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Analisi critica degli strumenti di valutazione della qualità della vita nei pazienti affetti da HIV

Critical analysis of the quality of life assessment in HIV patients

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ABSTRACT

The purpose of this work is to analyze to examine the quality of life in people living with HIV. Especially in this period characterized by a universal pandemic, the importance to analyzed Quality of life is highlight by the fact that, understanding how a person with a specific disease can face the problems and the outcomes connected to this disease modifying and affecting its everyday life allow us to create some specific services and prevention programs. To do that we need to understand the meaning of the construct, its dimension and the instruments it could be used to assess this undefined concept.

The first chapter will discuss the evolution of the concept of quality of life (QoL), beginning from an historical examination of the construct, continuing with a discussion of theoretical models and the seven basic qualities of the QoL, to conclude with an analysis of the specific measurement scales and methodological aspects. The content of this first chapter will enable the reader to apply the examined construct by studying the quality of life of people living with human immunodeficiency virus (HIV).

The second chapter will focus on applying the concept of quality of life to HIV patients. It will first describe the Human Immunodeficiency Virus (HIV) in detail, along with how it can

impact a person's quality of life. It will then proceed with an analysis of the specific dimensions of QoL affected by the virus, to conclude with a description of the instruments designated to assess QoL in HIV affected people.

To conclude, in the last chapter we are going to describe some measures of Quality of life of people living with HIV, analyzing what variables an instrument with this purpose needs to investigate and what are the properties it needs to possess. We'll examine both generic and specific HIV instruments with different psychometric properties in order to understand the best way to select the perfect tools based on our necessity. Therefore, In the appendix some HIV quality of life instrument manuals are reported.

CHAPTER 1: QUALITY OF LIFE

1.1 Concept origin and evolution

Some references of the QoL can be found in early Greek writings, specifically in the Aristotelian theory of wellbeing.

Aristotle strived to understand how to pursue the highest human good, referred to as Eudaimonia. This concept, etymologically composed by two Greek words: *eu* “good” and *daimonian* “spirit”, comes from Aristotle’s *Nichomacean Ethics*. For the philosopher, the eudaimonia¹ is the pursuit of a virtuous life, following one’s dispositions and essences. Humans need to act according to their true nature, their Daimon, in order to achieve real happiness.

Specific mention of quality of life in relation to patient health was documented much later and is connected to the definition of health that was proposed by the World Health Organization (OMS) in 1948. Health was considered not only as the absence of disease but as a “state of physical, social and mental well-being” (World Health Organisation, 1948). This concept gained popularity throughout the 1960’s in association with the construct of welfare, interpreted not only through economic growth but also through policies regarding social well-being.

¹ The term eudaimonia is usually translated as happiness.

New health care and social welfare programs were set as goals of a new “Great Society” but this vision of social achievement was accompanied by concerns regarding a social crisis. With economic improvements came an increase in crime, drug use, fragmented families, and social and public alienation. The social interest for welfare content led to an intense political debate. The social indicators movement (Jankowska, 2015; Noll, 2004), underlined the importance of analyzing not only economical aspects, but also social indicators as a true depiction of people’s living conditions. This movement assumes that it is important to monitor changes over time in a broad range of social phenomena including indicators of quality of life beyond traditional economic factors. The spread of this movement was related to the political climate between the 1960’s and 70’s. In this period of development, the concept of quality of life emerges as an alternative to the questionable concept of material prosperity becoming the new goal of societal development. As a result, a new area of research arose in order to establish the main social indicator that allowed people to understand the concept of personal well-being. Starting from the 1980’s, a research field named “Quality of American Life Studies” began to study the subjective point of view. Before that, researchers had only taken into consideration the objective and quantitative indicators regarding living conditions. Starting from the area of the social

sciences, the concept of quality of life became an interdisciplinary construct and in the 1980's it was at the center of a scientific debate. From a health science point of view, quality of life was used as an outcome to evaluate medical treatments. A distinction exists between the medical-based approach and the health-based approach. The first is oriented around objective indicators of the individual, functioning and focus on disease, without taking into consideration social indicators. The latter is more health related and takes into consideration both objective and subjective indicators of an individual's ability to function. This approach assumes a strong relationship between life measurement, social policy and change in goals.

There was a growing appreciation in how patients felt and how satisfied they were with their treatment, in addition to the traditional focus on disease outcomes. The focus had shifted from the idea of well-being defined on the basis of normative models² to a new approach connected to the singularity of the subject and the context. This new bio-psycho-social model introduced a new concept of health composed by values, as well as physical, psychological and social elements (Laranjeira, 2008).

² biomedical models.

From a philosophical standpoint, three theories regarding well-being were examined: the preference satisfaction theory, the hedonistic theory and the objective accounts theory. The first theory underlines the importance of the ability to choose, stating that something is good for a person only if the person themselves chooses it. Two movements deriving from this approach were created: the current preference satisfaction theory in which a person's well-being is promoted by the satisfaction of preference versus the informed preference satisfaction theory that states that what is good for a person is the satisfaction of the hypothetical preferences formed by more ideal conditions, or rather, satisfactorily informed and reasonable choices. The hedonistic theory defends that well-being consists of a conscious mental state that accompanies certain experiences towards which a person has a favorable attitude. The last theory states that something is good for a person in virtue of its characteristics, regardless of the individual's dispositions and attitude toward said thing (Bognar, 2005).

In 2001 Cummins, postulates that these two different indicators are essentially independent. He assumes that human beings have developed a homeostatic control in order to maintain a constant level of subjective QoL; only extreme conditions and a very low level of objective well-being can overcome this homeostatic control and affect an individual's

subjective well-being. In conclusion, in order to carry out a thorough analysis of QoL, it is necessary to combine objective and subjective indicators (Buntinx & Schallock, 2010; Cummins, 2000, 2001; Van Hecke et al., 2018).

Diener and Suh in an article of 1997, also reported the importance of both objective and subjective indicators

“A thorough understanding of subjective well-being requires a knowledge of how objective conditions influence a person’s evaluation of their life. Similarly, a complete understanding of objective indicators and how to select them requires that people’s values are understood and that there is a knowledge on how objective indicators influence people’s experience of well-being.”(Diener & Suh, 1997).

Specific mention of quality of life in relation to patient health was documented in 1948 and is connected to the definition of health that was proposed by the World Health Organization (OMS). Health was considered not only as the absence of disease but as a “state of physical, social and mental well-being” (WHO, 1948). This concept gained popularity throughout the 1960’s in association with the construct of welfare. New health care and social welfare programs were set as goals of a new “Great Society” but this vision of social achievement was accompanied by concerns regarding a social crisis (Bognar, 2005). With economic improvements came an

increase in crime, drug use, fragmented families, and social and public alienation.

The welfare was interpreted not only through economic growth but also through policies regarding social well-being. The social interest for welfare content led to an intense political debate. The social indicators movement assumes that it is important to monitor changes over time in a broad range of social phenomena including indicators of quality of life beyond traditional economic factors (Jankowska, 2015; Lançon et al., 2004; Noll, 2004). The spread of this movement was related to the political climate between the 1960's and 70's. In this period of development, the concept of quality of life emerges as an alternative to the questionable concept of material prosperity becoming the new goal of societal development (Jankowska, 2015; Noll, 2004) The social indicators movement, underlined the importance of analyzing not only economical aspects, but also social indicators as a true depiction of people's living conditions. As a result, a new area of research arose in order to establish the main social indicators that allowed people to understand the concept of personal well-being. Starting from the area of the social sciences, the concept of quality of life became an interdisciplinary construct and in the 1980's it was at the center of a scientific debate. From a health science point of view, quality of life was used as an outcome to evaluate medical

treatments. There was a growing appreciation in how patients felt and how satisfied they were with their treatment, in addition to the traditional focus on disease outcomes. The focus had shifted from the idea of well-being defined on the basis of normative models, the biomedical models, to a new approach connected to the singularity of the subject and the context. This new bio-psycho-social model introduced a new concept of health composed by values, as well as physical, psychological and social elements.

From a philosophical standpoint, three theories regarding well-being were examined: the preference satisfaction theory, the hedonistic theory and the objective accounts theory (Bognar, 2005). The first theory underlines the importance of the ability to choose, stating that something is good for a person only if the person themselves chooses it. The hedonistic theory defends that well-being consists of a conscious mental state that accompanies certain experiences towards which a person has a favorable attitude. The last theory states that something is good for a person in virtue of its characteristics, regardless of the individual's dispositions and attitude toward said thing (Bognar, 2005).

In the psychological field, the research underlines the presence of two dichotomies in the epistemological and

theoretical models that lead to some consequences in the methodological methods.

The first dichotomy regards the unidimensional and multidimensional approaches. The unidimensional approach examines QoL from one domain, while on the contrary the multidimensional approach takes into consideration a list of domains that complete each other. There was an evolution towards multidimensional approaches due to the fact that unidimensional domains, when individually analyzed, are not able to represent people's living conditions. A number of revisions were conducted on QoL domains in order to establish a definitive list that will be analyzed later in this work.

The second dichotomy regards objective and subjective indicators of quality of life. A 1990's study of this construct was characterized by a clear division between an objective vision and subjective vision. Some researchers focused on subjective aspects like work, health or earnings, which is the case of medical and sociological studies obtained by measurable variables. On the other hand, within the psychological field, a subjective approach to the QoL was preferred. According to this approach, the variable that needs to be analyzed is the subject's perception of their own life and well-being. Objective and subjective indicators were regarded as two sides of the same coin. In fact, objective elements can partially affect a person's

satisfaction with their own life because everyone reacts differently to specific circumstances according to personal beliefs, values and experiences. This view is based on the postmodernist movement which assumes that there isn't an objective reality, but only a subjective experience of the world (Laranjeira, 2008).

Cummins postulates that these two different indicators are essentially independent. He assumes that human beings have developed a homeostatic control in order to maintain a constant level of subjective QoL; only extreme conditions and a very low level of objective well-being can overcome this homeostatic control and affect an individual's subjective well-being. In conclusion, in order to carry out a thorough analysis of QoL, it is necessary to combine both objective and subjective indicators (Cummins, 2001). The importance to consider both objective and subjective indicators is underlined also by Diener and Suh in their 1997 work:

“A thorough understanding of subjective well-being requires a knowledge of how objective conditions influence a person's evaluation of their life. Similarly, a complete understanding of objective indicators and how to select them requires that people's values are understood and that there is a knowledge on how objective indicators influence people's experience of well-being.” (Diener & Suh, 1997).

The considerations that were made up until this point in history demonstrate the multidimensional nature of QoL, which in turn reflect a holistic vision of the human being. Following this consideration, much research was done in order to investigate the domains that make up the construct instead of the definition of concept. Different models propose disparate domain theories that will be analyzed in the following section.

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1.2 Models and domains

The first is the World Health Organization's model which defines QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"³. This model considers six dimensions of QoL: physical condition, psychological condition, environment, social relationships, level of independence and spiritual, personal and religious beliefs

In continuation, the Felce and Perry theory defines QoL as an overall concept composed by objective indicators and their subjective evaluation weighted by a personal set of values; together with cultural, geographical and historical influences. This theory takes into consideration five domains of QoL: physical well-being, emotional well-being, material well-being, social well-being and productivity (Agrati, 2019; Felce, 1997; Felce & Perry, 1995).

The third model is Cummins's theory of subjective well-being homeostasis. As previously stated, the subjective perception of well-being is highly stable and only extremely unpleasant events are able to affect it. The subjective wellbeing is managed by a system of psychological devices, which aim is

³ The WhOQoL group, The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the world health organization, 1995, p. 1405

to protect the Homeostatically protected mood. When a negative events overwhelms the homeostasis control we experience the dominance of negative affect, experiencing depression when this condition is chronic (Cummins, 2010, 2018; Cummins et al., 2014) The relationship between subjective well-being and objective social well-being is non-linear and depends on the concern that a person places on their resources and the influence of other domains. According to this theory, quality of life is composed of health, emotional well-being, material well-being, social position, productivity and security(Cummins, 2000, 2001, 2005).

Another definition of QoL was formed by Renwick and Brown, who defined QoL as the level of satisfaction that allows people to follow what they find important for their existence (Raphael, Brown, et al., 1996; Raphael, Renwick, et al., 1996). The above authors do not provide a theoretical foundation for this model, but instead choose a constructivist and practice-oriented approach considering QoL as a social construct. This model distinguishes three domains and three subdomains for each. The first domain is *Being* and is divided into physical being (body and health), psychological being (feelings and thoughts) and spiritual being (values and beliefs). The second is *Belonging*, which includes people and places in the person's life: composed of physical belonging (the places where the

person spends their time), social belonging (the people in the person's life) and community belonging (the resources in their environment). The last dimension is *Becoming* and concerns the daily activities of the person. It is made up of practical becoming, leisure becoming and growth becoming (actions taken to cope and develop as an individual) (Rebeiro Gruhl et al., 2018).

The last model that will be analyzed is Schalock and Verdugo's theory (Schalock et al., 2016; Verdugo et al., 2005, 2012) that has recently been shown to have the best model fit in terms of the factors included in its composition; according to Gomez, Verdugo and Arias research of 2011, the eight domains model of Schalock and Verdugo seems to be the most representative model of quality of life (Gómez et al., 2011).

This multidimensional model focuses on the individual as a whole and is composed of eight domains: physical well-being, emotional well-being, material well-being, interpersonal relations, social inclusion, personal development, self-determination and rights. These domains are the fundamental elements of QoL and they are studied on the basis of three levels: micro-, meso- and macro levels. Micro Level refers to personal growth and development, mesolevel concerns the contexts in which the subject is included, the macrolevel has to

do with social policies (Schalock et al., 2005; Van Hecke et al., 2018).

The authors also reported some examples of indicators that concretely define each domain, identified by a meta-analysis and the standards of selection are: validity (to measure what is supposed to be measured), reliability (to be accepted by different evaluators), sensitivity (to identify a specific trait), sustainability and specificity (to reflect the situation); as well as the need to reflect the culture of belonging. Emotional well-being is defined by self-esteem, fulfillment and freedom from stress, which can affect physical well-being, interpersonal relationships, self-determination, work and personal development. Material well-being is composed of employment, accommodation and financial means, which in turn influence personal development, self-determination, emotional well-being, social inclusion and self-esteem. Physical well-being is divided into health, free time and daily activity. It can have an impact on emotional well-being, interpersonal relationships, personal development, employment self-esteem and autonomy. The concept of interpersonal relationships is defined by interaction, relationships and support and can have some influence on self-esteem, social inclusion, personal development and emotional well-being. Personal development is composed of concern for education, competence and performance which can affect self-

determination, material well-being, emotional well-being and social inclusion. Self-determination is formed by personal goals and values, choices and independence and is linked to emotional well-being, material well-being, social inclusion and interpersonal relationships (Lachapelle et al., 2005; Wehmeyer, 2020; Wehmeyer & Schalock, 2017). Self-determined people perceive a connection between their actions and the outcomes they want to experience and develop a sense of personal empowerment. Social inclusion is divided into social support, social integration and contribution to the community and is connected to interpersonal relationships, emotional well-being, material well-being and self-determination. Social integration refers to the feeling of being a part of society and having something in common with others who take part in this society. Social contribution is the evaluation of the person as a vital member of society.

The last domain concerns people's human and legal rights and is linked to all of the previous domains. These indicators need to be applied to the context, defining situations and behaviors that a person can carry out in a specific context. To conclude, Schalock and Verdugo conceptualized specific factors within which the domains must be analyzed (Schalock et al., 2008; Verdugo et al., 2005). These factors are independence, well-being and participation. As a result of this examination,

some resemblance in the classifications of the domains can be perceived, despite the disagreement on the definition of quality of life.

1.3 Basics of Life

After studying the evolution of Quality Of Life and the different models that have been proposed, the basics of QoL can be discussed (Cummins, 2005; Verdugo et al., 2005). The first is multidimensionality: the concept of QoL cannot be described simply by measuring the material aspects of living; a thorough analysis of relationships, context, physical health as well as the psychological aspects of a person must be taken into account. The second basic quality is the holistic vision that considers which of the dimensions of QoL are interconnected. In other words, the aspects of a person's life that influence each other. The third basic quality is the union of objective and subjective elements. As stated previously, the subjective perception of life needs to be integrated by taking into consideration the objective indicators of quality of life such as employment, earnings and health.

The fourth basic quality is the feasibility and the scientific validity of QoL. The concept needs to be relevant to the subject, and as a consequence, the dimensions must also portray the living aspect that all human beings have in common. In fifth place comes inter and intrapersonal variability. The dimensions of QoL can have a different value on the basis of the

cultural model, along with personal characteristics, beliefs and habits. Through the concept of QoL, one can study how a person is able to pursue their hopes, needs and expectations along with their competences and weaknesses, while at the same time taking into consideration their social context, be it integrative, limiting or supportive (Keyes, 1998). The sixth basic quality is the life-span perspective of the concept. This dimension helps the individual to create a personalized life project, in fact, the value ascribed to the different dimensions can change during one's lifetime. The last basic quality concerns empowerment (Mazzoni et al., 2014; Moattari et al., 2012); through the application of the concept of QoL a person can be helped to express themselves by recognizing their values, needs and choices and by trying to achieve a better personal development and better living conditions (Agrati, 2019).

1.4 Assessment and methodological aspects

Before starting with the analysis of the QoL assessment instruments, further explanation is needed. The QoL construct and the concept of Health-Related Quality of Life (HRQoL) overlap with each other and this may lead to confusion (Bertelli et al., 2016; Busija et al., 2011; Karimi & Brazier, 2016). This term was introduced into the literature on health status measurement in the 1970's, motivated by the desire to measure the outputs of the health care system. In the respective literature, there is some confusion on the distinction between these two concepts that leads to an unclear classification of the instruments designated to measure said concepts. Some research has defined HRQoL as the measurement of a person's perceived physical, psychological and social well-being; a definition that doesn't distance itself very much from the definition of health (Heggenhougen & Quah, 2008). Another definition comes close to the concept of QoL because it refers to the domains of quality of life affected by health; but what are the aspects of QoL not affected by health? The last definition of HRQoL, which will be taken into consideration throughout this entire work, defines the concept as: the effects of a disease on everyday life, as perceived by the subject (Ebrahim, 1995). Following this point of view, HRQoL can be seen as a domain of QoL that explains only a small part of the outcome. As a result, the instruments

employed to study HRQoL measure the self-perceived health status.

SF-36: The 36 Short Form is the most commonly used HRQoL instrument and it was developed by Ware and Sherbourne. It consists of six domains: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain, and general health perception. The scores are divided in two sections: Physical Component Summary score (PCS) and the Mental Component Summary score (MCS).

The internal consistency is reported to be acceptable as the construct validity and the test-retest reliability was reported to be excellent (Brazier et al., 1992; Holmes & Ruocco, 2008; Tobe et al., 1970); regarding the validity it show a good convergent validity a god face validity and an adequate content validity (Busija et al., 2011). An Italian version was validated in appearing to be a valid and reliable multidimensional questionnaire as reported in Mosconi and Apolone survey (Apolone & Mosconi, 1998).

HUI: 1 Health utility index (HUI) is composed of 15 items divided in 7 domains: vision, ambulation, dexterity, emotion, cognition, hearing, speech and pain. It is available in

two versions HUI-2 and HUI-3. Regarding the emotion dimension HUI-2 focus on anxiety and distress rather than the comparison between happiness and depression like HUI-3, then, the cognition in HUI-2 focus on learning while in HUI-3 the main focus is on problem solving abilities. Regarding pain dimension HUI-3 is concerned with frequency and control of pain while HUI-2 primarily examine the severity of pain. In addition, the sensation dimension of HUI-2 was divided in vision, hearing and speech in HUI-3. It is very responsive to changes in health status and could be self-complete or interweaver-administered, it is available in different languages included Italian. It shows a good concurrent validity and a good responsiveness to change in health especially regarding HIV condition (Busija et al., 2011; Nosyk et al., 2009).

SIP: The Sickness Impact Profile is composed of 136 items describing activities of daily living and is divided into twelve categories: sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, and communication. Both the ISP and the SIP Revised present a good internal consistency an excellent test-retest reliability and a good face and convergent validity (Busija et al., 2011; Kenna et al., 2005; Kiluk et al., 2013). We

can also find an Italian version of this test that maintain the same psychometric properties (Marchionni et al., 1997)

EQ-5D: The EuroQoL 5-Dimensions is a preference-based HRQoL instrument composed of one question for each of the five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. This questionnaire also includes a Visual Analog Scale (VAS) that allows respondents to report their perceived health status ranging from 0 to 100.

The instrument shows an excellent correlation between its two dimensions and each dimension correlates positively with the similar dimensions measured by the MOS providing evidence of construct and convergent validity (Feng et al., 2021; Wu et al., 2002). At the same times it shows a low responsiveness to changes in health status due to adverse events, probably because there are only three levels for each item, with a greater number of possible responses it could be more sensitive to changes; another reason could be that factors other than health influence patient utility. Again, adaptation to illness might cause a lack of responsiveness especially in chronic conditions (Wu et al., 2002).

An Italian version of this instrument was validated in 2006 and following the Savoia et al. Study it showed a good

internal consistency, a good reliability and and excellent convergent and discriminant validity(Savoia et al., 2006).

Another important question concerns the choice between generic or specific quality of life instruments. The instruments used to assess a specific age group, disease or target group analyze the domains that are important to a specific group, while on the other hand, generic instruments examine all the domains considered to be valuable in order to obtain a complete analysis of QoL. Furthermore, the application of generic instruments makes it possible to compare the results obtained by people belonging to different control groups. A possible solution could be the employment of generic instruments with modules for different target groups or surveys with more inclusive questions. Another matter that must be addressed is the need for an instrument that integrates qualitative and quantitative aspects, of measurement, along with objective and subjective measures. The value one attaches to a domain and the goals of the assessments should be taken into consideration when developing or choosing QoL instruments (Van Hecke et al., 2018). Qualitative measurements focus on personal experiences and meanings making use of focus groups, interviews and observation methods. Quantitative measurements evaluate numeric variables using structured protocols and questionnaires. Some aspects of QoL can be objectively measured through

direct observation while other aspects require subjective evaluations. In 2012 Townsend-White et al argue that every domain needs to be assessed by separate measurable subjective and objective indicators (Townsend-White et al., 2012). Another debate concerns the use of self-made and proxy reports, seeing as the results of the self-made reports could be biased by presenting socially desirable answers, along with the fact that subjects with intellectual disabilities and mental or communication problems may find some difficulty in expressing themselves. Given the importance of the subjective component of QoL, the assessment should be primarily based on self-made reports, considering proxy reports as additional information. Now that the methodological aspects have been explained, the next sections will analyze some particular QoL instruments.

The first instrument to be presented is the World Health Organization Quality of Life assessment (**WHOQoL**); a patient reported questionnaire developed by the WHO in 1995 (Skevington et al., 2004). It is composed of 100 questions regarding the patient's subjective perceptions of health and well-being over a two-week period. The questions cover six domains plus one question regarding general QoL and health: 1) Overall Quality of Life and general health, 2) Physical health, composed by energy and fatigue, pain and discomfort and sleep and rest, 3)

Psychological health, divided into body image and appearance, negative feelings, positive feelings, self-esteem and thinking, learning, memory and concentration, 4) Level of independence, composed by mobility, daily activities, dependence on medical substances and medical aids, and ability to work, 5) Social relationships, formed by personal relationships, social support and sexual activity, 6) Environment, financial resources, freedom, physical safety and security, health and social care: accessibility and quality, possibility of acquiring new information and skills, home environment, participation and opportunities for recreation/leisure, physical environment (pollution, noise, traffic, climate) and transport, 7) Spirituality, religion and personal beliefs. The WHOQOL-BREF (Skevington et al., 2004) is a shorter version of the previous assessment and it comprises 26 items and four domains are composed of the same facets of the WHOQoL-100: 1) Physical health, 2) Psychological health, 3) Social relationships, 4) Environment. Each of the 26 facets is composed of four items that ask how a person feels about different aspects of their life. The items are rated on a five-points Likert scale where a *one* indicates low or negative feelings and a *five* indicates high or positive feelings. After the development of these two generic questionnaires, the necessity of disease specific items became clear. It shows a good internal consistency and discriminant

validity and a quite good test-retest reliability (Who, 1998). We can find also an Italian version of the instrument showing good psychometric properties with good internal consistency, an excellent concurrent validity and a good test-retest reliability (Girolamo et al., 2000).

The second instrument to be discussed is the Quality of Life Scale undertaken (**QoLS**) in the 1970's in the United States by Flanagan (M. Burckhardt et al., 2020). The original work was composed of 16 items representing five QoL domains: material and physical well-being, relationships with other people, social, community and civic activities, personal development and fulfillment and recreation. Following some descriptive research on a person with a chronic illness, one more item was included in order to evaluate an item that was able to reflect the importance of remaining independent to these patients. The 15-items scale has a high test-retest reliability over a three-week period and is internally consistent, similar reliability was estimated for the 16-item scale. The scale can also be used in chronic illness groups. A total score is determined by summing the individual scores of the singular items.

It presents a good internal consistency, an excellent test-retest reliability and a high convergent and divergent validity (Burckhardt & Anderson, 2003)

The third instrument is the Quality of life interview (**QOLI**), a self-made report instrument developed by Lehman in 1983 (Lehman, 1983). This covers the eight life domains of living, family, social relationships, leisure, work, safety, finances and physical health with three types of replies for each: a dichotomous reply (yes/no), an open response concerned with objective information and a reply located on a seven-point Likert scale exploring the social dimension of QoL. The information regarding the QoL domains is obtained from both objective and subjective indicators throughout 143 items (Lançon et al., 2004).

It presents a solid internal structure showing a good internal consistency both in objective and subjective scale, it appears sensitive to change and shows good concurrent and convergent validity (Lançon et al., 2004; Wasserman et al., 2006)

Another instrument that should be discussed is the McGill Quality of Life Questionnaire (**M-QOL**) developed by Cohen in 1996 to measure QoL of people with a life-threatening illness (Cohen et al., 2019; Sguazzin et al., 2010; Smith et al., 1997). This questionnaire analyzes four domains: physical well-being and symptoms, psychological symptoms, social and

existential well-being and support. It is a patient-reported instrument composed of 16 items (three are selected by the client) and one single-item on a global scale. The McGill Quality of Life Questionnaire- Revised (MQoL-R) improved the first version in order to address the issues that arose during the use of MQOL. It shows a good construct validity an reliability and a high internal consistency, properties that are maintained in the Italian version of the instrument (Henry et al., 2008; Sguazzin et al., 2010; Smith et al., 1997).

The Personal Well-being Index (**PWI**), which was developed in 2001 by Cummins, measures subjective well-being by asking people how satisfied they are with the seven life domains: standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, and future security (Lau et al., 2005). It is derived from the Comprehensive Quality of Life Scale (Com QoL) developed by Cummins in 1997. The PWI addresses the issues about the conceptual structure of ComQoL instruments. Specifically, it included a parallel scale evaluating objective QoL which seems to not be correlated with the main scale. In addition, the item “satisfaction with own happiness” introduced some conceptual complexity. The PWI is a seven items self-administered scale. Every item can be separately analyzed, or a

subjective well-being score can be calculated by summing the individual scores of each domain. It presents good test-retest reliability, high inter-domain correlations and good construct and convergent validity (International Wellbeing Group, 2013).

The Battery Instruments to Assess Quality of Life (**BASIQ**) is the Italian validation of the Quality of Life Instrument Package (QoL-IP). The BASIQ is made of three different yet related questionnaires: a direct interview (DI) with the subject, a proxy questionnaire completed by someone who knows the subject well (PQ)⁴ and an external assessor questionnaire (EAQ), completed by someone who knows the subject only superficially. It is composed of three areas (Being, Belonging and Becoming), each divided into nine sub-areas⁵. The QoL scores represent the relationship between the importance and satisfaction ratings. This instrument allows the interviewer to have a complete vision of the QoL by analyzing the subject, as well as a proxy point of view analyzing different aspects and collecting different impression about subject life and future goals (Bertelli et al., 2016, 2011).

It shows a very good internal consistency and reliability

Another interesting instrument is the Schedule for the Evaluation of Individual Quality of Life (**SEIQoL**) (M.

⁴ The PQ and DI scales are composed of the same 54 items.

⁵ The Basiq is based on the Renwick and Brown model I, explained in section 1.2.

Burckhardt et al., 2020; Hickey et al., 1996). It is an interview-based assessment that takes into consideration the individual's perspective allowing the subject to nominate, weigh and rate the dimensions that are considered important for the QoL. The instrument is designed to measure the aspects of life designated crucial by the subject, their current ability to function, their satisfaction with the chosen aspects and the weight the subject assigns to each. The SEIQoL is based on a phenomenological approach which means that the five dimensions identified by the subject need to be labeled and explained by observing their subjective meanings. Successively, the subject is asked to rate their current and hypothetical performance in each area and to assign a score to the nominated areas in relation to each other by forming a pie chart. The index is calculated from the sum of the product of the levels and the relative scores and it can be used for comparisons from a range of 0 to 100. It present good psychometric properties

It allowed to better understand what domains of quality of life are relevant for the patients having a deeper analysis of his experience than standardized questionnaires (Lucchiari et al., 2015).

CHAPTER 2: QUALITY OF LIFE OF PEOPLE LIVING WITH HIV

2.1 HIV and Quality of life concept

The HIV is a lentivirus, a subgroup of retrovirus causing deadly and chronic disease that affects the immune system and characterized by a long incubation period (Preedy & Watson, 2018; Spec et al., 2019).

Binding to a CD4 receptor and one or two co-receptors on the surface of the cell, The HIV virion enter in CD4-t cells which are lymphocytes that stimulate other cells to fight infections by helping to coordinate the immune response

After fusing itself to the cell, the virus releases its genetic material (RNA) that is converted in DNA by the reverse transcriptase enzyme. At this point, thanks to an enzyme called integrase, the viral DNA integrates itself with the cell's DNA and the enzyme RNA polymerase makes RNA copies of DNA. The HIV RNA is either inserted into new virus particles or translated into HIV proteins with which the new virus is created thanks to the action of the enzyme HIV protease. At the end, the HIV particle called virion is released from the cell's membrane, taking with it part of the cell's membrane and the CD4 cell is

destroyed. The reproduction and the release of the new viral cells is called gemmation.

The new viral cell is ready to infect other CD4 cells, and it can immediately start its replication, or it can remain inactive for a period of time. The HIV infection is divided in three stages: 1) Acute HIV infection, 2) Chronic HIV infection and 3) Acquired Immunodeficiency Syndrome (AIDS). The first stage occurs within two or four weeks from the initial infection. In this stage the virus can remain latent without manifesting any kind of symptoms, but some patients may show symptoms similar to those of the flu. These are caused by the fast replication of the viral cells, leading to a very high concentration of said cells in a short period of time, which in turn leads to an elevated risk of transmission through fluids such as blood or genital secretions.

During the second stage, an affected person may seem healthy, but the virus continues its replication, deteriorating the immune system while the risk of transmission remains.

The last stage, also known as AIDS, is when the immune system is seriously compromised and the person with HIV can manifest severe infections called opportunistic infection. The AIDS diagnosis is given when the CD4 number is less than 200 cells per cubic millimeter of blood (cells/mm³). There is no cure for HIV, but antiretroviral therapy stops the virus from

replicating, reducing the viral load and allowing affected patients to avoid or manage the third stage of the virus, while on the contrary, without treatment a patient's life expectancy is around three years.

In May 2016, in its 69th session, the World Health Assembly approved a new Global Health Sector Strategy for HIV for 2016–2021; this strategy formulated by the WHO established a 90-90-90 target, by incentivizing the health system to simultaneously 1. reduce the under-diagnosis of HIV cases by identifying at least 90% of actual cases, 2. guarantee treatment to at least 90% of HIV patients and 3. ensure that 90% of patients were treated using viral suppression treatments (J. V. Lazarus et al., 2016). In order to monitoring the progress towards 90-90-90, a periodic monitoring of the country-level is critical in order to find gaps and improve the services (Marsh et al., 2019). However, there could be some challenge to reach the targets, one may be treatment cost, Art cost have declined in these last years, but it needs to decline more; the cost reduction will come from new drugs and lower dosage. That will require fast innovation in order to avoid supply chain collapse (Jamieson & Kellerman, 2016).

As reported in a 2018 study conducted by Marsh et al. it (Marsh et al., 2019) was utopian to think that many region and country would reach the 2020 target. Indeed, as reported by the

study, “in 2018 approximately one in five People living with HIV globally still didn’t know their HIV status, 22% of those who knew their status are not accessing antiretroviral therapy and 14% of people on treatment didn’t have a suppressed viral load”. Despite of this poor results, for many country and regions, the examination conducted to monitor the progress toward 90-90-90 targets, have provided some useful information about what program delivery improvements are needed (Marsh et al., 2019).

For what concern the Italian progress the 90-90-90 targets are partially achieved, the three targets are around 70-80 % each, instead of the hoped-for 90% (Schiaroli, 2020). This is probably due to the Covid-19 reducing the availability of routine HIV care causing interruption in the scale-up of PrEP and difficulties in accessing to the hospital for screening and medication and in drug delivery (Guaraldi et al., 2021).

As was mentioned in the previous paragraphs, the WHO, by adopting a holistic approach to health and healthcare, defines health as “a state of physical, mental and social well-being, not merely the absence of disease and infirmity”, showing the need to take into consideration another dimension of health in order to promote well-being and in turn carry out suitable policies to achieve this goal. Furthermore, the WHO defines QoL as an “individuals’ perception of their position in life, in the context

of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns”.

In order to evaluate the consequences of the virus in the patients’ lives, this work will refer to the WHO’s paradigm of quality of life. Following this point of view, HIV may have a big impact in people’s daily lives, not only by reducing physical well-being due to a compromised immune system, comorbidities and systemic inflammation, but by also affecting the remaining aspects of Quality of life.

2.2 Physical well-being and neurocognitive impairment in people living with HIV

The Highly Active Anti-Retroviral Therapy (HAART) is a combination of two reverse transcriptase inhibitors and a protease inhibitor (World Health Organisation, 2006). The protease is a retroviral aspartyl involved in the modeling of the viral microproteins necessary for virus replication; it is a therapy introduced in 1996 in order to face HIV and prevent AIDS.

With the use of HAART, both mortality and hospitalizations were fully reduced, and a new hope arose. By 2000, the limitations of the available antiretroviral drugs became clear for different reasons: 1. The protease inhibitors were associated with potential metabolic effects like insulin resistance, cardiac arrhythmias or lipodystrophy, a condition of fat redistribution caused by early antiretroviral drugs.

2. The rapid development of drug resistance and 3. the pills needed to be swallowed frequently, more than once per day. For these reasons, HAART was prescribed only when the CD4 count dropped below 350 cells/mm³, as the risks of early administration were seen to outweigh the benefits. In recent years, a new kind of antiretroviral drug has been developed. These therapies are called Antiretroviral therapy (ART) and are associated with fewer side effects and a better drug resistance profile. Recently, the Fixed Dose Combination (FDC) was also

developed with just one pill per day, increasing the adherence to the therapy and the ease of the medicine intake. In 2019, the first bi-drug therapy was approved which combined a new generation integrase inhibitor and an older NRTI. There are six classes of antiretroviral agents and each target a different step in the viral life cycle: nucleoside reverse-transcriptase inhibitors (NRTIs), non nucleoside reverse-transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), integrase inhibitors, fusion inhibitors and chemokine inhibitors. The first two agents operate early in the viral life cycle by stopping viral replication while the PIs operate by later stopping the protease enzyme from assembling the new HIV material (Oguntibeju, 2012).

After the introduction of ART therapy, there was a shift in HIV status from a fatal disease to a mostly manageable chronic condition. Therefore, life expectancy increased, but there was also a higher risk of developing associated comorbidities which is one of the important factors that may affect QoL (Lorenco et al., 2014). Some chronic comorbidities can be a consequence of normal health-related changes, but others can be associated with the increase in toxicity due to a longer duration of ART and to the persistent immunodeficiency and inflammation connected to the virus. The most common comorbidities are diabetes mellitus, vascular disease, respiratory disease, hypertension, lipid disorders, kidney disease, hepatic

disease, neurocognitive impairments, sexually transmitted infections, psychiatric disorders and substance dependence. Opportunistic infections (K Chepkondol et al., 2020) and comorbidities usually need to be treated with different medicine by prescribing a polypharmacy; this can increase the risk of side effects caused by the drug-drug interaction and long-term effects and can affect the adherence to the treatment due to the consumption of several different drugs (Okoli et al., 2020).

HIV affects many organs including the brain and nerves by causing neurocognitive disorders (Heaton et al., 2011; Robertson et al., 2014; Rubtsova et al., 2020). Before the ART era, the association between HIV and HIV-associated dementia (HAND) was very common in the advanced stage of the disease. After the introduction of ART, the prevalence of the most severe form of HAND is declined, but some milder forms can still be reported (Heaton et al., 2011; Rubtsova et al., 2020). This condition primarily affects subcortical and front striatal brain processes by involving a variety of brain functions such as attention span, speed of information processing, concentration, working memory, executive function, abstraction skills, motor function and visuospatial processes. In particular, central executive component memory, attention span, executive functioning and processing speed are involved in the activities of daily living (ADL), basic tasks that are essential to live

independently and instrumental activities of daily living (IADL), more complex tasks of everyday living like: conditioning autonomy, work, social relationships; therefore, QoL.

With regard to everyday activities, neurocognitive impairment (NCI) can create a number of problems in the workplace by impacting employment status; NCI can simultaneously reduce the autonomy of decision making and the self-perceived independence of the subject. As a consequence, it can impact psychological and physical well-being as well as social relationships and self-determination. Some studies underline the correlation between depression and neurocognitive impairment, for example, a 2019 study by Rubin and Maki (Rubin & Maki, 2019) reports an association between depression and processing speed, episodic memory, executive function and attention, underling that the contribution of HIV to depression could be imputed to the chronic inflammation and alterations in dopamine and other neurotransmitters. A 2015 study by Chartier and colleagues (Chartier et al., 2015) also highlights the connection between depression, attention span and central executive performance, identifying the latter two as predictors of psychological disorders. On the contrary, two other studies deny the link between depression and impairment of attention or executive control (Armstrong et al., 2017; Kamat et al., 2013).

Another disorder reported in association with NCI is apathy. A study conducted by Shapiro and colleagues found a correlation between neurocognitive performance, attention span and information processing tasks and apathy, considered as a “depletion in initiation and motivation”. The results underline that high levels of apathy can predict “greater difficulty performing physical functional tasks, more limitation in activities requisite to social roles at home and in the community and less engagement in social communal activities”. These results were also confirmed by previous research conducted by Castellon and colleagues which reported an association between central executive and executive function performance and apathy (Castellon et al., 2000).

Another link exists between NCI and anxiety. For example, a study conducted by Janssen and colleagues reported a correlation between self-report measures of anxiety and depressive symptoms and speed of information processing (Janssen et al., 2015); whereas Robertons and colleagues found an association between neurocognitive status and testing of functions involved in the supervisory control and anxiety (Robertson et al., 2014). Every day functioning and psychological well-being can also be affected by pain and fatigue, which may also impact mental functioning, socialization and work of people living with HIV, hence impacting QoL and

treatment adherence (Aouizerat et al., 2013; da Silva et al., 2017; Madden et al., 2020). Pain can be a result of three factors: HIV infection and persistent inflammation, opportunistic disease and side effects of ART. The patient's perceived pain can be influenced by context (level of independence, social relationships, religion), gender (females seem to have a higher prevalence of painful symptoms) and personal and social aspects. Fatigue, characterized by exhaustion and lack of energy which in turn affects everyday activities, may also have different causes, but it is usually linked to HIV medications, long periods of inactivity, stress, depression and insomnia. In particular fatigue can affect concentration, thinking and learning. Another problem linked to HIV regards the HIV-associated neurocognitive disorders (HAND). The HIV infection is associated with reduced brain volume, which can impact functioning and the structure of gray matter and also affect the frontal nervous system. The relationship between NCI and QoL is complex and can be mediated by other factors such as age, gender, opportunistic infections and mental health. In particular, apathy, depression, anxiety and post-traumatic stress seem to be mediator factors as they simultaneously correlate with fatigue, insomnia, motivational system and pain. A 2017 study conducted by Rubin and colleagues, underlined a correlation between post-traumatic stress (PTSD) symptoms, perceived

stress, anxiety and perturbation in cognition and brain functioning (Rubin et al., 2017). Considering the global problems related to Covid-19 that the world has faced in the last two and a half years, an analysis of the impact of Covid-19 on the QoL of people living with HIV needs to be carried out. There are different points of view about the vulnerability of people with HIV to coronavirus SARS-CoV and the outcomes of the virus. Some studies, such as the 2021 research done by Sachdev and colleagues (Sachdev et al., 2021) underline that HIV, by causing the depletion of CD4 cells, leads to a deterioration of the immune system, which increases the risk of individuals with HIV in contracting infections and comorbidities despite the presence of effective ART therapy (Hadi et al., 2020; Han et al., 2022; Suwanwongse & Shabarek, 2020). At the same time, people with HIV seem to be at higher risk for severe Covid-19 symptoms due to the comorbidities they may already present, a higher systemic inflammation and some degree of immune alteration; all factors that can lead to the development of severe respiratory disease and thromboembolic disease. Other studies, on the contrary (de Medeiros et al., 2021; Etienne et al., 2020; Laurence, 2020), report similar rates of SARS-Cov among seropositive people on effective ART compared to the general population, specifying that they are more likely to be tested for Covid than the general population. A few other perspectives

(Meyer et al., 2022; Suwanwongse & Shabarek, 2020) observed a lower incidence of the virus due to the protective action of ART therapy. Besides the high risk for physical well-being linked to compromised immune system and comorbidities, as some researchers report, HIV can negatively interact with the SARS Covid vaccine. Regarding this last detail, as reported in some research, a COVID-19 vaccine booster may be needed in PLWHIV because a low CD4 count and a high HIV viral load could lead to a weaker response to the vaccine (Facciola et al., 2022; Tamuzi et al., 2022). Quarantine, social distancing, restricted public transportation, reduced access to hospitals and HIV clinics and dislocation of available resources⁶ can lead to a reduction of the people to have undergone the HIV test and a high risk of treatment interruption or retardation due to the difficulties in refilling ART and the high number of Covid patients recorded at the hospitals. Also, Pre-exposure prophylaxes (PrEP) programs were interrupted or reduced during the pandemic (Morgan et al., 2022). These challenges in maintaining the HIV care continuum could be worse in places with weak health-care systems. Additionally, isolation and social distancing may increase the risk of psychological disorders, namely depression and anxiety, which are already strongly associated with HIV .

⁶ Financial resources, doctors and entire hospital wards were relocated to face the spread of the virus so both acute and chronic medical conditions unrelated to COVID-19 were under prioritized.

2.3 Psychological Well-Being and Stigma of people living with HIV

Being diagnosed and living with a terminal and transmissible virus like HIV has an immense emotional impact on those affected. The diagnosis can expose the patient to a huge amount of stress by arousing a wide range of feelings like fear, anxiety, sense of guilt, anger, sadness and shame. This can lead to the development of mental health conditions, impact everyday functioning and affect QoL. Depression is one of the most prevalent psychiatric disorders among HIV patients and, as reported by some studies (World Health Organization, 2009; Abadiga, 2018), depression can be strongly associated with perceived social stigma, opportunistic infections, sleep problems, apathy and anxiety. Stigma manifests itself in three ways: 1) prejudice and negative emotions and feelings like anger fear and disgust, 2) stereotypical beliefs about the stigmatized person's characteristics and 3) discrimination and behavioral expressions of prejudice.

Stigma is a socially formed mark associated with a person's characteristics and HIV can be perceived and interiorized as a stigma; therefore, an HIV carrier can be seen as a person that may threaten another person's life and may possess

moral blemishes. In an article written by H. Deacon in 2006 (Deacon, 2006), stigma is defined as a “social process in which: 1. illness is constructed as preventable or controllable; 2. immoral behaviors causing the illness are identified; 3. these behaviors are associated with ‘carriers’ of the illness in other groups, drawing on existing social constructions of the ‘others’; 4. certain people are thus blamed for their own infections and; 5. status loss is projected onto the ‘others’, which may (or may not), result in a disadvantage to them”. Following this definition, the cause of HIV is often perceived as being derived from avoidable behaviors such as homosexuality, drug addiction and sexual promiscuity, hence evoking stigmatization and moralism. Furthermore, H. Deacon underlines the necessity to separate stigma and discrimination, identifying discrimination as a consequence of stigma, but also recognizing that stigma can have a negative impact on the self-concept even in the absence of discrimination, disempowering people and having deleterious effect in people life (Algarin et al., 2021).

The fear of being socially stigmatized or discriminated against may change peoples’ behavior by leading them into social withdrawal. Three stigma processes form part of this mechanism: enacted stigma, anticipated stigma and internalized stigma. The first refers to the degree to which people believe they have experienced prejudice and discrimination; anticipated

stigma concerns the expectation of discrimination and prejudice from others in their community and internalized stigma refers to how people introject these prejudices. This mechanism can lead the subject to develop what is known as disclosure anxiety (Earnshaw & Chaudoir, 2009; Rzeszutek et al., 2021; Zhou et al., 2020).

Disclosure anxiety is derived from sharing one's HIV status and the concern about other peoples' prejudice can contribute to feelings of worry over losing one's job and being forced into social isolation. The perception of social isolation can be associated to feelings of guilt, blame and isolation which are associated to depression (Evangeli & Wroe, 2017; Quinn & Chaudoir, 2009). Some studies underline the role of gender, ethnicity, types of relationships and culture in the effects of disclosure. For example, in the Comer, Henker, Kemeny and Wyatt (Comer et al., 2000) study, an association between a greater disclosure and increased depression was found in Latin American women, probably due to the perceived stigmatization and discrimination accompanied by a sense of shame; on the contrary, no link was found between disclosure and mental health in African American and Caucasian women. It is possible to understand the unique association between disclosure and mental health among Latin American women after carrying out a cultural interpretation, indeed, a collectivistic cultural

disclosure of the seropositive status may place a burden on family and friends. Other studies focus on the types of relationships existing between people living with HIV and their loved ones (Kalichman et al., 2003; Zea et al., 2005). The results of these studies show that disclosure to one's partner and closest friends is more common than to family members, probably due to the fear of rejection and the belief that friends may respond in a more supportive way.

Another source of anxiety can be the concern about their condition being infectious. Under ART therapy, the virus cannot be transmitted by sex if a person takes antiretroviral therapy as prescribed, in order to maintain a low viral load, but anxiety can derive from decades of stigmatization and irrational beliefs, indeed a people living with HIV can fear the transmission of the virus despite the use of safer sex strategies, resulting in emotional distress. This anxiety can have consequences in one's sexual life and relationships, including fear of rejection, low sexual desire, diminished sexual freedom and a sense of isolation (on behalf of the CHIWOS Research Team et al., 2020).

Despite the fact that ART therapy has transformed HIV from a fatal to a chronic disease, anxiety related to death continues to be a problem among patients, resulting from future-oriented cognition and irrational apprehension and beliefs. It is

an abnormal fear of death that can contribute to the development of several mental health disorders such as depression, nevertheless, social support and religiosity could be protective factors (Braunstein, 2004; Miller et al., 2012). Depression is one of the most common psychological disorder in people living with HIV, influencing not only the health status but also the adherence to the therapy (Abadiga, 2019; Seid et al., 2020; B. X. Tran et al., 2019).

The comorbidity of depression and HIV results in higher distress and self-stigma, loss of appetite and sleep problems. Depression is associated with a lower CD4 cell count, elevating the mortality risk and reduced adherence to therapy (Reis et al., 2020). HIV affects the immune system and triggers the release of inflammatory cytokines which induce behaviors that are similar to depressive symptoms. Moreover, as reported in the previous paragraph, chronic inflammation and alteration in dopamine can contribute to depression. Additionally, stigma, in particular self-stigma and discrimination have a strong association with depression among people living with HIV. Other variables can influence the severity of psychological problems in relation to age, gender, social support and culture. A study conducted by Ayano, Demelash, Mebratu Abraha and Tsegay (Ayano et al., 2021), underlines that adolescents and in particular adolescents living with HIV have a higher risk of

being stigmatized, discriminated and marginalized in addition to manifesting higher rates of mental disorders.

Another disease associated with depression can be found in sleeping problems (Gutierrez et al., 2019; Rogers et al., 2020). Sleep disturbances are associated with disease progression, employment status, poor medication adherence and poor health outcomes, for example impaired cognition, as well as cardiovascular and metabolic disease. Sleep problems connected to anhedonia and dysphoria can also interfere in everyday functioning, work life and personal relationships, which in turn can have significant repercussions on one's mental health by instigating the development of depression, or by exacerbating or maintaining its symptoms. Abnormal sleep patterns can have multiple causes such as immune dysregulation (Cruess et al., 2003), the effects of HIV on the nervous system, and lipodystrophy caused by antiretroviral therapy. Other causes can be associated with psychosocial factors like perceived stress, poverty and substance abuse.

Another type of stigmatization is derived from the chronic nature of the aforementioned diseases, in fact, the necessity to take medication and do periodic examinations can be seen as a barrier for employers.

In conclusion, these mental diseases, often interconnected, can have a notable impact on the daily life of people living with HIV, affecting QoL as a consequence.

2.4 Social relationships, Independence and Spirituality

Stigma and anxiety regarding disclosure can also affect the social well-being (Herrmann et al., 2013). The fear of rejection and social discrimination can lead the patient to self-withdraw, restricting their social relationships and intimacy. Indeed, people affected by the fear of being stigmatized and discriminated against can become reluctant to expose their seropositive status because disclosure can be a double-edge sword, with both positive and negative impacts. On the one hand, it can elicit shame and condemnation, causing a sense of vulnerability, social isolation, low self-esteem and depression, while on the other it can be an important step in receiving social support from loved ones (Chapman Lambert et al., 2020; Hansen et al., 2009; Mi et al., 2021). Finding an appropriate support system in the community through qualified figures like psychologists, counselors and doctors, from self-help groups or peer support programs, or simply from friends and family can be an important resource for people living with HIV. This kind of support can help people living with HIV to benefit from a better

adherence to treatment, a lower probability of developing depression and anxiety, higher self-esteem and in general an increase in QoL (Reis et al., 2020). To feel supported and understood by family and friends and to be able share one's seropositive status with people living in the same situation can help people living with HIV to adjust to their seropositive condition, as this social release can be considered an external coping resource.

Being affected by HIV entails that one must face several stressors at the moment of the diagnosis, as well as during the disclosure to others, to name a few. Coping strategy, as defined by Lazarus and Folkman is, "constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (R. S. Lazarus & Folkman, 1984). Two kinds of coping strategies have been identified: an active problem-focused strategy based on managing the cause of the distress, and a passive emotion-focused strategy that manages the emotional distress caused by the situation (Brown et al., 2019; Moneyham et al., 1998; Pakenham & Rinaldis, 2001; Reeves et al., 1999). The individual response to said distress varies according to the situation and its mutation over time. Some evidence underlines that avoidance and denial, two passive coping strategies, are associated with positive outcomes in

dealing with short-term stressful situations, but they appear to be less effective under long term circumstances(Leserman et al., 2000). Denial is a common reaction to the diagnosis but can become deleterious if this strategy is protracted, as it is associated with increased psychological distress such as anxiety and depression, poor adjustment and delayed treatment. Some of the positive strategies that are commonly used to counteract these distressers are humor, altruism and seeking support in others.

Faith can also be used as a positive coping strategy; indeed, spirituality and religion can have protective effects; While a religion obeys a certain precept and believes in a divine entity, spirituality refers to a person's spiritual beliefs and trust in a particular religious orientation. Feeling supported by the community as well as by a supreme being can help patients to reduce health concerns, anxiety and distress by adopting a more optimistic view of their situation which can lead to a better adherence to the treatments and an increased self-esteem.

On the other hand, religion can foster HIV stigma which can interpret HIV as a punishment or can manifest intolerance to the perceived causes of HIV such as homosexuality, drug addiction or sexual promiscuity (Lassiter & Parsons, 2016; Shaw & El-Bassel, 2014; Szaflarski et al., 2006).

Employment is another important key determinant of QoL but coping with prejudices or anticipated prejudices can be difficult. Sometimes employers and coworkers can be concerned with the productivity and labor force participation of PLWHIV because of the fact that some health problems may arise, limiting certain aspects of the affected employee's functioning. Productivity losses may result from absenteeism due to health problems or medical examinations, or from presenteeism when a person can deliver a lower quantity or quality of work due to illness or fatigue. Moreover, a person affected by HIV can fear being discriminated against and stigmatized by employers and coworkers. This dread may lead them to avoid the disclosure of their pathology or their return to their job, making them feel isolated and lacking in independence (Dray-Spira et al., 2007). As research carried out by Rodger and colleagues report, this could be simply a concern derived from the fear of being rejected, in fact, only 11% of the interviewed employees reported discrimination and stigmatization, underlining a gap between precepted and actual stigma in the workplace(Rodger et al., 2010).

Work is not only a financial resource but also a source of role identity, structure and meaning as it can lead people living with HIV to develop self-esteem by making patients feel

independent but also socially supported (Annequin et al., 2015; Verbooy et al., 2018; Woods et al., 2016).

CHAPTER 3: ASSESSMENT OF QOL

3.1 How a good tool is made and what it needs to measure

In order for a test to be a good measure of QOL it must possess some psychometric characteristics and assess some main dimensions.

The first important characteristic is validity and it's achieved when a test can measure what it intended to. There are four different types of validity: face validity is about whether or not a test appears to measure what it's supposed to measure and refers to how it appears on the surface; content validity investigate is a tool represent or not the content according to experts based on theory; construct validity analyze if the proposed constructs are well represented and investigated and it's divided in convergent validity, whether or not the instruments agree with other related instruments and

discriminant validity which compares the tool with unrelated measures, criterion validity evaluates the accuracy with which a test measure the outcomes it was designed to measure and it's composed by two different type of criterion validity: predictive which analyzes if the instrument can predict the future outcomes and concurrent which compares the test to another well-established test. Another important psychometric characteristic of a test is the reliability or consistency that means that a test should present similar results even if the same person takes that test at two or more different times in different places or circumstances, guaranteeing agreement between unconnected attempts to measure the construct. following, a test should be objective that means that it shouldn't be exposed to personal or subjective judgments, avoiding bias. The last psychometric characteristic refers to the norms that provide a basis for comparison for the individual scores.

In conclusion the tool should be replicable across a range of patient populations and discriminate across a continuum from asymptomatic to people living with HIV with different levels of CD4 count. In addition, the instrument should be sensitive to the changes of health given the dynamic nature of the disease and should be easy to administer and appropriate to the setting.

As we already reported, an instrument assessing QoL of people living with HIV must assess at least social, physical and

psychological domains eventually expanded the scope also analyzing spirituality, stigma, independence and employment status. There isn't an agreement about the number and nature of the dimensions of quality of life. In a 2003 study conducted by S.Skevington and O'Connell (Skevington & O'Connell, 2003) is reported that an agreement could be found on the importance of the physical domain that is common to all instruments including an assessment of pain or symptoms and independence level. Another dimension that could be found in every assessment is the psychological domain that typically evaluates negative emotional well-being. On the contrary only few instruments include cognitive functioning domain which is important to understand Aids and ART effects on Quality of life. A social domain is also included in most scale, investigating role-functioning and/or social support. Only really few instruments take into consideration sex concern, stigma and spiritual dimension despite their importance in managing the seropositive status.

In order to choose the best instrument, we need to have a precise idea of what we want to assess and in what field we will use the tool.

3.2 General versus specific HIV quality of life instruments

Quality of life can be assessed using generic or condition specific measures. The choice between these two kinds of measurement depends on what kind of dimension we need to investigate. Disease specific measures allows to study the impact of a specific condition to the QoL proving to be more sensitivity to change (Dutra et al., 2019; O'Brien et al., 2021).

The benefits linked to the employment of generic instruments include the possibility to compare the test results across different conditions and with a normative group thanks to the availability of normative data; besides, they allow to study the impact of HIV and comorbid conditions on quality of life. Meanwhile, generic tools may lack of sensitive to changes in disease status or treatment.

A measure frequently used in research with people with HIV is the European Quality of Life 5 Dimensions (**EQ-5D**) test

(B. Tran et al., 2012; Wu et al., 2002). As we already said it can be defined as a Health-related quality of life measure divided in 5 dimensions: mobility, self-care, usual activity, pain/discomfort, anxiety/depression. the second part is composed of a visual analogue scale that assess self-report health status. This instrument has shown to be able to discriminate between different disease severity based on CD4 count and viral load (Delate & Coons, 2001; Wu et al., 2002). Regarding the convergent validity it has been compared to Medical Outcomes Study-HIV (MOS-HIV) scales showing a good correlation (Delate & Coons, 2001; Joyce et al., 2009; Leplège et al., 1997). In a systematic review conducted by Wen et al. EQ-5D demonstrate a high criterion validity but a low construct validity and internal consistency⁷ (Wen et al., 2022). On the contrary in a study conducted by Cooper et al. a good construct and convergent validity and a good response to treatment initiation and the development of opportunistic infection

Another Health-related quality of life instrument is the Health Utility Index (**HUI**) which is available in two versions HUI2 and HUI3. It is composed of 15/16 items and divided respectively in seven and eight domains. Coons et al. (Coons et

⁷ A measure based on the correlations between different item of the same test

al., 2000), describe HUI-2 as strongly related to disease severity correlating with MOS-HIV (Bayoumi & Redelmeier, 1999). Meanwhile, Hui-3 has been shown to be responsive to serious AIDS-related events showing a significant relation to viral load (Joyce et al., 2009)l. The researchers considered this test a useful measurement of QOL if utilized with an HIV specific measure. HUI-3 was, also, tested for validity and reliability in patient with advanced AIDS by Nosik et al., demonstrating good validity compared to the MOS-HIV and showing to be responsive to the changes. Wen at al. (Wen et al., 2022) reported a moderate criterion validity of the instrument.

The last HRQOL measurements I'll describe are two shot form tests derived from the Medical Outcomes Study (MOS): Short Form-12 and Short Form-36. The first one composed of 12 items is divided in8 domains: physical functioning, role-physical, role-emotional, bodily pain, general health, vitality, social functioning and mental health (Ware & Sherbourne, 1992). Wen et al. (Wen et al., 2022) reported a high construct validity and internal consistency and Gakhar, Kamali and Holodniy (Gakhar et al., 2013) reported a good validity and reliability concluding that it could be a useful instrument to investigate HRQOL in HIV population. They also reported a good correlation with disease severity. Short Form-36 composed

of 36 items is divided in 9 domains: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health and reported health transition with two summary scores: physical and mental health. The reviews reported good to acceptable internal consistency and construct validity. The instrument has been also found to be responsive to how the patient reacts when they begin ART therapy, number of symptoms and changes in viral load and CD4 count

. The test has been translated in several languages and can also be electronically administrated. In the Cooper et al. systematic review and Gakhar, Kamali and Holodniy

, a good Cronbach's alpha has been found underling a good internal consistency.

World health Organization quality of life assessment short form (**WHOQOL-BREF**) is a QOL instrument developed from the WHOQOL-100 (previously explained) created from a collaboration between 15 countries to ensure semantic and conceptual equivalence across different languages and cultures. It's composed of 26 items and 4 domains: physical health, psychological health, social relationships and environment and it is frequently use in the assessment of QOL in people living with HIV. Good psychometric properties as discriminant construct

validity, reliability, internal consistency and correlation with disease severity and CD4 count are generally reported

. Only two language versions of the instrument were rated as very low in internal consistency (Wen et al., 2022). This instrument could be used as a generic assessment of QOL in people living with HIV but to obtain a further explored profile of a person living with this particular disease it should be useful to adopt the HIV targeted instrument.

McGill Quality of life questionnaire (**MQOL**) is a QOL assessment that comprises 16 items and 4 domains: support, existential well-being and physical and psychological symptoms. It was created through interviews with people living with HIV. This is one of the few instruments assessing existential well-being which is a really relevant QOL dimension for people living with HIV, indeed, according to Cooper et al. reviews and Skevington et al. study (Cooper et al., 2017; Skevington & O'Connell, 2003) the face validity is increased by the inclusion of this dimension. However, it present poor discriminant validity and only one subscale scores are able to distinguish between people with HIV who had high and low CD4 counts. Clayson et al. reported a good internal consistency and test-retest reliability also resulting to be responsive to

symptoms severity, stage of illness, viral status and CD4 count
(Clayson et al., 2006; Holmes & Shea, 1998a).

3.3. Specific Quality of life instruments

WHOQOL-HIV derives from the WHOQOL-100 including some additional questions in order to investigate QoL in people living with HIV. It is composed of 101 items and six dimensions: physical, psychological, level of independence, social relations, spiritual, religion and beliefs, overall quality of life and general health (O'Connell & Skevington, 2012). Assessing independence and religion permit to investigate some of the crucial dimensions of QOL for people living with HIV. The instrument shows a good internal consistency and high construct and discriminant validity and reliability, moreover it shows to be able to distinguish between different stages of HIV disease progression. A short form, the WHOQOL-BREF, composed by 26 items and four domains similarly demonstrates good psychometric properties (Chapman Lambert et al., 2020; Cooper et al., 2017; O'Connell & Skevington, 2012; Skevington

et al., 2004; Skevington & O'Connell, 2003). The Italian version also present good psychometric properties demonstrating to be a valid and reliable instrument to assess patient life satisfaction in different stage of infection (Starace et al., 2002)

The Medical Outcomes Study HIV (**MOS-HIV**) is the most widely used among HIV specific tools. It is based on the SF-20 and composed of 35 items across 10 domains: physical functioning, pain, social functioning, role functioning, emotional well-being, energy/fatigue, cognitive function, health distress, health transition, general health and overall quality of life, generating two different summary scores: physical and mental health. 16 items were adopted from sf-20 adding 25 items to obtain an HIV QOL measurement (Davis & Pathak, 2001; Holmes & Ruocco, 2008; Wu et al., 1997). The measure displays a good internal consistency, convergent and discriminant validity. Although the test-retest was considered inadequate (Chapman Lambert et al., 2020; Davis & Pathak, 2001; Cooper et al., 2017; O'Connell & Skevington, 2012; Wen et al., 2022) and the reviews reported mixed findings regarding construct validity, from poor to good. It shows correlation with opportunistic infections, increased symptoms of AIDS. It has been translated in 14 languages reporting different reliability and validity due to the cultural adjustment. Its extended

utilization is justified by the fact that the instrument contains some relevant dimension for people living with HIV like sex life, sleep and eating (Badia et al., 1999; Chapman Lambert et al., 2020; Cooper et al., 2017; O'Connell & Skevington, 2012; Wen et al., 2022). It was validated also an Italian version of the instrument showing good convergent and discriminant validity and reliability (Schifano et al., 2003)

HIV/AIDS-Targeted Quality of Life Instrument (**HAT-QOL**) created through discussion groups with people living with HIV, is composed of 42 items and 9 dimensions: health and sexual functioning, disclosure, health and financial worries, HIV mastery, life satisfaction, medication concern and provider trust (Davis & Pathak, 2001; Holmes & Ruocco, 2008; Holmes & Shea, 1998a, 1999). It shows generally good internal consistency, however it had low internal consistency in sexual functioning, HIV mastery and medication concerns dimensions (Davis & Pathak, 2001; Holmes & Shea, 1999). Regarding the validity it shows mixed results (Clayson et al., 2006; Holmes & Shea, 1998b, 1998b; Wen et al., 2022).

The Functional Assessment of HIV infection (**FAHI**) is an instrument adapted from a cancer scale and it is composed of 44 items and five domains: global well-being, physical well-

being, emotional well-being, social well-being and cognitive functioning. It is fairly short and quite easy to complete (Viala-Danten et al., 2010). The last version demonstrated very good psychometric properties including convergent and discriminant validity, moreover it demonstrated a good correlation to changes in the disease status (Clayson et al., 2006; Coons et al., 2000; Gakhar et al., 2013; Peterman et al., 1997; Wen et al., 2022). However, Davis and Pathak reported poor internal consistency for the HIV subscale (Davis & Pathak, 2001).

HIV quality of life-31 (**HIV-QOL 31**) is one of the few HIV quality of life developed outside north America. It is a French instrument created with people living with HIV guaranteeing to cover a broad range of relevant problems connected the seropositive status (Gakhar et al., 2013; Leplège et al., 1997). It is composed of 31 items and six domains: sex life, pain, psychological aspects, relationships, limitations caused by HIV, symptoms and impact of treatment and care. The measurement shows a high internal consistency and the capacity to discriminate between groups based on disease severity (Cooper et al., 2017; O'Connell & Skevington, 2012). Wen et al reported low construct validity, relevance and comprehensibility but high internal consistency (Wen et al., 2022).

Despite the ability to cover a broad range of problems relevant to people living with HIV, this instrument has not been widely used to assess QOL in People living with HIV so few psychometric data are available.

The Multidimensional QOL for patients with HIV/AIDS (**MQOL-HIV**) is a 40 items instrument assessing 10 domains developed through interviews with patients affected by HIV: Physical health, physical functioning, mental health, social functioning, cognitive functioning, social support, financial status, sexual functioning, partner intimacy and access to care (Cooper et al., 2017; Sguazzin et al., 2010; Smith et al., 1997).

Smith et al. reported a good internal consistency reliability and test-retest reliability and the domains are responsive to changes in disease severity and viral load discriminating between different groups of patients. (Clayson et al., 2006; Smith et al., 1997; Woods et al., 2016). At the contrary O'Connell and Skevington (O'Connell & Skevington, 2012) state that only five dimensions and the index are sensitive to clinical changes also reporting a poor internal consistency in physical and mental health and physical and sexual functioning. Also a Spanish study conducted by Badia et al (Badia et al., 2000) reports a poor test-retest reliability and inadequate discrimination between disease stages.

The **PROQOL-HIV** (Duracinsky et al., 2012) is a test developed through interviews with people living with HIV and it is composed of 43 items assessing 8 domains: Physical health and symptoms, treatment, impact, emotional distress, health concerns, body change, intimate relationships, social relationships and stigma. It is one of the few instruments taking into consideration the patient's experience with treatments (Cooper et al., 2017). Wen et al (Wen et al., 2022) indicate a moderate construct validity, a high internal consistency and criterion validity but a low reliability. As reported by Duracinsky et al. (Duracinsky et al., 2012) the content validity as maintained including cultural nuances, finding common threads but also remaining vigilant to differences, also wording items differently for some particular countries.

CONCLUSION

During our analysis we underling that Quality of life is a construct without a univocal definition and with a variable set of different dimensions to assess. This eclectic characteristic is reflected in the assessment that can take into consideration different dimensions of the construct defining different instruments.

In the specific case of people living with HIV we need to pose some question to us. 1.What's the purpose of our analysis? The selection of the instruments can change if we are assessing quality of life in a specific subject in order to understand some QOL dimension or if we are leading a research; 2. What kind of dimensions we want to access? It is important to understand what's the aim of our assessment choosing the right instrument based on what dimensions it can assess, perhaps we can choose a general instrument in order to

study the general QOL, a specific instrument to assess the critical dimensions connected to HIV QOL, remaining sensitive to changes in the disease status, or the combination of the two to have the complete picture; the last question regards the psychometric characteristics of the instruments that can vary from an instrument to another and on the basis of the cultural context in which it is applied and the language in which it is translated.

As already said, the use of a general instrument like EQ-5, MOS or HUI, allow us to compare the results cross different conditions or a normative group and study the impact of HIV and comorbidities in QOL. Among the reported generic instruments, the SF-36 has more evidence supporting its use in HIV and can be helpful to have also a shorter version like SF-12 in case the length of the test became a problem. If the target of the test is an asymptomatic HIV infected people, it isn't recommended to choose the Eq-5D test because of its pronounced ceiling effect.

Regarding the HIV specific measures MOS-HIV and FAHI are brief and practical to administer and are being created through HIV patients inputs; MOS-HIV in particular has been used in multiple clinical trials and studies offering comparability. FAHI is a more specific instrument focused on treatment-related problems.

MOS-HIV and SF-36 couldn't been used together because they share many items and domains.

WHOQOL-HIV BREF and PROQOL-HIV have been recently developed so there are few psychometrical studies, but they are the most cross-culturally valid instruments.

If the purpose is to evaluate the treatments responsiveness is essential so we could use MOS-HIV, EQ-5D and SF-36.

In clinical practice we need to utilize a valid and reliable but also simple to complete and score instrument, so MOS-HIV couldn't be the right choice because it is easy to administer but difficult to score because it includes different rating scales and response options.

To conclude we can't chose an instrument without taking in consideration this main information, understand the different defining models, and dimensions of the concept can help us to acquire awareness about what instruments can suits our necessity based on what analysis we are implementing, in what field we are we are operating and what are the dimensions we want to assess (Clayson et al., 2006; Emerge Consortium et al., 2017).

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I APPENDIX: WHOQOL-HIV TOOL

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
5 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
8 (F52.2)	To what extent are you bothered by people blaming you for your HIV status	1	2	3	4	5
9 (F53.4)	How much do you fear the future?	1	2	3	4	5
10 (F54.1)	How much do you worry about death?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
12 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
13 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
14 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
15 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
16 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
17 (F51.1)	To what extent do you feel accepted by the people you know?	1	2	3	4	5
18 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5

19 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
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		Very poor	Poor	Neither poor nor good	Good	Very good
20 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
21 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
22 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
23 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
24 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
25 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
26 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
27 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
28 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
29 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
30 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
31 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form? _____

How long did it take to fill this form out? _____

Do you have any comments about the assessment? _____

THANK YOU FOR YOUR HELP

II APPENDICE: HAT QOL TOOL

Important instructions

The questions in this questionnaire ask how things are going in different areas of your life. Please answer all questions, even if you do not think they are relevant to you. Before starting to answer the questions, however, there are two types of questions you need to know more about.

- A. You will find some questions that ask about your job/routine daily activities.
If you have a job, answer these questions thinking about your job. If you do not have a job, answer these questions thinking about the activities you usually do during most days of the week. Examples include housework, other sorts of chores, going to school or volunteering in an organization.
- B. You will find some questions that ask about your doctor.
If you usually see a nurse, a nurse practitioner or a physician's assistant, answer these questions thinking of this person rather than your doctor.

1. The following questions ask about your overall function in the past four weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have been satisfied with my physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been physically limited in my ability to do routine household chores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, pain has limited my ability to be physically active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, I have been worried about not being able to do my job/routine daily activities as I have in the past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the past 4 weeks, I have felt that having HIV has limited the amount of work I can do at my job/routine daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. In the past 4 weeks, I have been too tired to be socially active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. In the past 4 weeks, my health has limited my social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. The following questions ask how you have felt about your HIV medications in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, taking my medicine has made it hard to live a normal life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, taking my medicine has made me feel better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, taking my medicine has made me feel more sick than I think I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, taking my medicine has made me feel as if I am fighting HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. The following questions ask about your disclosure worries in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have limited what I tell others about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been afraid to tell other people that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, I have been worried about my family members finding out that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, I have been worried about people at my job/routine daily activities finding out that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the past 4 weeks, I have been worried that I will lose my source of income if other people find out that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. The following questions ask about your health worries in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have not been able to live the way I would like to because I am so worried about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been worried about my health getting worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, I have been worried about my CD4 count	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, I have felt uncertain about what the future holds for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the past 4 weeks, I have been worried about when I am going to die	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. The following questions ask how you have felt about your doctor in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have felt as if my doctor was someone who listens to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have felt confident in my doctor's ability to care for people with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, I have felt certain that my doctor has my best interest in mind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Performance of a new HAT-QoL instrument in asymptomatic seropositive individuals

6. The following questions ask about your financial worries in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have been worried about having to live on a fixed income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been worried about how to pay my bills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, money has been too tight for me to care for myself the way I think I should	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, I have had enough money to do the things I enjoy doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. The following questions ask how you have felt about being HIV positive in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have had regrets about the way I lived my life before knowing I had HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been angry about my past HIV risk behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, I have been able to accept the fact that I have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. The following questions ask about your life satisfaction in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have enjoyed living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have felt a strong will to live	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, I have been content with my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past 4 weeks, I have felt in control of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the past 4 weeks, I have felt good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. In the past 4 weeks, I have felt motivated to do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. In the past 4 weeks, I have been satisfied with how socially active I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. In the past 4 weeks, I have been pleased with how healthy I have been	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. The following questions ask about your sexual function in the past 4 weeks.

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
a. In the past 4 weeks, I have been satisfied with my sexual life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past 4 weeks, I have been interested in sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past 4 weeks, it has been difficult to get sexually aroused	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for taking the time to complete all questions. If you have any questions or concerns, please feel free to discuss them with your health care provider.

III APPENDIX : FAHI TOOL

FAHI (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
B8	I am bothered by a change in weight	0	1	2	3	4
BMT6	I get tired easily	0	1	2	3	4
HI7	I feel fatigued	0	1	2	3	4
HI12	I feel weak all over	0	1	2	3	4
L2	I have been coughing	0	1	2	3	4

FAHI (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

**EMOTIONAL WELL-BEING/
LIVING WITH HIV**

Not at all A little bit Some-what Quite a bit Very much

GE1	I feel sad	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4
HI1	I am unhappy with my appearance.....	0	1	2	3	4
HI2	It is hard to tell other people about my infection	0	1	2	3	4
HI4	I worry about spreading my infection	0	1	2	3	4
HI5	I am concerned about what the future holds for me	0	1	2	3	4
B7	I worry about the effect of stress on my illness	0	1	2	3	4
HI10	I am embarrassed by my illness	0	1	2	3	4

FAHI (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>FUNCTIONAL AND GLOBAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
HI6	I feel motivated to do things.....	0	1	2	3	4
HI11	I am hopeful about the future	0	1	2	3	4

FAHI (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days

SOCIAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
HI3	I have people to help me if I need it.....	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

COGNITIVE FUNCTIONING

		Not at all	A little bit	Some- what	Quite a bit	Very much
L1	My thinking is clear	0	1	2	3	4
HI8	I have trouble concentrating.....	0	1	2	3	4
HI9	I have trouble remembering things	0	1	2	3	4