

# A Web-Based Data Collection Platform for Frailty Evaluation in Senior HIV+ Patients

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## Abstract

After the discovery of the antiretroviral therapy, life expectancy of HIV+ patients have become longer. This represents a new challenge for the consultant in HIV medicine, who needs to consider how HIV influences chronic diseases. The HIV+ patient is frailer than any other person of the same age not suffering from the viral infection. The aim of the present work is to develop a web-based platform to allow the self-administration of the new questionnaire SELFY MPI which was developed within a project involving several European groups. The SELFY MPI questionnaire was set up, which enables data collection about quality of life and cognitive functions. Between June and September 2018, a group

of 50 HIV+ senior patients, was involved. The platform collects pseudo-anonymous data. The subsequent statistical analysis highlighted a correlation between the two outcomes of SELFY MPI and the laboratory exam parameters TCD4+ and viral load. The potential of this platform is to support clinical research about the effects of HIV in chronic disease management and to provide a follow up instrument for evaluating different aspects of the geriatric patient life during the years.

## Keywords

Frailty evaluation, Multidimensional Prognostic Index, Pseudo-anonymous Chronic diseases management, Follow-up instrument.

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## 1. Introduction

Over the past 30 years remarkable progress has been made in HIV treatment by antiretroviral (ARV) drugs, reducing mortality and improving life expectancy and quality of care of patients. Further improvements could be achieved by developing compounds and formulations that improve efficacy, safety and tolerability of HIV drugs [1]. Further challenges still remain, since at the end of 2017 about 15 million HIV positive individuals were not receiving treatment [2]. The World Health Organization (WHO) in 2015 considered ageing and health and estimated that the number of people aged 60 years and older will increase between 2015 and 2050 from 900 million to 2 billion [3]. Moreover, WHO reports that in the period between 2000 and 2015 AIDS related deaths decreased by 28% [4]. In 2014 the joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 90-90-90 initiative [5,6], aiming to help overcoming the AIDS epidemic. The program planned to achieve by 2020 three main goals: diagnose 90% of all people

living with HIV, administer Antiretroviral (ARV) therapy to 90% of all people with diagnosed HIV infection, and achieving viral suppression for 90% of all people receiving ARV suppression.

According to UNAIDS there were about 37.9 million living at the end of 2018 with HIV and at the end of June 2019 about 24.5 million were accessing ARV therapy. While at the beginning of the HIV/AIDS epidemic only a few cases in senior patients were reported, nowadays patients who survived the early epidemics are getting older. A study aiming to quantify changes and implications for HIV care in the Netherlands predicted that by 2030 the median age of HIV infected patients on ARV therapy will increase up to 56.6, and that the proportion of HIV infected patients aged 50 years or older will increase from 28% in 2010 to 73% in 2030 [7].

As a result of improved HIV AIDS management and of the increasing number of new HIV diagnoses, the age of people living with HIV has been rising to a great extent, and this trend is

steadily increasing. Moreover, HIV itself has been regarded as a possible cause of acceleration in the aging process. Greater rates of non-AIDS defining illnesses are associated with AIDS. The death rate among patient with HIV which is attributed to liver, lung, cardiovascular and neoplastic diseases has considerably increased, and this represents a major challenge. In addition, frailty occurs at higher rates and an increased prevalence of it in HIV-infected compared with uninfected adults has recently been shown [8-12].

Frailty occurs in individuals with HIV at rates comparable with older individuals without HIV, and is an emerging global health burden, with major implications for clinical practice and public health [13,14]. In this respect, future work with standardised methodology for accurate description of the problem is needed. Frailty describes vulnerability in aging and is a state of increased vulnerability after a stress or event which increases the risk of adverse outcomes [15-17]. Several definitions and measurement of frailty have been proposed and used for frailty assessment and personalised intervention plans, both relating to older people and, more specifically, to older people with HIV [18-20]. In geriatric medicine the Comprehensive Geriatric Assessment (CGA) has become the internationally established method to assess older patients [16,20,21]. The Multidimensional Prognostic Index (MPI)-a CGA based bed-side assessment tool-was developed as a prognostic tool and has been validated in frailty assessment [18,20,22,23]. The MPI is a prognostic index which has been tested and approved worldwide as a mortality indicator for a considerable number of chronic diseases. It is derived from standardized comprehensive geriatric assessments that include information from eight domains, such as for example basal and instrumental activities of daily living, cognitive and nutritional status, comorbidities and drug use, etc. [24].

A project involving groups based in several European countries developed and validated a new self-administered MPI (SELYF MPI) for community-dwelling subjects. The Bland-Altman (BA) methodology [25] used to measure the accordance of MPI with SELFY MPI demonstrated that the mean difference between results obtained in the two ways was not clinically significant. SELFY-MPI could be used as a predictive tool in subjects of different ages. The new project, where this study is inlaid, started with the objective to understand whether SELFY MPI could be a precise and accurate predictive tool even for the HIV infectious disease [26].

A software platform was developed to enable pseudo-anonymous data collection and self-administration for use by the medical staff during the waiting period of patients for surgery. The data were collected in the Galliera hospital in Genoa and were automatically stored in the database of Liguria Region Clinical Network, which is a web-based platform developed by the Department of Informatics, Bioengineering, Robotics and System Engineering (DIBRIS) of the University of Genoa. This network collects almost automatically and in a pseudo-anonymous way different types of clinical data from all Liguria hospitals [27,28].

## 2. Materials and Methods

The SELFY MPI is a questionnaire divided into seven macro-sections. The first six sections contain a list of questions concerning a specific aspect of patient daily life:

**Barthel ADL and Barthel MOB:** questions about Activities of Daily Living and activities related to Movements.

**IADL:** section about the Instrumental Activities of Daily Living that contains eight elements based on cognitive and physical functions, for example the use of mobile phone

**MNA:** Mini Nutritional Assessment, it is a very important monitoring and evaluation instrument for the detection of elderly patient that suffers from malnutrition. In the SELFY MPI, only a short form has been integrated and it is composed of six questions related to the physical condition of the patient, in particular his/her weight, which is a parameter that should always be monitored in case of HIV [7].

**CIRS:** Cumulative Illness Rating Scale is an easy but effective standardized instrument that gives a complete evaluation about the diseases of each organic system [8].

**SFES Scale:** is a Social-Familiar Evaluation Scale; this aspect is closely related to other risk factors, like psychological problems such as stress or anxiety, and they are mostly present in patients that do not live with their families.

The last section, called TYM TEST (Test Your Memory), contains aptitude tests and personal questions. This type of test is useful for the diagnosis and management of patients suffering from memory problems.

### 2.1 Integration into the Liguria Clinical Network

The main purpose of the Liguria HIV Network is to collect, process and make available data relating to HIV+ patients for clinical studies. One of the clinical studies that have been conducted using this platform is a project relating to the specific class of patients that respond correctly to therapies and that maintain the viral load approximatively null.

A patient can enter the platform only if he/she has the authorization and access credentials. Subsequently, a clinical staff member (physician, psychology, nurse...) has to open the specific study created for SELFY MPI and then he/she can choose to enlist a new patient or to visualize a questionnaire which has already been completed or to fill up a new one for the same patient.

The user can also open a personal page containing all information relating to the selected patient divided into sections. Some examples are section containing the results of laboratory exams, anamnesis information, etc.

### 2.2 Sample feature

Between June and September 2018, a group of 50 HIV+ patients (28 men and 22 women) was involved. No distinction about gender or race was made. They only had to know Italian language at a suitable level to understand the questions in the

SELFY MPI and to be over 50 years old. The latter condition is due to the objective of SELFY MPI study that was to evaluate the frailty of “elderly” patients. According to literature, indeed, a patient becomes “senior” at the age of 50 because they begin to present health problems like those of a geriatric person. The mean age of the sample was 58.5 years (range 50-73).

### 2.3 Outcome Assessment

The outcomes of the questionnaire are two coefficients, SELFY\_MPI cohabitation (SELFY\_MPI COAB) and SELFY\_MPI SFES, which represent two frailty indices that have to be correlated to laboratory exam results. It was expected that patients who obtained high SELFY\_MPI indices probably would have high values of viremia and low TCD4 count.

A partial result and a score have been calculated for each macro-section of the questionnaire. The score can take three values:

- 0: Mild risk
- 0,5: Moderate risk
- 1: Severe risk

This score is based on the partial results obtained in the specific section and on the reference range established by physicians for each category. For example, the number of drug administrations that the patient has to receive every day is classified as mild risk from 0 to 3, moderate risk from 4 to 6 and severe risk equal or more than 7.

The two outcomes are then calculated as means of 8 scores of the following parameters:

- Seven scores are used in the calculation of both: Barthel ADL, Barthel MOB, IADL, MNA, CIRS, number of medicine and TYM TEST.
- One different score: SFES Scale or housing condition (patient living alone, in a structure or with his family).

## 3. Limitations

The main difficulties that medical staff experienced were:

- Difficulties due to the different languages of treated patients. Most people involved in the study were Italian, because for a non-Italian to understand the meaning of the questions and the answers can be difficult.
- Difficulties due to the different psychological status of patients waiting for out-patient services, for example stress or anxiety.
- The result of the questionnaire is based on trust that patient responds truthfully the questions

## 4. Results

### 4.1 SELFY\_MPI Instrument

This software instrument has been developed as a list of web pages, for each page the patient has to answer all questions and

then he/she has to click the button “Save and go on”. The “go back” button of the browser has been disabled in order to retain the data accuracy.

The only part that the patient should complete on paper is the TYM TEST, especially the aptitude test because, for example, he/she has to draw the exact time that is asked in the text. The medical staff member then has to calculate the final score of the TYM TEST section and copy it in an appropriate web-page.

The user can insert the results of the TYM TEST immediately after the patient has completed the other pages of the questionnaire or he/she can click the button “Insert Later”. The two outcomes are automatically calculated only after when the questionnaire is completed. When all sections are correctly completed, medical staff member can open the resume page of the questionnaire, in which he/she can find the partial result and the score of each section, the total score and the two outcomes of SELFY\_MPI.

### 4.2 Statistical analysis

The data analysis has highlighted that no patients could be classified as SELFY\_MPI Severe. Then, merging SELFY\_MPI data with laboratory exams results, the observations that should be cited are:

- Patients with a Moderate SELFY\_MPI COAB have a Nadir CD4 77% lower than Mild SELFY\_MPI COAB ( $p < 0,001$ ). The previous relation is a rather borderline if we consider the SELFY\_MPI SFES.
- Patients with a Moderate SELFY\_MPI COAB present a risk of having the last TCD4 count under the threshold value of 200 that is 6,7 times greater than patients with a Mild SELFY\_MPI COAB.
- There were no specific associations between SELFY\_MPI outcomes and viral suppression months. Normalizing data with the median value of 27 months, a mild link ( $p = 0,87$ ) can be observed between SELFY\_MPI SFES and the probability of having more than 27 viral suppression months. For each decimal point of SELFY\_MPI SFES increasing there’s a 41% decrease of the probability of having more than 27 viral suppression months.

## 4. Conclusion

This web-based method of administering SELFY\_MPI questionnaire is an innovative instrument which allows the medical staff to quickly collect data, minimizing error probability. A further advantage is the possibility of examining different types of data in the same platform and therefore directly linking SELFY\_MPI data with laboratory exam results. This platform has contributed to the study of the assessment of frailty of elderly HIV+ patients at Galliera hospital.

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