

Adherence and non-adherence to antiretroviral therapy from a capability theory perspective

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It is widely recognized in the medical research literature that a rigorous adherence to antiretroviral therapies is needed in order to effectively achieve the virological, immunological and clinical benefits of these treatments. Nevertheless, these kinds of medications are characterized by particularly complex and heavy dosing regimens that increase the chances of non-compliance with the treatment. Several studies have attempted to identify common reasons, determinants and predictors of non-adherence. However, most of these research papers embrace a clinical perspective so they are grounded in the problems of day-to-day adherence, or they lack a theoretical basis. Consequently, they fall short in helping us to understand what kinds of dynamics underlie the motives that people living with HIV take into consideration when, for example, they face the problem of how to incorporate such a demanding treatment regime into their lives within the context of their other life activities.

We suggest that a deeper understanding of non-adherence to therapies requires a focus on the HIV positive persons' experience of the treatment and, consequently, on the impact of the antiretroviral therapy on their quality of life. It is important, in particular, to look at the last two phenomena in terms of how HIV positive people integrate the HIV infection as a chronic illness into their life. This is because when health changes, owing to a chronic illness such as HIV, values and perspective on life might also change and the need for a different lifestyle might arise.

My paper explains why and how we think that a capability approach combined with concepts from fuzzy set theory would enhance our understanding of these problems.

Introduction

According to the last estimate of UNAIDS (the Joint United Nation Programme on HIV/AIDS) there were 38 million adults and children living with HIV in the World at the end of 2003.

There are two main features of the socio-economic consequences of HIV infection that I would like to highlight here.

First of all, AIDS is an illness that that it is present in both developed and developing countries but that strikes with higher rates and with far higher consequences in particular areas that are already socially and economically depressed. It is sufficient to mention, with regard to this, that of the nearly 3 million deaths for AIDS registered in 2003, 2.2 million, that is 75% of them, were in sub-Saharan Africa¹. Asia, with almost 60% of the world population, is registering the fastest-growing AIDS epidemic in the world owing, above all, to a marked increase in HIV infections in China, Indonesia and Vietnam which together make up close to 50% of Asia's population². In total, almost 30 million people living with HIV are in developing countries³.

Secondly, people living with HIV need access to several classes of drugs⁴. In particular, among all of them, people living with HIV need access to that class of drugs that to date is the only known effective way to treat HIV, antiretroviral drugs. These latter drugs, in fact, are the only ones that can limit the damage that HIV does to the human immune system. Thanks to this property, this class of drugs has succeeded in

¹ UNAIDS (2003). AIDS epidemic update. Geneva, Joint United Nations Programme on HIV/AIDS.

² Ibidem

³ Ibidem

⁴ Ibidem

transforming HIV from a fatal to a chronic illness with stable conditions. Several studies have found that antiretroviral drugs, which were introduced in 1997, have led to the dramatic fall of the death and the morbidity rates attributable to AIDS⁵.

Antiretroviral drugs have two relevant characteristics that need to be raised. The first characteristic, relevant from a socio-economic perspective, is the fact that these drugs are expensive. This fact has an immediate consequence considering the heavier impact of the epidemic on poorer countries reported above. According to the UNAIDS estimate to date still only an incredible minority of the 30 million people living with HIV in developing countries receive anti-retroviral drugs. Since antiretroviral drugs are able to significantly prolong the life of people who are HIV positive, the lack of access to them triggers a chain of social and economical consequences such as loss of adult population and a growing number of orphans⁶.

The second characteristic, more relevant from a clinical and socio-psychological perspective, is that antiretroviral drugs are usually taken in combination. This characteristic of antiretroviral drugs is due to the biological nature of the HIV virus. The HIV virus is such that it has an extraordinary capability to mutate into new forms. Therefore scientists found that the best way to combat the virus is to take a combination of different antiretroviral drugs at the same time. If a combination of drugs makes it less likely that resistance to any of them will be a problem, at the same time this makes the antiretroviral treatment characterized by particularly complex and heavy dosing regimens. This feature of the treatment has an immediate impact on the rates of adherence to the regimen among people living with HIV. Antiretroviral drugs, however,

⁵ Ibidem

⁶ Danziger (1994). "The social impact of HIV/AIDS in developing countries." Social Science & Medicine **39** (7).

despite their complexity, are among the treatments that require the strictest adherence in order to make them work properly. It is widely recognized in the medical research literature, in fact, that a rigorous adherence to antiretroviral therapies (over 95%) is needed in order to effectively achieve the virological, immunological and clinical benefits of these treatments.

Already from this basic sketch of only two elementary socio-economic and clinical characteristics of the HIV infection the strong necessity of a comprehensive approach to the problem of antiretroviral drugs access and adherence tends to emerge. A comprehensive approach that, to be able to give answer to both the socio-economic and behavioral questions related with antiretroviral therapies has to be able to account for the relationship between individuals agency (the capacity to exercise control over one's life), social structures (the norms and rules of a certain society) and people's everyday activities and social relationships, in a word, their lives. However, despite several appeals in the direction of more comprehensive models in the literature, those studies that have attempted to identify common reasons, determinants and predictors of non-adherence so far have fallen short in helping us to understand what kinds of dynamics underlie the adherence and non-adherence behaviors. This is due mainly, as we will soon see, to a couple of problems that can be recognized transversally in most of this literature. Firstly, it is due to the fact that the literature exists in a theoretical vacuum – especially the literature that embraces a clinical perspective grounded in the problems of day-to-day adherence. Secondly, in the best hypothesis, this literature is based on a theoretical framework that is heavily “one-sided”, as in the case of the literature that adopts an individual risk-factor epidemiological approach. This last perspective is based on a kind

of methodological individualism⁷ that is not able to account for the relationship between the individual agency and the societal structure. This is true despite the fact that contextual variables can be taken into consideration in this kind of research. The problem is that the role of the societal structure both with its limiting and enhancing power is accounted merely in terms of the “demographic characteristics” of the individuals. In this way, the manner in which contextual variables are generated is taken for granted and they are considered exogenous factors to the social actor, “as if individuals were dropped into a set of conditions that are not socially constructed nor patterned”⁸. In other words, there is no account of the way in which those contextual conditions are socially constructed and of the bi-directional, ongoing relationship between the social actor and his/her context.

Amartya Sen’s capability approach to human development and equality, being hinged, more and more centrally in his last works, on the “idea that freedom of choice is quite central to leading a good life”⁹, immediately brings into consideration both the factor of the individual agency and of the social influences on it. Sen’s capability theory in fact suggests that a central role in the evaluation of equality has to be given to the real freedom that people have to make the choices that they value and to live the lives they wish. So equality is not a matter of distribution of “primary goods”, as for the Rawlsian

⁷ See Williams (2003). "The determinants of health: structure, context and agency." *Social Health & Illness* **25** (3). and Diez-Roux "Bringing context back into epidemiology: Variables and fallacies in multilevel analysis." *American Journal of Public Health* **88** (2).

⁸ Krieger (1994). "Epidemiology and the web of causation: Has anyone seen the spider?" *Social Science & Medicine* **39** (7). cited in Shim (2002). "Understanding the routinised inclusion of race, socioeconomic status and sex in epidemiology: the utility of concepts from technoscience studies." *Social Health & Illness* **24** (2), p. 133.

⁹ See Sen (1988). "Freedom of choice : Concept and content." *European Economic Review* **32** (2-3). and Sen, 1999, *Development as Freedom*, Oxford, Oxford University Press,

school of distributive justice¹⁰, nor a matter of utility yielded from goods and its distribution amongst a population, as for the utilitarianism, on the contrary Sen elects as valuational space for assessing equality issues that which people are actually able to extract from goods given their particular needs and abilities¹¹. So at stake in the capability perspective is the real opportunity of individuals to pursue valuable beings and doings, in other words their power to choose their lifestyle. From this point of view it becomes very important to examine how choices are structured by the situation, the context in which an individual lives. To achieve this goal Sen's theory, as it has been pointed out¹², needs a theory of the individual and, therefore, a more complete theory of agency. This would also imply a finer distinction, under the general umbrella of the concept of capability, between different types of valuable things a person can do, be or have, according to the theoretical basis of the theory of the individual that would be chosen¹³. From this point of view Sen's capability theory has been criticized for lacking a structured conception of personhood and a complete theory of values and of agency¹⁴.

If the capability theory has received attention so far mainly from a philosophical point of view, there is no doubt that the contribution of the reflection on agency and personal behavior typical of psychology, and of the interconnectedness between agency and structure typical of sociology would bring an important contribution to the full development of the capability approach.

¹⁰ Rawls, 1973, A theory of justice / John Rawls, Oxford :, Oxford University Press,

¹¹ Sen, 1992, Inequality reexamined / Amartya Sen, New York : Oxford [England] :, Russell Sage Foundation ; Clarendon Press,

¹² Gasper "Is Sen's capability approach an adequate basis for considering human development?" Review of Political Economy **14** (4).

¹³ Ibidem. Des Gasper, for example, introduces the distinction between O-capability (O for options and opportunities) and S-capability (S for skills and capacities).

¹⁴ Ibidem.

In the following paragraphs I first review the main concept of the capability approach discussing them with regard to the situation of people living with HIV. Then, I review the theoretical assumptions and structures explicitly or tacitly postulated in the different approaches and models suggested in the literature to identify common reasons, determinants and predictors of non-adherence with antiretroviral therapy. Finally, I discuss the main aspects of this literature from a capability approach perspective and how contributions from psychological theories can help in eliciting a list of capabilities for people living with HIV. A methodology for eliciting a list of capabilities will then be introduced and discussed.

Core concepts of the capability approach

The capability approach is based on three main concepts: commodities, functionings and capabilities.

The noun commodity is used in its economic meaning, that is, as a synonym for goods. In formal terms Sen represents commodities through a vector. This latter is a list of commodities possessed by a person. An example of this kind of resource vector in the context of people living with HIV might be: [home care, privacy rules, antiretroviral drugs]. With regard to people living with HIV and, more generally, with regard to people living with chronic illness, instead of the economic term commodities or goods, we might prefer to use a more general term such as resources. This term, in fact, seems more suitable to recall intuitively the particular nature of the bundle of goods that patients can access. This bundle, depending on the goal of the research, might be comprised more of services than real goods.

A corollary concept related to the commodity vector is the one of commodity characteristic vector. Following the example of Gorman¹⁵ and Lancaster¹⁶, Sen suggests that what really matters with regard to commodities are their characteristics, that is “the various desirable properties of the commodities in question”¹⁷. Each commodity has many characteristics. With regard to the resource vector used as an example above, [home care, privacy rules, antiretroviral drugs], the following is a possible characteristic resource vector: [medical and professional care in a more comfortable environment, protection from social stigma, suppression of viral load].

Evidently, the resource home care has other characteristics apart from bringing medical and professional care in a more comfortable environment. It can also reinforce self-confidence and provide support for social meetings. The characteristics of what we have called resources, as evident, are certainly more complex than those ones of normal goods. This is due to the fact that they can be services aimed to provide an answer to specific problems confronted by the HIV population. So, each commodity has several characteristics. Taking all the relevant characteristics of the resources available to the HIV patients into consideration might better enable us to reach a more comprehensive understanding of the context being studied.

Finally, the same commodity or resource vector can be used in different ways. Each resource vector, in fact, has several possible utilizations. What use of the resource vector each subject will make is determined both by personal and social factors. We will

¹⁵ Gorman (1956). "The demand for related goods." Journal paper J3129 (Iowa Experimental Station, Ames, IA), cited in Sen, 1985, *Commodities and capabilities*, Amsterdam ; New York : New York, N.Y., U.S.A. ;, North-Holland ; Sole distributors for the U.S.A. and Canada, Elsevier Science Pub. Co., p. 9.

¹⁶ Lancaster (1966). "A new approach to consumer theory." Journal of Political Economy **74**, cited in Sen, *Commodities and capabilities*, p. 9.

¹⁷ Sen, *Commodities and capabilities*, p. 9.

give an example of this concept of utilization in the next paragraphs. Before doing this, however, we need to introduce the other two central concepts of Sen's capability approach, that is functionings and capabilities.

With regard to functionings, "a functioning is an achievement of a person: what he or she manages to do or to be. It reflects, as it were, a part of the 'state' of that person"¹⁸. More specifically, "the concept of functionings reflects the various things a person may value doing or being. The valued functionings may vary from elementary ones, such as being adequately nourished and being free from avoidable disease, to very complex activities or personal states, such as being able to take part in the life of the community and having self respect"¹⁹. From this point of view, a functioning has "to be distinguished from the commodities which are used to achieve those functionings"²⁰, since being a functioning, an achieved valued doing or being, it involves people's talents and social environments. As Sen specifies, a functioning has to be distinguished also from the happiness that that functioning generates. So, for example, the fact of having home care cannot be confused with the happiness or unhappiness that results from that functioning. To sum up, "a functioning is thus different both from (1) having goods (and the corresponding characteristics), to which it is posterior, and (2) having utility (in the form of happiness resulting from that functioning), to which it is, in an important way, prior"²¹.

The claim of Sen with regard to functionings is that they reflect the well-being of a person. In Sen's words, "functionings are constitutive of a person's being, and an

¹⁸ Ibidem, p. 10.

¹⁹ Sen, *Development as Freedom*, p. 75.

²⁰ Sen, *Commodities and capabilities*, p. 10.

²¹ Ibidem, pp. 10-11.

evaluation of well-being has to take the form of an assessment of these constituent elements”²². This claim stands on an intuitive postulate. Basically, that how well a person is “must be a matter of what kind of life he or she is living, and what the person is succeeding in ‘doing’ and ‘being’”²³. The assessment of the well-being of a person has to take then the form of the valuation of the functionings vector that reflects these ‘doings’ and ‘beings’.

From a formal point of view, if x_i is “the vector of commodities possessed by person i ”²⁴, c is the function (not necessarily linear) that converts a commodity vector into a vector of characteristics of those commodities²⁵ (see our examples above for these last two concepts), f_i “a personal ‘utilization function’ of [the person] i reflecting one pattern of use of commodities that i can actually make (in generating a functioning vector out of a characteristic vector of commodities possessed)”²⁶, then the achieved functioning b of the person i is expressed as $b_i = f_i(c(x_i))$.

It is important to stress that this way of formalizing functionings allows us to take into consideration both the factor of human diversity and of social influences that are around the assessment of functioning achievements. Indeed, the choice of the commodities (in our terminology resources) vector, is limited by the actual person’s command over resources, a command generated in economical terms by the person’s income, by the prices, and so on. Ergo, the choice of the resources vector x_i , is confined to the set X_i of his/her entitlements²⁷. At the same time, the choice of the utilization

²² Sen, *Inequality reexamined* / Amartya Sen, p. 39.

²³ Sen, *Commodities and capabilities*, p. 28.

²⁴ *Ibidem*, p. 11.

²⁵ See *ivi*.

²⁶ *Ivi*.

²⁷ For an analysis of the concept of entitlements in economic terms, see Sen, 1981, *Poverty and famines: An essay on entitlements and deprivation*, Oxford, Clarendon,

function f_i is made among the elements of the feasible set of utilization functions F_i . This set represents the set of ‘utilization functions’ f_i that the subject i can choose.

In conclusion, on both the two last sets and on F_i in particular – that is on the patients’ utilizations of their resources – social and personal factors play a fundamental role. Some of these factors are related to the personal choices of subjects, some others are not under subjects’ control. For example, the stage of the illness, or the age, or nutritional knowledge and so forth, which are, within certain limits, all factors beyond subjects’ control, might influence the functioning achievable through the resource [antiretroviral drugs] and its characteristic [suppression of viral load]. In these last cases the functioning achievable might go from well recovered to moderately or even poorly recovered. Nevertheless, the functioning achievable through the resource antiretroviral drugs can depend also on subjects’ personal choices with regard to the utilization of that resource and its characteristics. In this case too, these choices might be influenced both by personal and by social factors. Evidently, the utilization factor becomes more relevant and complex when we think of it not with regard to one resource only, but with regard to the entire resource vector of each subject. For example, with regard to a resource such as home care, there are certainly several factors that influence the conversion of the characteristic vector of this resource, [medical and professional care in a more comfortable environment], into the functioning, e.g., [living comfortably at home with medical assistance]. If we focus only on those factors that are under a subject’s control, a possible utilization of the resource vector [home care, privacy rules], by a patient, could result in the functioning vector [living comfortably at home with medical assistance, being moderately free from social stigmatization]. Other utilizations by the same patient

might be choosing not to use the home care service, only outpatient or hospital ones, and being freer from social stigmatization. These last choices might be generated by factors that are related both to the personal characteristics of the patient and to social causes²⁸.

Let's now turn, finally, to the concept of capabilities. In Sen's formulation, "a person's "capability" refers to the alternative combinations of functionings that are feasible for her to achieve. Capability is thus a kind of freedom: the substantive freedom to achieve alternative functioning combinations (or, less formally put, the freedom to achieve various lifestyles). For example, an affluent person who fasts may have the same functioning achievement in terms of eating or nourishment as a destitute person who is forced to starve, but the first person does have a different "capability set" than the second (the first can choose to eat well and be well nourished in a way the second cannot)"²⁹.

From a formal point of view, "capability is a set of vectors of functionings, reflecting the person's freedom to lead one type of life or another"³⁰.

The reasons for which Sen claims the relevance of the assessment of capabilities with regard to a better understanding of well-being are the following.

Firstly, Sen points out that "if the achieved functionings constitute a person's well being, then the capability to achieve functionings (i.e. all the alternative combinations of functionings a person can choose to have) will constitute the person's freedom – the real opportunities – to have well-being"³¹. This view of capabilities as a person's opportunities for well-being has certainly an instrumental value, since it opens a window on the assessment of the 'position' of the person in question in the society. This last issue,

²⁸ See for some examples of these factors Borgia P. (2002). "Assessing effectiveness of home care for persons with AIDS: analysis of methodological problems." *AIDS care* **14** (5).

²⁹ Ivi.

³⁰ Sen, *Inequality reexamined* / Amartya Sen, p. 40.

³¹ Ivi.

in particular, is certainly important with regard to the HIV population. Nevertheless, the problem of the well-being freedom is certainly relevant also from a moral and policymaking point of view, since it enables us to focus the discussion also on the problem of the equity and of the equality in health care systems³².

Secondly, the “connection between well-being and capability takes the direct form of making achieved well-being itself depend on the capability to function. Choosing may itself be a valuable part of living, and a life of genuine choice with serious options may be seen to be – for that reason – richer”³³. Even this second connection between well-being and capability is certainly relevant from the point of view of people living with HIV. We will come back to this last point in the following part of our work.

One of the main methodological problems in socio-psychological research related to people living with HIV is the complexity of HIV illness across the spectrum from early disease to AIDS³⁴. A first consequence of this, as it has been pointed out in several contributions in the Health Related Quality of Life (HRQoL) literature³⁵, is that when health changes, values and perspective on life changes. Things that in the past were considered important may after a health change seem insignificant and, vice versa, things that were not valued become relevant and meaningful. This problem opens several very relevant and complex methodological problems, namely if these registered changes are changes in the meaning of Quality of life (QoL) or if they are changes in the assessed level of it³⁶. We cannot discuss such a complex methodological issue in this context.

³² Sen (2002). "Why health equity?" *Health Economics* **11**. and Williams (2003). "Comment on Amartya Sen's 'Why Health Equity'." *Health Economics* **12**.

³³ Sen, Inequality reexamined / Amartya Sen, p. 41.

³⁴ See all the contributions in *Quality of Life Research*, vol. 6, 1997.

³⁵ See, among others, Morris J.N. (1986). "Last days: a study of terminal ill cancer patients." *Journal of Chronic Diseases* **39**.

³⁶ See Allison P.J. (1997). "Quality of Life: A Dynamic Construct." *Social Science & Medicine* **2**.

Rather, we raise it to stress an important aspect of the assessment of QoL in HIV patients, an aspect that is not usually embraced in the several different models aimed to understand people living with chronic illness behavior and their quality of life³⁷. Indeed, in capability theory terms, this change of values and perspectives on life generates the need for different combinations of functionings, or in less formal terms, the need for a different lifestyle. Therefore, not only does the capability theory, being an individualistic approach, enable us to take into consideration these changes in the capability set, but it also gives us the possibility of assessing the actual freedom of the patients to determine this change of lifestyle. The capability to realize these changes, the possibility to satisfy the new emotional and psycho-physical needs is certainly related to the patients' well-being and, more specifically, to their quality of life. This characteristic of the capability approach seems relevant both for the clinical, the research and also the policymaking community. As a matter of fact, the potential constraints in achieving the new set of functionings, determined by this shift in the personal values, are rooted both in the entitlement set X_i and in the utilization function set F_i . From this point of view, one of the goals of both the clinical and the resource allocation and policymaking communities might be, first of all, to detect these changes, and then, finally, to try to expand the limits of choice reflected in X_i and F_i .

With regard to the selection of capabilities, it is important to follow a rigorous methodology. There are only a few contributions that address this problem. Sen himself has never offered a complete list of capabilities nor he has addressed the methodological problems involved in the selection of capabilities in a precise way. Despite the fact that

³⁷ See Taillefer, Dupuis, Roberge and LeMay "Health-related quality of life models: Systematic review of the literature." Social Indicators Research **64** (2).

this is due also to political philosophical reasons ³⁸, the fact of non-providing a list is rooted as well into the fact that Sen conceives the capability approach as a framework that can be implemented in different ways in different fields. Consequently, the methodological and technical problems involved in the selection of capabilities should be studied in each specific field of application. An example of a methodological reflection about the operationalization of the concept of capability comes from the feminist literature³⁹. We will introduce a methodology for eliciting a list of capabilities for people living with HIV and chronic illness more in general at the end of our paper.

Models for adherence behaviors

To date, a vast majority of the literature on the adherence to highly active antiretroviral therapies (HAART) of persons living with HIV has been based on a behavioral and reductionist approach. A tacit assumption of these studies has been that if a given therapy is not followed as prescribed by the health practitioner, then the problem must be with the patient⁴⁰. This premise is a consequence of the belief that the doctor's point of view and understanding of the patient situation is always the right and appropriate one⁴¹. As a consequence, non-adherence⁴² to HIV/AIDS therapies has been

³⁸ Carter (2003). Functionings, Capabilities and the Value of Freedom. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom. 7-9 September 2003 – University of Pavia, Italy. URL = <http://cfs.unipv.it/sen/papers/Carter.pdf>.

³⁹ Robeyns (2003). "Sen's Capability Approach and Gender Inequality: Selecting Relevant Capabilities." *Feminist Economist* **9** (2-3).

⁴⁰ Wright (2000). "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." *AIDS Care* **12** (6).

⁴¹ This belief tends to emerge clearly by analyzing the historical evolution of the lexicon used in medical reports to describe non-compliant behaviors. For example, with regard to tuberculosis, despite the fact that after the introduction in 1945 of curative antibiotics health officials "carefully eschewed the derisive language of earlier times", still alcoholic men (more subject to non-adherence behaviors) were called "recalcitrant". The term recalcitrant was defined as "stubbornly resistant to authority", evidently implying that physician imposed regimens patients were to obey. See the paragraph titled "A historical perspective" in Lerner, Gulick and Dubler (1998). "Rethinking Nonadherence: Historical Perspectives on Triple-Drug

considered as a pathological behavior. Accordingly, the goal of most research on adherence has been “identifying the barriers to patient co-operation and finding ways to make him or her more open to the doctor’s influence”⁴³. On the basis of this view of the problem the aim of researchers⁴⁴ has been: a) trying to develop measures of adherence (in order to check the magnitude of the “pathology”), b) identifying determinants of non-adherence (to identify the causes of the “pathology”), c) developing programs to modify patient adherence (to correct deviance and restore “normality”). So, the research has been focusing on determinants of compliance to prescribed regimens, on the search for “risk groups”, for a ‘typical’ non-compliant patient⁴⁵, but it has hardly ever taken into consideration the “*processes* of everyday self-care management”⁴⁶ and decision-making in chronic illness. More precisely, for the reasons that we will explain more clearly soon, when these processes of decision-making in chronic illness have been taken into consideration their understanding has been “extrapolated from knowledge gained in relation to one-time decisions, or decision making in contexts that are only superficially

Therapy for HIV Disease." Ann Intern Med **129** (7), p. 574. and, among others, Rothman "Seek and hide: Public health departments and persons with tuberculosis, 1890-1940." The Journal of Law, Medicine & Ethics **21** (3-4)..

⁴² The term *adherence* itself has been introduced recently as a preferable notion to *compliance*.

Compliance, in fact, began to be considered a vector of “judgmental and pejorative assessments of patient behavior and putting too much emphasis on patient failings in respecting norms exclusively defined by the medical professional” after that some physician started to advocate withholding HAART (Highly Active Antiretroviral Therapies) in cases where risks of patient’s non adherence were too high. The position of these physicians was determined by the potential public health threat represented by the possible generation in the HIV virus of resistance to the new therapies owing to non-adherence behaviors. Once “the political and social implications of the issue became clearer, the term “compliance” was heavily criticized by many, including NGOs”. The notion of adherence is “thought to allow for a more balanced perspective between physician and patient”. See Moatti and Souteyrand (2000). "Editorial: HIV/AIDS social and behavioural research: past advances and thoughts about the future." Social Science & Medicine **50** (11), p. 1525.

⁴³ Ibidem Wright "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." p. 704.

⁴⁴ Chesney, Morin and Sherr (2000). "Adherence to HIV combination therapy." Social Science & Medicine **50** (11), p. 1600.

⁴⁵ Wright "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." p. 704 and 706.

⁴⁶ Paterson, Russell and Thorne (2001). "Critical analysis of everyday self-care decision making in chronic illness." J Adv Nurs **35** (3), pp. 336, emphasis of the author.

related to the complexity and pervasiveness of living with a chronic disease”⁴⁷. This kind of research has therefore implied rational choice processes behind self-care management in chronic illness. However, several studies have shown how people violate the basic principles of rationality in their everyday acting⁴⁸, and this phenomenon tends to emerge even more clearly with regard to everyday self-care decision-making, especially for people living with chronic illnesses. There are in fact several factors that weigh on the choice process and it has been shown how particularly relevant are the meanings people living with chronic illnesses ascribe to the decision and to the process of decision making itself⁴⁹. In other words, people living with chronic illness do not detach their self-care decision-making from the way they experience their illness and their body responses to situations and treatments, in a word, from the “day-to-day questions and challenges raised by living with a disease”⁵⁰. This emphasis posed on rational cognitive processes in adherence/non-adherence research is the same as that which can be found in research focused on *risk elimination* for prevention and education programs, such as safe sex prevention campaigns, pregnancy prevention campaigns and so on. This research as well shares this common presumption that “people with chronic illness discern what is necessary to achieve a self-care goal and then make a decision to do whatever is necessary to achieve it”⁵¹. It is important to stress, however, that we are not trying to suggest that the self-care decision-making processes of people living with chronic illness

⁴⁷ Ibidem, p. 335.

⁴⁸ Kahneman (1994). "New challenges to the rationality assumption." Journal of institutional and theoretical economics **150**.

⁴⁹ Weller S.C. (1997). "Predicting treatment-seeking in Guatemala: comparison of health service research and decision-theoretic approaches." Medical Anthropology Quarterly **11**.

⁵⁰ Wright "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." p. 705.

⁵¹ Paterson, Russell and Thorne "Critical analysis of everyday self-care decision making in chronic illness." p. 336.

is devoid of logic. A close reading of the literature that tries to bring into the foreground not only the subjective experience of being ill – with its existential and symbolic elements – but also the context (in the widest sense of this expression) of medical practice – that is in terms of the communication processes between patient and health practitioner, of services and facilities offered in the place where treatment takes place and of the institutional and regulatory environment of the health care system – makes immediately clear that the ways in which people living with chronic illness explain their non-adherence behaviors seem quite rational⁵². What has to be taken into consideration to understand the kind of thinking⁵³ involved and the logic behind it is the individuals' perception of "HIV disease and treatment and its personal implications for each of them"⁵⁴ day-by-day. Inside this perspective patient choices sound rational, outside of it, on the background of a model of behavior that leaves room only for a narrow linear and utilitarian conception of decision-making, then they might not⁵⁵.

This attitude towards the understanding of non-adherence behaviors is evident once we review the logical structure of the main treatment models for non-adherence that have been proposed in the literature. These are: the Health Belief Model⁵⁶, the Theory of Reasoned Action⁵⁷, and the Theory of Planned Behavior. These models take into consideration the underlying cognitive factors that may explain variation in health care behavior. They are part of that family of psychological action theories and models called

⁵² Wu (2000). "Adherence and Health Care Utilization in HIV/AIDS- Rational or Rationalizing?" J Gen Intern Med **15** (12), p. 892.

⁵³ Markman and Gentner (2001). "THINKING." Annual Review of Psychology **52** (1).

⁵⁴ Wu "Adherence and Health Care Utilization in HIV/AIDS - Rational or Rationalizing?" p. 892.

⁵⁵ Donovan and Blake (1992). "Patient non-compliance: Deviance or reasoned decision-making?" Social Science & Medicine **34** (5).

⁵⁶ Rosenstock (1974). "The health belief model and preventive health behavior." Health Education Monographs **2**.

⁵⁷ Terry, 1993, The Theory of Reasoned Action: Its application to AIDS preventive behavior, New York, Pergamon Press,

expectancy-value theories. This family of theories shares the fact that a person's attitude is proposed to be influenced by his or her beliefs about the consequences of the behavior (i.e. costs and benefits), weighted by the person's evaluation of these consequences.

“According to the expectancy-value formulation, a person will have a positive attitude towards performing the behavior if he or she believes that performing the behavior will lead to mostly positive outcomes; that is, positive outcomes are considered likely, while negative outcomes are considered unlikely”⁵⁸. However, the Health Belief Model and The Theory of Reasoned Action are made up of different components of thought.

The Health Belief Model proposes that “readiness to take preventive health action arises from an evaluation of the level of threat associated with a disease (assessed with measurement of the perceived susceptibility to the disease and its severity), as well as an analysis of the costs and benefits of taking action”⁵⁹. Specifically the model is made up of four components: perceived susceptibility, perceived severity, perceived benefits and perceived barriers. With regard to adherence to antiretroviral therapy, *perceived susceptibility* can be interpreted as the chance that resistance against medication would take place if people would not take medication as prescribed⁶⁰. *Perceived severity* is the subjective perception of the seriousness of these implications of not taking one's medication adequately⁶¹. *Perceived susceptibility* and *perceived severity* together form what is called *perceived threat*. According to the Health Belief Model *perceived threat* “is one of the general forces that should lead to action”⁶². Finally taking a specific action

⁵⁸ Ibidem, p. 13.

⁵⁹ Ibidem, p. 5.

⁶⁰ Vincke J and Bolton R (2002). "Therapy Adherence and Highly Active Antiretroviral Therapy: Comparison of Three Sources of Information." AIDS PATIENT CARE and STDs **16** (10), p. 488.

⁶¹ Ivi .

⁶² Ivi .

is also considered to be determined by *perceived benefits* and *perceived barriers*. The *perceived benefits* are seen as the belief in positive outcomes for following the treatment and they are usually weighted against the *perceived barriers* of taking one's medication, such as interrupting one's social life.

The central premise of the Theory of Reasoned Action is that people make behavioral decisions on the basis of a systematic reasoned consideration of the available information⁶³. People are then assumed to be rational actors who make reasoned behavioral decisions⁶⁴. According to this model, "the immediate determinant of behavior is the person's *intention* to perform it. The determinants of people's intentions are, in turn, proposed to be the favorability of their *attitude* towards the behavior and the extent of perceived normative pressure to perform the behavior (*subjective norm*)"⁶⁵. The Theory of Reasoned Action has three further components: the *behavioral beliefs*, which are the beliefs concerning the consequences of performing the behavior, and the *normative belief*, which are people's perception of the pressure from others to perform the behavior. Now, people's attitudes toward a behavior are considered to be a function of their *behavioral beliefs*, weighted by the *outcome evaluation*, which is the value placed on each of the consequences. While the *subjective norms* is proposed to be a function of *normative beliefs*, weighted by their *motivation to comply* with these others⁶⁶.

⁶³ Terry, The Theory of Reasoned Action: Its application to AIDS preventive behavior, pp. 7-8.

⁶⁴ Ibidem, p. 7.

⁶⁵ Ivi

⁶⁶ Ibidem pp. 8-9.

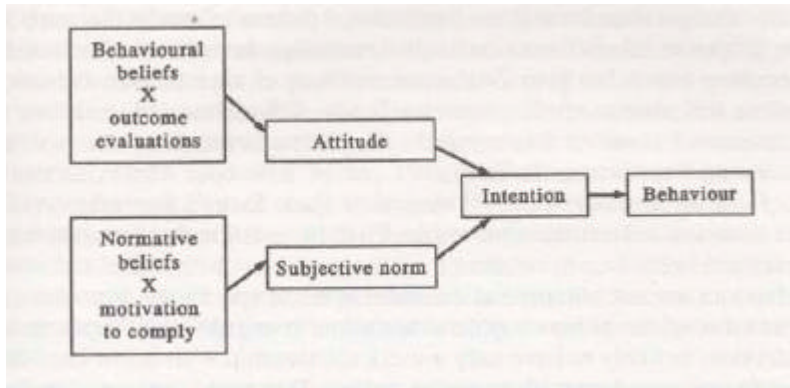


Figure 1. Source: (Terry 1993 Cited, p. 9)

The Theory of Planned Behavior is an extension of the Theory of reasoned Action that suggests that the extent to which the behavior is under volitional control also needs to be taken into consideration⁶⁷.

Even from this really basic sketch of the main characteristics of these models two relevant aspects emerge clearly: first of all, their rationalistic view of people self-care decision-making, secondly their individualistic approach that determines a one-sided view of the problem of adherence⁶⁸ that doesn't allow an account of "neither the behavior nor attitude of the doctor nor the structures of the health care system"⁶⁹.

The necessity for more comprehensive models is widely recognized in the literature and some alternative models, such as a Self-Regulatory Model⁷⁰, have been proposed. The aim of self-regulatory theory is to provide "a unifying framework that broadens a patient-centered understanding of the dynamic factors involved in adherence

⁶⁷ Ibidem, p. 27.

⁶⁸ Wright "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." p. 704.

⁶⁹ Ivi .

⁷⁰ Reynolds (2003). "The problem of antiretroviral adherence: A self-regulatory model for intervention." Ibidem 15 (1).

behavior”⁷¹. It “suggests that people seek to understand their illness by developing a working model or representation of what the illness is, its cause, its effects, how long it will last and whether it can be cured or controlled”⁷². In this model, “individuals are thought to be motivated to regulate or minimize their health-related risks and act to reduce these health threats in ways consistent with their perceptions of them”⁷³.

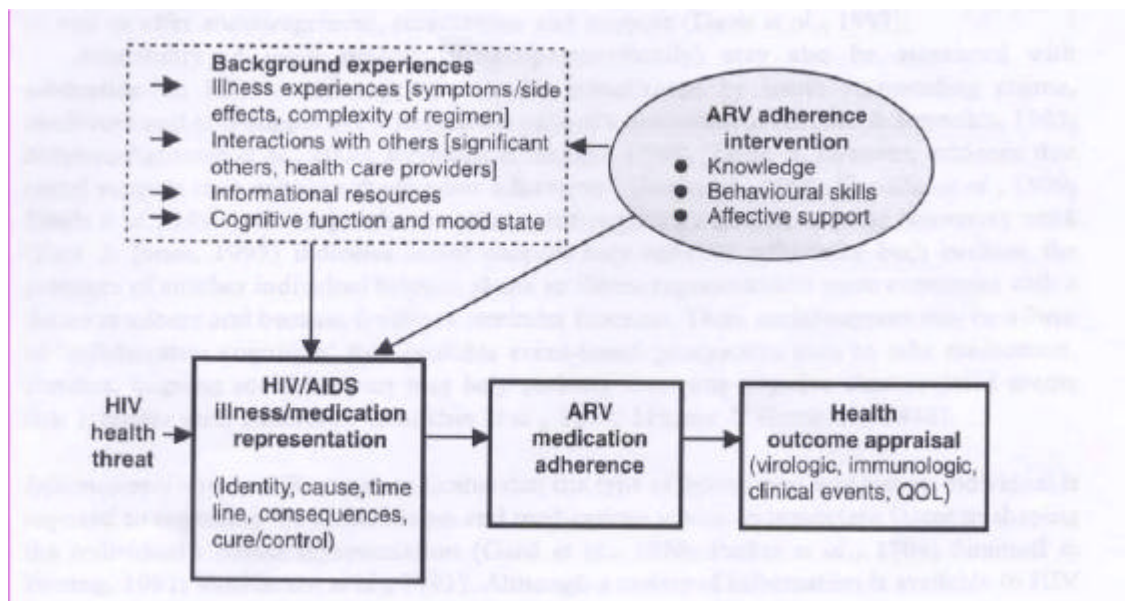


Figure 2. Source: (Reynolds 2003 Cited, p. 118)

However, despite the fact that this model at least acknowledges the relevance of the patient perspective, it doesn’t succeed in explaining or broadening our understanding of the processes and relationships through which the individual perspective is embedded in his or her context.

⁷¹ Ibidem, p. 118.

⁷² Ivi .

⁷³ Ivi .

New theoretical approaches to adherence and the capability approach contribution

A new concept, known as *concordance*, has entered the debate around adherence programs and behaviors. This term has been introduced to stress a new conception of the relationship between patient and caregiver. A relationship that cannot be any more, as in the traditional model, one where the patient can only have a passive role aimed at complying with the doctor's choices. On the contrary, the physician-patient interaction would become more of a sort of collaboration, "negotiation of the most realistic and efficacious strategy for dealing with the disease"⁷⁴. It is worth quoting in full the following definition of *concordance* given by a multidisciplinary group of health professionals, academics and members of the pharmaceutical industry in UK:

"Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. This alliance, may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment"⁷⁵

From this point of view the patient is considered again a full person with his, her own style of life, needs and values of which health, is only one⁷⁶. The goal of this

⁷⁴ Wright (2000). "The old problem of adherence: Research on treatment adherence and its relevance for HIV/AIDS." *Ibidem* **12** (6), p. 707.

⁷⁵ Party (1997). From compliance to concordance: Achieving shared goals in medicine taking. Report of the Working Party. London, Royal Pharmaceutical Society of Great Britain/Merk, Sharp and Dohme: pp. 8, pp. 8, quoted in {Bissell, 2004 #505, .}

⁷⁶ Alkire, 2002, *Valuing Freedoms: Sen's Capability Approach and Poverty Reduction*, New York, Oxford University Press, p. 147.

approach though is not to “cede decision making to patients but rather to promote nonjudgmental dialogue and negotiation between patient and physicians”⁷⁷.

Now, the concepts of *participation* and *informed choice* have always had a central role in Sen’s writings. The capability approach, being a liberal approach, as Martha Nussbaum has written, “does not aim directly at producing people who function in certain ways”⁷⁸ – in our case, for example, to produce people who function well from the health point of view – but rather aims “at producing people who are capable of functioning in these ways, who have the training and the resources to so function should they choose. The choice itself is left to them”⁷⁹. The concordance model can then be read from a capability perspective in terms of an expansion of valuable capabilities. In particular, it can be regarded as an expansion of the end of *autonomy*. The concept of personal autonomy has been discussed from several different points of view in philosophy. In general terms it emerges that “the value of autonomy is tied to the value of self-integration. We don’t want to be alien to, or at war with, ourselves; and it seems that when our intentions are not under our own control, we suffer from self-alienation”⁸⁰. Moreover, the psychologist Sharon Brehm in the sixties introduced the so-called theory of psychological reactance. The concept of reactance is that unpleasant feeling that people experience when they feel that their freedom to choose an action is threatened. This same feeling would also motivate them to perform the threatened behavior, thus

⁷⁷ Lerner, Gulick and Dubler "Rethinking Nonadherence: Historical Perspectives on Triple-Drug Therapy for HIV Disease." p. 576.

⁷⁸ Nussbaum (1990). Aristotelian Social Democracy. in Liberalism and the good. R. Bruce Douglass. New York, Routledge. quoted in Carter Functionings, Capabilities and the Value of Freedom. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom. 7-9 September 2003 – University of Pavia, Italy. URL = <http://cfs.unipv.it/sen/papers/Carter.pdf>: p. 21.

⁷⁹ Ivi.

⁸⁰ Buss (Winter 2002). Personal Autonomy. The Stanford Encyclopedia of Philosophy, Edward N. Zalta (ed.).

proving that their free will has not been compromised⁸¹. The psychologist Sharon Schwartz includes “self-direction” – intended as ambition to independent thought and action, and, consequently, as ambition to choosing, creating and exploring – in the list of universal human values. These values are conceived to be guiding principles in people’s lives and, therefore, potential action motivators⁸². The freedom to choose or to do something, which in Sen’s view and, more generally, from a liberal point of view has value per se, requires the capability to act autonomously, even in health-care. As Conrad has written: “[...] many chronically ill people view their behavior differently, as a matter of self-regulation. In this light non compliance supports people’s desires for *independence* and *autonomy*, desires that align closely with therapeutic goals of caregivers”⁸³. In conclusion, there are several reasons to take into serious consideration the issue of personal autonomy as a fundamental requisite of models aimed not only at understanding the behavior of people living with HIV with regard to antiretroviral therapy, but also for clinical models aimed at improving adherence behaviors. In the medical ethics debate the problem of autonomy has been recently embraced. Beauchamp and Childress to this regard write: “Being autonomous is not the same as being respected as an autonomous agent. To respect an autonomous agent is, at a minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs. Such respect involves respectful *action*, not merely a respectful *attitude*. It also requires more than obligations of non-intervention in the affairs

⁸¹ Brehm, 1981, Psychological reactance : a theory of freedom and control / Sharon S. Brehm, Jack W. Brehm, New York :, Academic Press,

⁸² Schwartz, Sagiv and Boehnke "Worries and values." Journal of Personality **68** (2), Schwartz and Bilsky (1987). "Toward A Universal Psychological Structure of Human Values." Journal of Personality & Social Psychology **September** **53** (3).

⁸³ Conrad (1985). "The meaning of medications: Another look at compliance." Social Science & Medicine **20** (1), pp. 15, my emphasis.

of persons, because it includes obligations to maintain capacities for autonomous choice in others while allaying fears and other conditions that destroy or disrupt their autonomous actions”⁸⁴. The capability approach offers a theoretical basis to the *concordance* approach in health care because it highlights the central importance of the topic of how capable people are of functioning, that is, for example, with regard to people living with HIV, how capable they are, how free they are to choose to have a suppressed viral load (functioning) thanks to the antiretroviral therapy (commodity/resource). As we saw above, in the second paragraph, this last issue is certainly relevant when we wish to assess the well-being of people living with HIV. However, this is our point, it is of central importance also from a clinical perspective, that is a perspective that aims to improve the functionings of people living with HIV functionings. In order to make people living with HIV capable of achieving relevant functioning through the use of antiretroviral therapy it is crucial to make them capable to do so. In order to make them capable to do so, as it has emerged by examining the recalled relevant literature, it is of crucial importance to promote that capability which is their *personal autonomy* in managing the cure. The focus of the traditional approaches to adherence behavior exclusively on obstacles to functionings and, more in particular, on programs aimed to making them functioning well (by suppressing the ir viral load), has totally overlooked the central question of the agents’ freedom to bring about functionings in the context of living with a chronic illness. From this point of view, the capability approach does not offer only a theoretical framework for the *concordance* model, it also offers an operational interpretation of it that intrinsically take into account the centrality of the

⁸⁴ Beauchamp, 1994, *Principles of Biomedical Ethics*, Oxford, Oxford University Press, p. 125., quoted in Alkire, *Valuing Freedoms: Sen's Capability Approach and Poverty Reduction*, p. 146.

agent and its freedom to choose. To increase the capabilities people have in fact is one way of operationalizing the capability approach. This way of operationalizing it, following the reflection of Sabrina Alkire⁸⁵, “requires one:

- a) to identify valued capability goals and strategies (e.g. using participation);
- b) to work in the short term to establish functionings instrumental to these goals;
- c) to use a procedure in the implementation that safeguards negative freedom”⁸⁶.

This approach to the operationalization of the capability approach considers that capability “at the micro level simply refers to an absence of coercion and the ongoing possibility of choice”⁸⁷. Interpreting the three phases of the operationalization of the capability approach just listed in terms of the adherence problem, let’s say that the goals to achieve are the virological and immunological benefits of the antiretroviral treatment and that this is a shared goal between patient and prescriber. The beginning of antiretroviral therapy to achieve this goal requires considerable self-care skills and knowledge, knowledge of the illness and motivation that can be reached through devising treatment plans. Lerner and colleagues⁸⁸ make a complete list of what these devising plans should include.

“First, patients should be given access to 1) culturally appropriate educational pamphlets, videos, and CD-ROMs describing how pills should be taken and the possible side effects of the pills; 2) professionals who can help them identify necessary physical, psychological, and social supports, such as peer group advisors, transportation, and child care; and 3) technologies, including printed medication charts, beepers, and pill boxes,

⁸⁵ Alkire, Valuing Freedoms: Sen's Capability Approach and Poverty Reduction, p. 174.

⁸⁶ Ivi

⁸⁷ Ibidem p. 175.

⁸⁸ Lerner, Gulick and Dubler "Rethinking Nonadherence: Historical Perspectives on Triple-Drug Therapy for HIV Disease." p. 577.

that may facilitate reliable drug ingestion. Second, patients should receive help in 1) identifying lifestyle characteristics, such as homelessness, irregular work schedules, or frequent travel, that may interfere with the treatment plan and may need to be changed before therapy is initiated; 2) arranging for housing, food stamps, or drug rehabilitation if such assistance is seen as a precondition to initiation of treatment; and 3) designing a "draft plan" that links regimens to established daily routines, such as watching a specific television program, brushing teeth, and checking the mail. Third, patients should be offered 1) an experimental "dry run" with dummy pills to test the viability of proposed treatment plans; 2) regular feedback on viral load and T-cell counts after therapy begins; and 3) tools with which to assess the treatment plan, such as medication diaries and electronic timing devices. Fourth, patients should be assured of continued access to these types of supports for as long as treatment is medically indicated. It should be stressed that provision of adequate funding for all HIV-positive persons who begin and continue to require triple-drug therapy is fundamental to this effort of facilitating treatment"⁸⁹.

As Alkire points out, considering the amount of energy that these plans would imply, then the need to safeguard choice may be secondary for the period needed to build those basic functionings fundamental to achieve the bigger goal⁹⁰. It is important to stress though that such activity aimed at developing self-care skills and knowledge of the illness develops in light of the final goal of making able participants to choose critically whether or not they will keep adhering to the therapy or not. In fact, "this precludes coercive measures that will not develop this capability to choose eventually but allows the

⁸⁹ Ivi .

⁹⁰ Alkire, *Valuing Freedoms: Sen's Capability Approach and Poverty Reduction*, p. 175.

temporary use of self-enforcement techniques”⁹¹, just such as those ones suggested by Lerner and colleagues.

A central point in the operationalization of the capability model is certainly to identify valued capability goals and strategies. This can be done methodologically in several ways. By means of focus groups involving experts, that is clinicians and patients, through a review of the literature or, as we suggest, by means of asking directly to people living with HIV. In a project actually running we will use a phenomenological approach to elicit what these values are. From our point of view, in fact, this approach is the best one to have access to the *lived world* of people living with HIV and so to enhance our understanding of their personal and social world not from a clinical or medical perspective but as they perceive it. This approach will give us also the possibility to address the fundamental issue of what is the kind of thinking, both in terms of its kind⁹² and in terms of its content, that underlies how people decide what functionings to value. The understanding of this issue has been traditionally addressed mainly from a philosophical point of view in the capability approach. However the understanding of it from a psychological and sociological point of view may yield great clinical, social and economic benefits.

⁹¹ Ibidem, p. 176.

⁹² Markman and Gentner "THINKING."

Appendix.

Relevance of fuzzy set theory for the capability approach

A fuzzy set is a set in which the membership is a matter of degree rather than a matter of belonging either totally or not at all. As Sen himself points out, the concepts of “well-being”, of “inequality” and we can add of “capability” as “freedom to choose” too, are “broad and partly opaque”⁹³. It is important to stress what opaque means. The use of terms related to the different forms of ignorance⁹⁴, has to be pointed out clearly to avoid referring to the wrong tool when we are going to address the kind of uncertainty that affects the phenomenon being studied. In the case of Sen’s concepts of functionings and capability we are facing examples of fuzzy concepts. This means that they are concepts the meanings of which are such that we have difficulty putting a sharp and unquestionable edge to delimit their extensions. There will always be some elements that are uncertain with regard to the fact of whether they “belong or not” to the extension of these concepts. These kinds of concepts manifest themselves in different degrees. For example, most of the functioning that we have cited above, from being *nourished* to being *medically assisted in a comfortable environment*, very often will be only partially achieved, rather than fully achieved or not achieved at all. The same is true for capabilities. In other words, it seems more meaningful to consider a capability set – which is, as specified above, a set of vectors of functionings – as a fuzzy set, that is a set that allows a gradual membership rather than an all or nothing one.

Fuzzy logic is then useful as a tool to formalize concepts like these last ones. However, there is a second reason for which fuzzy set theory can be considered of great help for the assessment of the quality of life of people living with chronic illness. As pointed out by Sen himself, just because of the fuzzy nature of functionings and capabilities, it is important to admit *incompleteness* with regard to their assessment and valuation. There are different kinds of incomplete orders. Now, order is an essential concept in fuzzy set theory. So the study and the applications of the mathematical structure of fuzzy set theory can be of great help for the assessment of quality of life. As

⁹³ Sen, *Inequality reexamined* / Amartya Sen, p. 48.

⁹⁴ Smithson, 1989, *Ignorance and Uncertainty: Emerging Paradigms*, New York, Springer Verlag,

Sen tends to stress, it might be an error to look for a complete ordering when we deal with fuzzy concepts. So, evidently, clarifying if a complete order is possible or even conceivable in the field of quality of life in HIV research, what kind of order we are dealing with, and so on, are certainly all central questions if we want to develop instruments that are well-developed in terms of measurement. All these questions are also entirely relevant if we are going to apply fuzzy logic in a rigorous way.

Even what is usually considered a weak point of the fuzzy set theory actually turns out to be a good one when thought about with regard to the capability approach. This is the fact that membership functions, in fuzzy set theory, are contingent. This last point seems to be a positive one if we think of the fact that social and personal factors influence both the conversion from resources to functionings and capabilities. From this point of view then, the contingency of the fuzzy set membership functions might result in a positive feature, since it can enhance the formalization of the personal and external factors in a clear way.

To sum up, Sen's "capability approach" offers us the possibility to construct a formal account of the concept of quality of life within a relevant theoretical framework. Consequently, it gives us the possibility of addressing some of the enduring conceptual and measurement problems in the field in a meaningful and effective way.

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