to help him move on without stopping his life:

*The fact that I wasn't the first one, a huge burden was lifted from within; that within my company [of friends] I wasn't alone. [...] and it is known to everyone, it's not so shocking. Those who have learned about it, my friends, it's as if it never happened. [...] my social circle was very positive. They weren't avoiding me or do ....[anything strange].. at least for me [not sure about other situations].[...] but [it should have been nice] to be more accepted from society.*

Consecutively, Gregory is very careful with his words, yet he managed to express all the meaning of the social support, and acceptance in a simple, but meaningful phrase:

*My family is beside me. [...] I think I will fight for this alone. I am not into seeking help from a psychologist and the community. With my family, with my job [...].*

Even though he rejects professional help or help that derives from community settings, he still takes as a norm that his family and somehow his job will help him.

#### ***Subtheme 5. Moving on with hope***

Hope can act as a coping mechanism towards stressful and in some cases irreversible situations. For Andrew and Chris hope is acting as a motivational factor that helps them move their life forward. As Andrew describes:

*[...] and I would like to think that at some point it [a cure] will be discovered.[...] I need to perceive it positively.*

This positivity deriving from the belief that a cure may be found, is part of the overall transitional mechanism he underwent post diagnosis. Examining Helen's passage we can observe the same motivational principles underlying hope:

*...you know what would help me a lot? If there was something I could take and made all of this disappear. The science has evolved. And I wish it will keep evolving. This is what I am waiting for since I am still young. And I see other people who are younger and HIV+. And it happens to me also. And it is making my life difficult.*

We can observe that she is hoping for a cure since she is young and things can change drastically with the evolution of medicine.

Subthemes	Description
Communicating the bad news	The way they were informed affected greatly their journey towards understanding, adapting and accepting the diagnosis.
Conscious loneliness	Wanted consciously to be left alone in order to, mourn, grief and gather their pieces.
Getting information	Been informed and educated about HIV as well as having previous knowledge helped into adapting better to the new life.
Receiving support	Support either from family, friends or society provided a safe cocoon in order to adapt and to straighten the per se behaviour.
Moving on with hope	Hope acted as a coping mechanism that helped individuals move on with their daily lives, primarily because of the advancements in medicine.

**Table 2: A journey towards acceptance**

## DISCUSSION

The aim of this study was to explore the lived experiences of adaptation for PLWH, after an HIV positive diagnosis. Throughout the study the stages that helped PLWH to adapt and cope with the HIV diagnosis were identified. Even though every individual is unique and some cases were more 'accepting' than others, all of them presented some common psychological and emotional behaviours that helped them adapt. The stages of adaptation presented and described can be categorised into five different subthemes: 1) communicating the bad news 2) conscious loneliness, 3) getting information, 4) receiving support, and 5) moving on with hope.

Findings reveal that the participants were initially shocked and had trouble adjusting in their new life. However, after receiving enough information about the disease they managed to cope. It is imperative to understand these stages adopting a biopsychosocial approach in order to comprehend to a greater extent the role of each stage, in relation to emotional stability.

The way a person is informed about being HIV positive can have a significant effect per se which can affect greatly the adaptation process. Been diagnosed as HIV positive can lead to poor medical choices and adherence, and experiences of psychological deterioration or distress (Anderson et al., 2010). Literature suggest that initial diagnosis is often accompanied by suicidal thoughts, distress and poor behavioural choices (Hult et al., 2009; Lopez et al., 2018). However, a significant role is played by the health professional delivering the diagnosis. Indeed, Wayal et al. (2011), argue that delivering an HIV diagnosis, or *communicating the bad news*, is one of the most difficult but important part of HIV diagnosis and treatment. The current research is consistent with the above findings since participants reported higher levels of acceptance and understanding if the way they learned about their condition was in a manner which included, empathy and proper information from the health care professionals (*Subtheme 1. Communicating the bad news*).

Participants experienced a multitude of feelings, different behaviours and psychological states, the first of which was *conscious loneliness* (*Subtheme 2. Conscious loneliness*). Loneliness and social isolation are linked with poorer health choices and susceptibility to psychological stressors (Gordijn, & Boven, 2009; Fekete, 2018). Indeed, the majority of the participants are experiencing both social isolation and emotional deterioration in the form of depression.

Specific stereotypes have been developed in the western societies regarding people with HIV which in turn affects their social interaction, inter-relationships and overall dealings with society (Wagner et al., 2016). Hubach et al. (2015), suggests one of the most important stereotypes leading to emotional withdrawal within HIV positive MSM, is the fact that infecting another person will lead them to lose more in terms of psychological wellbeing and stability. Isolation is well documented within the mental health literature, and a lot of chronic illnesses often are accompanied by it; non-malignant chronic pain (Nilsen, & Anderssen, 2014), multiple sclerosis (Wilkinson, & Nair, 2013), ankylosing spondylitis, fibromyalgia, osteoarthritis, rheumatoid arthritis (Kool, & Geenen, 2012) are but a few chronic pain diseases with well documented relation to isolation.

The difficulties associated with the concepts of acceptance, understanding, depression and overall QOL, were significantly affected by the amount of general information and specific education the individuals had around the area of HIV. Kasatpibal et al. (2014), argue that just by delivering educational interventions, thus enhancing the knowledge of the individuals regarding infections and prevention, is an effecting approach towards improving behaviour that reduces HIV risk MSM. A systematic review conducted by Millard et al. (2013), suggested that self-management education programs had a significant positive result on psychosocial behaviour and QOL but only in short term improvements. Furthermore, a 10%-50% of the PLWH are reported to experience depression which in turn affects the physical, cognitive, social and overall QOL (Millard et al., 2013). A Cochrane review examining self-management interventions for people suffering from a variety of chronic conditions, found that these interventions improve the overall health status, cognitive function and symptoms, and increase the image of self-worth per se (Foster et al., 2007). These findings are consistent

with the current study's findings which suggested that self-education as well as any form of information around the area of HIV helped into better understanding the current situation faced, and that the initial diagnosis triggered either depressive symptomatology or depression (*Subtheme 3. Getting Information*).

Living with HIV can be a daunting task alone but given the nature of the disease and the perceived stigma PLWH receive regarding their condition can prove to be a very challenging situation. Apart from HIV hindering the health professional-patient relationships, stigma is also affecting the QOL of the individuals. Additionally, apart from the stigma PLWH receive from their disease, they are also stigmatised for their mode of life and sex practises or for being a drug user (Wagner et al., 2016). Zeligman et al. (2016), suggest that social support can be greatly affected by stigma which results in inhibiting social support effectiveness and skills.

Social support can have various forms from either family, friends, groups or therapy. Social support is linked with medical adherence, psychological support as well as playing a significantly positive factor affecting mental health, not only in HIV but also in other chronic conditions (Casale et al., 2015; Kim et al., 2015). Indeed, our results suggest that social support helped PLWH with their transition coping. Furthermore, stigma was either avoided or with the help of social support, it wasn't influential (*Subtheme 4. Receiving support*). These findings are in line with those of other studies that value issues of social and family support as they may positively affect the PLWH at an emotional level. They further demonstrate that social support help them to adjust in normal life and cope with dignity (Castro et al., 1998; Brashers, Neidig, & Goldsmith, 2004).

The last theme observed is that one of hope (*Subtheme 5. Moving on with hope*). Hope is a strong factor affecting the health outcome and overall QOL of an individual. Scioli et al. (2012), argued that hope was correlated to health as well as affecting the immunological status (CD4). Furthermore, they managed to observe a relationship in the level of hope and in consistency over time. Research in relation to hope and HIV have showed that hope is an effective resource in order for an individual to reach a long term survival by maintaining proper mental wellbeing (Ncama et al., 2008; Yadav, 2010). In our case, hope motivated the individuals to move forward and in some cases provided relief from the HIV situation.

A dynamic approach is unveiling regarding the stages of adaptation the individuals are developing in order to cope and process the post HIV+ diagnosis. For the most part the subthemes are requiring for the individual a form of self-oriented approach and focus rather than an external assistance. The superordinate theme that the five themes fall under is named after '*A journey towards acceptance*' for this particular reason. The "journey towards acceptance" is a metaphorical way of introducing the stages an individual is undergoing alongside the struggles and challenges they may face until they are able to accept or adapt into the new reality. Even though adaptation is a process involving a variety of aspects, acceptance must come from within.

A sequence of transitional activities for PLWH were identified by Perrett and Biley (2013), such as, considering the risks, strengthening through hope, assuming direction, seizing opportunities, broadening vision, planning for the future and moving from the expectation of living with a terminal illness towards the acceptance that life can remain as before the diagnosis.

Although PB-NUT is found to be an effective tool regarding the transitional process, it can be partially applied to our research, as our study identified some different patterns regarding the stages of adaptation underlying an HIV diagnosis. However, acceptance and hope act in both cases as two approaches that can assist an individual with closure and moving on with their lives (Table 3).

<b>PB-NUT</b>	<b>Present Research</b>
Considering the Risk: Moving from denial to acceptance	Communicating the bad news
Strengthening through hope: moving between vulnerability and empowerment	Conscious loneliness
Assuming Direction: moving from being controlled from HIV to controlling HIV	Getting information
Seizing opportunities: Moving from destroying life to saving life	Receiving Support
Broadening Vision: moving from self-focus to self-comparison	Moving on with Hope
Planning for the Future: moving from escaping to distracting	
Existing as-was: moving from everything changing towards everything remaining the same	

**Table 3. PB-NUT vs Present Research: Patterns regarding the stages of adaptation after a positive HIV diagnosis.**

The results are promising in terms of applicability within the Greek community. It is important to note that these findings must be interpreted in the light of the cultural particularities and characteristics of the Greek social context as these described in the introduction section. Follow up studies can focus on educational needs and interventions for both the PLWH and the health care personnel, regarding issues of adaptation and coping with the disease. Even though this study included only Greek participants, the findings may have transferability to PLWH in other countries.

Two main limitations apply to this study that needs to be addressed. First of all, the sample group, even though normal for a qualitative study of this kind, it examined only one female individuals. However, there was no causality between the gender and the level of acceptance. Likewise, the age gap between the participants needs to be addressed. Ages ranged from 24 to 54 years old. Even though that can be perceived as a limitation due to differences that may apply in society (e.g. medical advancements), the study examines the stages of adaptation towards the disease. In addition, no differences seemed to exist on adaptation practices between younger and older participants. Although the era may differ, the emotions remain the same. Furthermore, it is important to document the fact every diagnosis is different in terms of how it is perceived by the individual.

Consequently, both issues should be addressed with cautiousness as the experience of HIV can be viewed and dealt with differently across different demographics. Additional research is recommended, as the study site and the time frame of this research study did not allow further exploration of the above mentioned issues.



## CONCLUSIONS

It is of significant importance to identify the experiences that are related to adaptation for people diagnosed with HIV. An HIV positive diagnosis can affect the very core of the individual. Biologically and psychologically the very being, the essence of -self- is been targeted and in need of a reform. Indeed, education, empathy, family, and social support can help the individual make small steps towards a greater journey, that of acceptance. Focusing on the parts that connect us and not the ones that makes us apart we can tackle problems such as social alienation and loneliness deriving from fear of the unknown. In particular, receiving an HIV diagnosis will inevitably lead an individual to undergo some stages that has an effect on the per se adaption towards life as a whole. Understanding these stages can help health care professionals in order to create and deliver targeted interventions that can help improve significantly the quality of life of the PLWH.

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### Highlights

- Experiences of people diagnosed with HIV provide in depth knowledge on the adaptation process.
- Positive communication, information and education affect adapting and accepting the diagnosis.
- Social and family support enhance adaptation patterns and coping behaviour.
- Hope as a coping mechanism motivate individuals to move forward and preserve well being.

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