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The Information-Motivation-Behavioural skills model of ART adherence in Romanian young adults

Running title: The IMB model of ART adherence in Romanian youth

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Developing theory-driven and culturally-appropriate support for treatment adherence is critical to positive health outcomes in adolescents and emerging adults living with HIV/AIDS. Romanian young long-time HIV survivors represent a special population requiring urgent assessment of specific adherence-support needs. We adapted the Information-Motivation-Behavioral Skills (IMB) model of adherence to this population via thematic analysis of data from focus groups with service users and medical professionals. We identified various adherence-relevant themes consistent with previous IMB-model research, but also new themes such as the role of informational conflicts, long-term goals and altruistic motivation, which reflect the long-term treatment experience and the developmental characteristics.

Keywords: adherence < Treatment Issues; Information-Motivation-Behavior Skills model < Research; qualitative research < Research; youth < Age; Europe < International; needs assessment < Service Practices

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Introduction

Adolescents and young adults represent over 70% of the people living with HIV/AIDS (PLWHA) in Romania, most of them infected at early ages in hospital settings because of contaminated blood transfusions or nonsterile medical equipment (Buzducea, Lazăr, & Mardare, 2010), as part of the nosocomial spread of HIV in the early stages of the epidemic (1986 to 1992) in Europe and the United States (Franceschi, Maso, & La Vecchia, 1995). Of the estimated 10000 Romanian children affected at the time, about 7000 are long-term HIV survivors, and 68% of these are actively monitored (Buzducea, et al., 2010). Although this cohort has extended histories with antiretroviral therapy (ART), the transition to adulthood brings a new challenge as behaviors change from having adherence largely managed by a caregiver to self-management, which tends to be associated with reduced adherence (Sawyer & Aroni, 2005). Whereas newer formulations provide more ‘forgiveness’ for non-adherence, sustained near-perfect adherence is still recommended for positive clinical results (Conway, 2007). A recent national survey (Blagoslov, Luca, Ene, Duiculescu, & Lazăr, 2008) revealed that 63% young PLWHA reported non-adherence to ART, suggesting that non-adherence may be common in young adults. Despite universal access to HIV treatment and care in Romania, effective services for supporting consistent use of available treatment are underrepresented in the literature and in practice. Therefore urgent research and interventions are needed to support the attainment and maintenance of optimal medication adherence in this cohort (UNAIDS, 2012).

Identifying the determinants of ART adherence is the first step toward developing empirically-guided, well-situated targeted interventions, but research on this population is scarce. Several factors such as long-term lack of symptoms, fear of disclosure, travel, forgetting, or distress have been identified as relevant for non-adherence in young Romanian PLWHA (Blagoslov et al, 2008). However a comprehensive theory-based needs assessment

would offer a more adequate basis for intervention development (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011).

The Information-Motivation-Behavioural Skills (IMB) model of ART adherence offers a systematic framework for theory-based interventions (Fisher, Fisher, Amico, & Harman, 2006; Fisher, Amico, Fisher, & Harman, 2008). Information relevant to adherence includes basic accurate information about the regimen, requirements of adherence, and drug interactions and side effects, as well as misinformation and incorrect heuristics. Motivation includes one's beliefs and attitudes about the consequences of adherence, and includes both personal and social aspects. Behavioral skills are those skills needed for individuals to adhere to one's regimen and one's self-efficacy in using those skills. Further, the model includes a set of moderators which may dilute the potential effect of IMB model-based interventions in some contexts (including acute psychological health issues, homelessness, and active drug abuse). The model has received support from previous research with other populations on ART and has been the basis for a number of different adherence interventions (Amico et al., 2007; Amico et al., 2009; Amico, Toro-Alfonso, & Fisher, 2005; Fisher et al., 2008). It has been previously used in risk behaviour interventions in young people (Fisher et al 1996), in investigating challenges of ART adherence in HIV-positive youth (Rongkavilit et al., 2010), and ART-related views in youth at risk of HIV infection (Simon, Altice, Moll, Shange, & Friedland, 2010).

In developing IMB model based interventions, the authors recommend a 3-step process: elicitation work with the target group, intervention development and implementation, and rigorous evaluation (Fisher et al., 2006). We report on the first phase of this articulation process: the qualitative exploration of the causes of non-adherence in young Romanian long-term HIV survivors within the framework of the IMB model. Specifically, we sought to characterize the kind of content within each of the core IMB constructs that would

be most relevant to this unique group of young adults living with HIV and also to identify any factors outside of the IMB model constructs that participants found influential to their daily negotiation of medication taking.

Design

We organized two focus groups each with approximately 10 young PLWHA and one focus group with 9 health care professionals (HCPs: doctors, nurses, social workers, psychologists). We aimed for a maximum variation sample based on gender, education and adherence levels estimated based on clinical assessment file for service users, and clinical specialty and years of experience in working with PLWHA for HCPs. Thirty service users and twelve HCPs (from a health centre serving a relatively large and geographically concentrated number of young long-time HIV survivors) received a written invitation detailing the purpose of the meeting (i.e., discussion group on adherence to medication), its location (the health centre) and time, and measures for ensuring confidentiality. Interested individuals contacted the study team and gave their consent prior to the focus groups following standard procedures of the health centre regarding activities with service users' and HCPs' participation. No financial compensation was provided for participation; travel costs were reimbursed if applicable. The Bucharest Institute of Virology and the Baylor College of Medicine Institutional Review Boards approved the study procedures.

Two authors (psychologists trained in qualitative research and group moderation methods) planned and moderated the focus groups (ALD and AMS). We developed and applied a semistructured format following recommended procedures (Morgan, Krueger, & King, 1997; Stewart, Shamdasani, & Rook, 2007). Questions (Table 1) included brief queries followed by targeted exploration of the core IMB content areas, as well as general topics. Last, participants gave general written comments on the perceived barriers and facilitators of adherence related to the services offered by the health centre. The meetings lasted

approximately 90 minutes and were well-received by both service users and HCPs. We recorded and transcribed all focus groups verbatim.

INSERT TABLE 1 ABOUT HERE

Analytic Approach

We conducted a thematic analysis following a heuristic schema proposed by Ware, Wyatt, and Bangsberg (2006) to guide the application of a theoretical model of adherence to a new sociocultural context. It consists of addressing four key issues: relevance, comprehensiveness, accuracy and complexity. Addressing relevance means identifying whether the model's concepts are represented in the target groups' experiences regarding adherence. The issue of comprehensiveness involves the extent to which there are new concepts important for the new setting which should be added to the model. Accuracy represents identifying the most representative indicators of the basic concepts in the new settings. Finally, complexity means investigating whether the model is able to retain the richness of the target group's experiences regarding adherence in the new context.

For our study, we translated this schema into four investigation topics. We first examined all adherence discourse for statements that referred to patients' knowledge about the treatment, their motivation to take the medication as prescribed, and their abilities to apply different strategies in different contexts to take the medication as prescribed. Second, we searched for discourse referring to additional determinants of adherence specific to this target group that fell outside of the three main constructs, and also for content referring to moderators as stated in the IMB model. Third, we identified the statements describing the specific types of information, motivating factors and behavioral skills which participants found necessary for adequate adherence, focusing both on indicators common to the ones already identified in the model and on indicators specific to this particular sociocultural

context. Fourth, we used results of content and theme analyses to characterize the complexity of the phenomenon of adherence in our cohort.

One analyst (INITIALS REMOVED FOR BLINDED REVIEW) first compiled the data coding of the Romanian text using an adapted scissor-and-sort technique (Stewart et al., 2007) and translated the selected statements in English, then discussed themes and interpretations with two other researchers (INITIALS REMOVED FOR BLINDED REVIEW). We segmented the transcripts and the written documents obtained from the group activities by identifying all adherence-related statements, and then reviewed them in the context of the full transcript; thus we attempted to consider the segments identified without separating them from the larger discussions. This strategy allowed us to remain aware of the contextual connotations while considering content code and theme identification, and thus to retain the complexity of the phenomenon of adherence in our cohort by preserving the rich contextual meaning of the themes identified.

We analyzed each statement first to identify whether it belonged to one of the three categories identified in the IMB model as described in Fisher et al. (2006): information, motivation, behavioral skills. We considered as new within-construct themes any statements that we judged as reflective of information, motivation, or skills, but not corresponding to any specific factors described in previous IMB models. We interpreted statements as belonging to more than one category where appropriate (e.g. statements about lack of social support or about difficulties of managing privacy were coded both within motivation and skills). We supplemented this deductive methodology with an inductive approach; we further examined the text for new themes which could be relevant to adherence in this cohort but not mapping onto the IMB model. We excluded from these analyses any issues not directly related to adherence (e.g. infection prevention, contraception, interpretation of medical tests).

We evaluated the transcripts from patients' focus groups and the transcript for the HCPs' group separately. However, given the substantial overlap in both patients and providers noting similar content, we considered results as representing both sets of participants, unless otherwise noted.

Results

The 20 participating service users (12 women) had a mean age of 21.4 years (range 20 to 23), 40% came from rural areas, and had an average of 11 years of education (30% university level, 25% elementary school level or below) and had a mean ART treatment duration of 8.5 years with a mean of 14 years since confirmation of their HIV diagnosis. All HCPs (3 doctors, 1 nurse, 3 psychologists, 2 social workers) were women (almost all HCPs in this setting are women), had a mean age of 40 years, and on average 9.4 years of working with PLWHA. We present results related to each of the three IMB-model constructs, and give selected examples of statements from service users and HCPs (English translation of the Romanian text).

Information

Both service users and HCPs considered knowledge of drug actions as relevant for adherence, particularly the perception of the treatment as prolonging life and the awareness of the variability of individual responses: "It stops the multiplication of the HIV virus in the organism." (mentioned by a service user as hypothetical advice for taking medication); "Most importantly, they have to know that they depend on this treatment. . . . From the moment they stop taking it, the time interval until an adverse event will occur which can be fatal varies in each case." (HCP)

Service users and HCPs mentioned the importance of knowledge of the medication regimen, its potential side effects, drug actions and interactions: "First of all they have to

know very well. . . the name, the dosage, how, side effects. . . after a meal, one hour before the meal. . . and administering with food.” (HCP); “[I want to know] how do Norvir and other pills affect my liver?” (mentioned by a service user as a topic on which more information is needed).

Discourse amongst service users, also supported by HCPs, suggested a feeling of being generally well informed about how medication interacts with alcohol and smoking cigarettes; however, the accuracy of the information and its influence on non-adherence raised some concern.

A patient once told me: “I have spoken to the doctor and he told me not to drink alcohol”. Well, actually, [the patient said]: “if I intend to go to a party and I drink alcohol, [the doctor told me] not to take the pills, that evening”. (HCP)

Service users and HCPs mentioned several misconceptions. For example, some users may hold the belief that skipping doses does not affect health and is acceptable as long as one feels healthy: “You feel well, so what's the point [in taking the treatment].” (service user). Some may believe that experiencing side effects is an indicator that the treatment is not adequate: “[I don’t understand why] they tell me “you are not resistant to [the pills]”, even though I feel sick when I take them?” (service user). Some may think that any regimen will eventually lose potency regardless of adherence: “Or they think that they have been taking them for so many years, and they must have become resistant, for sure, so maybe it is time to change something.” (HCP). Other misconceptions expressed were believing that adherence means living a monotonous life; that one will always have treatment options irrespective of adherence behaviors; that taking only one of several medications still represents good adherence; that medication timing is not part of one’s regimen requirements; or that it is acceptable to wait for HIV to advance before starting treatment. Some of these beliefs, such as concerning the development of resistance and associating adherence with a boring life,

also include a notable motivational component; thus supplying accurate information (e.g. on the role of adherence in allowing individuals to remain on a given medication regimen, or on the rationale behind specific adherence requirements) may enhance adherence via multiple pathways.

Service users and HCPs described situations in which patients might experience doubt and confusion when information they were provided or otherwise “know” were mismatched with experiences.

If I think of some specific cases like X, to whom we have been repeating for years that she is in a very bad state, and “no one knows when something will happen to you, but it will for sure”, since we started telling her that she had 2 kids. And she still feels well, and does not take medication; it means that she thinks somehow that we tell her these things, [she thinks they are] false. (HCP)

This “informational conflict” also contained reference to the belief that one is not currently receiving the most adequate treatment or most accurate information. We identified several discourse sequences where a user could recognize and repeat the “party line” and then qualify it with disbelief and the sharing of evidence of experiences that challenged the accuracy of the “standard information”. We often coded these sequences as both information and motivation, however they did appear most reflective of the covariance between these two determinants.

When discussing the relation between medication adherence and other self-care behaviors some patient-participants displayed a kind of all-or-nothing thinking as they described all multiple self-care behaviors as essential and viewed adherence as only one of several behaviors required for positive clinical outcomes: “Together with alcohol and tobacco all is in vain and leads to the destruction of the organism.” (mentioned by service user as hypothetical advice for a newly diagnosed person).

This type of factual belief could lead to increased motivation through synergies across self-care behaviors, but could also deter adherence when one aspect of self-care becomes impossible or difficult to achieve (e.g., eating healthy) and the individual does not consider incremental steps toward self-care as valid or effective.

Motivation

Service users and HCPs shared several motivational barriers to adherence, such as negative experiences with side effects (“When you take them and feel sick [you say] that's it, I don't take them anymore.” – service user), concerns about long term negative consequences of being on ART (“Taking the treatment might affect one organ or all of them.” - mentioned by a service user as an argument against taking medication), pill fatigue (“As reason for feeling discouraged, I have also come across: they say they have had enough of so many of them” – HCP), believing that taking ART was a reminder of one's HIV status (“Because I know what I take them for, I would have rather taken the treatment for something else.” – service user), and frustration at planning one's life around treatment (“If he does not take medication, for him the immediate benefit may be the fact that [...] he doesn't have to be preoccupied with what time it is” – HCP) and having to take medication for the rest of their life. (“Yeah, right, if you take them they'll cure you (with or without them it is the same thing).” – service user)

Difficulties related to obtaining refills, whereas part of the behavioral skills category in the IMB model, emerged here as a motivational factor in terms of negative real or anticipated experiences with the process of getting refills fostering negative attitudes toward adherence: “Busy waiting rooms; for some, the long distance from the hospital; long waiting times in the day of appointment.” (mentioned by a HCP as factors that decrease motivation)

Among the factors sustaining adherence motivation were the feeling of personal control over clinical outcomes, the perception of personal vulnerability (“I have been through

a lot and I don't want to go through that again, I stayed in hospital for so long.” – service user), and the hope for future medical progress in HIV treatment (“Every year the treatment/science progresses and better and more efficient treatments show up.” – service user).

The awareness that high ART adherence helps extend life translated at the motivational level in conversations about future goals, careers, and life goals, which make adherence a priority: “And [I want to take medication] especially when I think that I have a reason to live and to fight, for my little boy.” (service user)

Service users and HCPs considered the support of family and feeling positively about doctors and nurses providing HIV-care as an important adherence factor: “The staff's [positive] attitude towards them, the promptness with which their problems are solved.” (mentioned by a HCP as factors that increase motivation).

In the context of a medical system which provides HIV treatment via special state-funded programs, service users and HCPs mentioned free access to therapy as a positive aspect of the doctor-patient relation: “It is free; you receive a very expensive treatment.” (mentioned by service user as a factor that increases motivation).

We identified social comparison (observations of how others have succeeded or failed in relation to adherence) as a type of social influence particularly important to this group, in addition to the existing IMB constructs of social norms and social support. Patients seemed assess the effectiveness of taking medication and personal vulnerability also by noting the results (health, illness, death) of other people's adherence behaviors: “And they speak with each other “see, I feel good, I have not taken any pills anymore the last 3 months”. “I'll not take them either, let's see.”” (HCP)

Service users also shared the experience of feeling frustrated at not having the lifestyle typical of others their age, and feeling different from others in their social network or the typical young adult.

When I go on school camps or go out with friends in the neighbourhood and I can't take [the pills] in front of them, it is very discouraging. [I mean] with friends that are not like me, and I have to get inside the toilet [to take them]. (service user)

The central role of social support as a motivator, and prioritizing adherence for social reasons, such as extending one's life as long as possible to be there longer for family members also highlight the importance of the social context: "Many you will leave behind will suffer if you choose not to take [the treatment], and then you can't turn back time." (mentioned by a service user as an argument for taking medication).

However, as further detailed in the next section, we also identified situations where social influence had a negative influence on adherence behaviors, such as using nonadherence to influence one's social/interpersonal relations (i.e., some patients reported intentional nonadherence when angry with a parent or caregiver as a way to punish them).

Behavioral skills

Service users and HCPs discussed several behavioral skills relevant for specific situations, including skills in information seeking ("[I search] on [name of search engine], but sometimes you can't find as many explanations as you need." – service user), management of side effects ("and I have really bad side effects from them. After I take them. . . . What can I do to be able to take them? Because I want to take them." – service user) and taste of ART ("Many people take it with juice or anything, or with something immediately after, so that the taste does not linger." – service user), including medication into daily routine ("Some have a set routine, so they know, in the morning they wake up, wash, eat, take medication." – HCP), maintaining privacy when taking ART ("When you visit friends or family that don't know

about your diagnosis . . . I go to the bathroom. . . . You can always lie. . . . You can say you take something else.” – service user), addressing disclosure of HIV status (“[at work] the boys were asking me why do you take pills, and I was telling them, I was not ashamed. Because hiding doesn't work.” – service user), and using reminder devices/strategies (“[To remember] you set up the alarm on your phone to go off in the morning and in the evening.” – service user) as well as relying on others for reminding them of dose times (“In my case, my mother gives me the medication, I mean she shakes me in the morning [to wake me up]; in the evening she puts them in front of my computer and pop! I mean I take them” – service user). These skills have been identified in previous literature as relevant for adherence, both as objective abilities and as perceived self-efficacy in adhering to ARV treatment in specific contexts (e.g. Fisher et al., 2006).

They also discussed the issue of flexibility of drawing on different skills in different contexts, such as very busy schedules and being away from home longer than intended.

Some take them just before leaving home. They know if they go somewhere that night and they don't come back [until morning], they take them before leaving home. And they don't have to worry about it until the next day, when they come home and take them again. (HCP)

Behavioral skills for two situations (taking medication when drinking alcohol, and when emotionally distressed) showed a specific interpersonal connotation in our group; service users and HCPs mentioned using non-adherence as a tool to exert power over relationships with parents or to retaliate for feeling controlled by parents.

Some people that skip some doses have conflicts with their parents, I think. I came across this. If the parents sometimes say something which hurts them: “Why should I take them?” Because [their parents] have struggled with them and now what are they going to do? (service user)

Service users and HCPs talked about dealing with lack of privacy as a set of behavioral skills, but also as a factor lowering motivation due to concerns of unwanted diagnostic disclosure. They mentioned several strategies to cope with the social implications of medication: finding a private location (e.g., toilet), disclosing the diagnosis, inventing an excuse for taking pills, and so forth.

I had the medication with me in a bag [at work], and I was taking them, and the boys were asking me why do you take pills, and I was telling them, I was not ashamed. Because hiding doesn't work. (service user)

Other specific situations requiring behavioral skills were when practical support is not available, when important events require optimal physical condition, when feeling bad physically, and when the number of pills increased because of additional treatments.

When I have been suspected of having tuberculosis and they gave me treatment. . . which I took on empty stomach until noon and there were about 14 pills. Plus my treatment. And I was exhausted, because it was on empty stomach and they were too many. (service user)

By expanding the content of the three concepts as described above, we were able to categorize all adherence-related statements as belonging either to information, motivation or behavioral skills constructs. Whereas we did not identify any additional core constructs that would require alterations to the IMB model structure, by integrating new content we adapted the three constructs to best represent the complexity of ART adherence in our cohort, and reflect the processes these young adults are navigating in their transition to adulthood (Figure 1).

INSERT FIGURE 1 ABOUT HERE

Discussion

Through the qualitative exploration of the IMB model of ART adherence within a cohort of Romanian young long-time HIV survivors, we identified a number of behavioral determinants of adherence which could be considered as belonging to the three main categories: information, motivation, and behavioral skills. Ware et al. (2006) recommended considering four key issues in the application of a theoretical model to a new sociocultural context, relevance, comprehensiveness, accuracy and complexity, which we discuss below.

Relevance and comprehensiveness

These two issues focus on whether the model's main concepts are applicable to the new setting, and whether there are other concepts important in the new context which would enhance the model. We identified numerous examples of facilitators of and barriers to adherence, which we evaluated as generally falling within one of the three IMB model constructs identified a priori. The participants discussed a substantial number of barriers when prompted by the IMB model-based questions and did not mention facilitators or barriers that fell outside of these constructs, which supported the application of the IMB model to this population. However, the specific content identified in each of these areas for our cohort and the emergence of themes that drew from multiple constructs simultaneously imply that the IMB model's discrete constructs might be more amorphous in lived experiences than the model suggests. Whereas this is quite consistent with the IMB model's structural hypotheses in terms of interrelations between the core constructs, the adaptation for the current population might require a more nuanced and contextualized definition of the constructs.

In our group, we did not identify distinct moderators separate from the core IMB model constructs. In terms of structural moderators, we recorded only one comment which referred to the issue of occasional stockouts. However, stockouts have not been a significant

clinical issue in this cohort before or during data collection. We considered that personal and social moderators, such as substance use or depression, are best represented within information, motivation, and skills as opposed to separated from these constructs. From clinical practice with our population, we could not identify any other relevant factors unrelated to the IMB model; most service users in this cohort have good psychological health, free access to medical care and medication, and few chemical dependencies, religious beliefs, beliefs in alternative healing systems, or acute conditions that would interfere with medical care.

Accuracy

Addressing the accuracy of the IMB model in the present clinical setting means identifying the content associated with the three concepts in the new setting. Whereas we encountered most previously-identified IMB themes in our focus groups, we also distinguished specific content which we considered as reflecting two central characteristics: the long treatment experience of our cohort and their developmental stage situated between adolescence and adulthood, also described as “emerging adulthood” (Arnett, 2000). In our view, these two characteristics represent a parsimonious explanation of the new content identified, which offers several possible solutions for adapting adherence interventions to this population.

The long-term treatment experience in the context of a constantly changing scientific understanding of HIV/AIDS might have influenced the development of misconceptions in relation to administration of therapy, assessment of current treatment efficiency and availability of future treatment options. The patients have had to update repeatedly their personal theories regarding their condition and treatment, as information they were receiving has changed constantly reflecting scientific progress and the resulting new treatments available (e.g., the availability of new ART transforming AIDS from a deadly, incurable

disease to a chronic condition, the change in perspective regarding the possibilities of procreating or transmitting the disease). The difficulty of updating personal theories might have facilitated the development of misconceptions. The long-term treatment experience might have shaped also the motivational role of test results and fear of hospitalization; long-term survivors develop a particular relationship with the medical system, where past experiences of hospitalization and regular medical tests become central reinforcers of adherence behaviors. Adherence interventions in this population might benefit from exploring the role of prior treatment experiences in the development of misconceptions and in motivating current behaviour.

It is important to understand the developmental context of misinformation in this cohort. The abundance of misconceptions characterizes adolescent cognition in many subject areas, as the development of the various cognitive competences gradually challenges pre-existing naïve conceptions (Byrnes, 2003). Young adults display improved decision making and planning and an increasing ability to integrate complex information in problem solving (Eccles, Templeton, Barber, & Stone, 2003). Thus the misconceptions about treatment options and administration, as well as the information conflict identified in part of the discourse are likely to be increasingly amenable to change at this stage and give way to a focus on gaining flexibility for sustained adherence. Health behavior change interventions need to take into consideration this cognitive progress.

One could also view misinformation as an expression of the patients' efforts to develop their own interpretation of treatment as part of the age-specific identity exploration and search for autonomy. During emerging adulthood youth actively seek to test new behaviors, beliefs and values, and to take own responsibility for their chosen goals, in their attempt to construct their individual (Arnett, 2000; Zarrett & Eccles, 2006). In this context, the personalized interpretations regarding ART might reflect young adults' natural tendency

toward exploring how it is to be in charge of own treatment, coupled with feelings of being experienced with treatment, and with beliefs of knowing best what fits their body and lifestyle. Moreover, disbelief might reflect the questioning of authority inherent in their search for autonomy, which may impact negatively on the doctor-patient relationship. Patients understandably perceive the provision of information in terms of prescribed behaviors as “doctors’ nagging”. Health professionals developing behavior change interventions for this group would, therefore, need to balance the necessity of challenging their belief systems with the task of respecting their need for autonomy and decision making (e.g. presenting this information as a range of behavior options).

Both identity exploration and search for autonomy take place in interaction with the social world, and involve the emergence of self-regulated action (Zimmer-Gembeck & Collins, 2003), and the exploration and examination of different social roles (Alsaker & Kroger, 2006). Thus, social relationships have an increased importance at this stage, as reflected in several themes: the role of social comparison, the long-term plans constructed in a social context (e.g. family, career), the awareness of the impact of their behavior on significant others, the importance of social life (going out with friends), the role of interpersonal conflicts as a source of emotional distress, the difficulties of maintaining adherence when practical support from others is lacking. Arnett (2000) highlights the fact that individuals might not always experience identity explorations as enjoyable, although they are part of broadening the range of life experiences prior to selection of adult roles; they might also lead to risk behaviors and in some circumstances to negative outcomes. Exploring nonadherence behaviors through imitation might be one example of identity exploration with negative consequences, such as decreased health status, hospitalization, witnessing loss of peers. Moreover, growing up together with others who share the same difficulties likely further increased the frequency with which patients used the results of others’ adherence

behaviors (health, illness, or death) to decide whether adherence is worth pursuing. This fact suggests that interventions which help increase awareness of the variability of treatment effectiveness might be particularly relevant to this cohort.

The development of personal identity involves the selection of several commitments which would define adult individuals in relation to their social context (Erickson, 1968, as cited by Alsaker & Kroger, 2006), as well as developing “qualities of character” such as “accepting responsibility of one’s self” and “making independent decisions” (Arnett, 2000). Thus, participants described future personal and social goals (career, sports performance, family) and hope for a future discovery of a cure as important motivators, and adherence as a means of achieving chosen goals appeared as one of the many domains in which this transition to independence takes place. For example, in our cohort a new type of behavioral skill proved necessary to cope with situations when practical support is not available, and reflects the transition from carer-delivered treatment to self-medication. Also, participants specifically discussed the behavioral skills necessary for coping with emotional distress in the context of parent-child relationships; thus, we can interpret the ability to identify internal motivation for adherence in conflict situations as part of the developmental task of achieving autonomy which would provide a viable alternative to using adherence to retaliate in conflict situations. Therefore behavior change interventions would benefit from focusing on the motivational role of chosen goals, and from developing behavioral skills which enable the transition to independence central to this developmental stage.

Alternative interpretations of the new content identified in our cohort could be outlined in terms of cultural differences. For example, in a recent qualitative exploration of the IMB model among Thai youth, Rongkavilit et al. (2010) reported social responsibilities as an important motivational factor specific to their population; they interpreted this finding in light of the prevalent Buddhist philosophy and collectivistic worldviews in Thai society. We

could consider the altruistic motivation identified in our participants' discourse as similar to the motivational role of social responsibilities. However, whereas Romanian culture is rather individualistic and our participants did not explicitly discuss religious issues, emerging adulthood is a shared characteristic of the two samples and therefore would likely be the preferred interpretation for the similar findings. More research on various age cohorts and cultures would be necessary to clarify the distinct influences of cultural worldviews and age-related processes in motivating ART adherence.

Thus, whereas the initial IMB model content provided a relatively good coverage of the behavioral factors relevant for adherence, this qualitative investigation proved useful in increasing the model's accuracy in the new setting (Figure 1). The fact that both service users and HCPs discussed most themes is an indicator of accuracy, likely explained by the long-term relationship characteristic to this cohort, which allowed the HCPs to develop an in-depth understanding of the problems the service users face.

Complexity

Many themes identified are in fact complex clusters of related meanings. For example, a bad doctor-patient relationship might reflect lack of support, but also the perception of an external pressure ('nagging') caused by the HCPs' increased efforts to change the patients' behavior. Adherence in this context might come as an attempt to please the doctor or decrease the 'nagging', instead of being the patient's personal choice. Also, many themes are present in more than one category. For example, knowledge about side effects represents an information factor, feeling discouraged when experiencing side effects or at the prospect of experiencing them is a motivational aspect, whereas strategies to reduce side effects are behavioral skills. The presence of cross-category themes implies that a more complex structure of adherence might lie beneath the overall relations represented in the IMB model, and might be relevant for clinical practice and worth exploring in future studies.

Limitations

The results of the present study need to be assessed in light of several limitations. Firstly, convenience sampling might have limited the range of participants to those more easily accessible; it is likely we might have had different contributions if we particularly targeted users with limited access to health services (because of distance from the centre, nonadherence, etc.). By organizing only three focus groups, we might have limited the content sampling. However, the resources available dictated these limitations.

Secondly, social desirability could have limited content elicitation. Organizing the focus groups within the health centre could have increased the desirability of adherence-consistent narratives to the detriment of reporting sensitive issues and anti-adherence statements. We have attempted to reduce social desirability by asking participants to discuss opinions other than their own, or to imagine hypothetical scenarios. Additionally, the facilitators experienced that participants felt comfortable in discussing topics contrary to socially desirable responses.

Thirdly, in our qualitative analysis we only aimed to identify themes that service users and HCPs considered relevant to adherence behaviors. The investigation of their relationship to adherence behaviors represents a subsequent step in adapting the IMB model to the present setting. Moreover, we focused on applying the IMB model and making necessary adaptations to best reflect use of this model in this specific population; this data set may provide additional insights if approached from different theoretical perspectives on medication adherence (Munro, Lewin, Swart, & Volmink, 2007).

Implications for clinical practice and research

The new content identified in this population suggests several clinical recommendations that may prove useful in supporting adherence, particularly in populations of treatment-experienced emerging adults. Exploring prior treatment experiences in long-term

HIV survivors may provide opportunities to clarify and correct misconceptions. Moreover, clarifying the motivational role of past experiences may help boost motivation for treatment adherence. Clinical intervention would also benefit from considering the cognitive, emotional and social development processes characteristic to emerging adulthood: their increasing ability to integrate complex information, and the tension between the various social and emotional needs related to exploring their identity and independence in relation to their social environment. Thus, the clinician may find it useful to support the development of more complex and nuanced illness and treatment representations, to promote informed personal choice from a range of behavioral options for adherence, to support the development of social and emotional skills relevant for adherence, or to identify the impact of social motivation and personal goals on adherence behaviors,

The present study is the first step of developing an IMB model-based adherence-support intervention in this new population, to be succeeded by intervention development, implementation, and evaluation (Fisher et al., 2006). The results of this qualitative exploration have informed the development of a validated tool for assessing adherence determinants in our sample, and have guided the improvement of usual care in the health centre where the research took place. Future research would need to investigate the effectiveness of these recommendations in similar populations,

Conclusions

In the present study, we aimed to apply Fisher et al.'s (2006) IMB model of ART adherence to a cohort of Romanian young long-time HIV survivors. We examined qualitatively data from focus groups with service users and HCPs to identify behavioral determinants of adherence. We examined the adequacy of the IMB model to this new setting based on four criteria proposed by Ware et al. (2006): relevance, comprehensiveness, accuracy and complexity. We concluded that the three main concepts of the IMB model,

information, motivation, and behavioral skills were relevant for the targeted population, and sufficiently comprehensive. We increased the accuracy of the model by identifying new themes within the three main concepts which reflected the characteristics of this cohort (particularly young and treatment-experienced). The model also provided a good framework for retaining the complexity of adherence in the new context; which might be further optimized through a focus on operationalising the links between constructs for future assessment specifically for this population (e.g., defining the overlap between information and motivation and developing content that best represents this). The IMB model qualified by the results of this elicitation work provides an excellent basis for future evaluation and intervention work within this young, treatment-experienced population.

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Figure 1: The IMB model of ART adherence in Romanian HIV+ young adults (*new content in italics*). Adapted from “An information-motivation-behavioral skills model of adherence to antiretroviral therapy.” by Fisher, Fisher, Amico, & Harman, 2006, *Health Psychology*, 25(4), p. 465. Copyright 2006 by the American Psychological Association. Adapted with permission.

Table 1. Interview structure summary

Category	Questions – service users	Questions – HCPs
Information	Think about the last few months. What was unclear for you regarding treatment and what did you try to find out? What do you think you know well about treatment? What are you not sure of and would like more information about?	Think about the last few months. What would you say are the most common types of information that the service users needed or asked for? What would you have expected them to ask and they didn't? What would be the minimum information that a service user with HIV should have in order to have good medication adherence?
Motivation	What motivates you (or other people you know) to take the medication, and what makes you feel less motivated? What do you think your parents or doctors would add? What reasons do you often hear as justifying a less adherent behavior but you consider false?	What do you think motivates service users to take medication and what makes them feel less motivated? What other reasons do you think service users would add? What reasons do you often hear but consider false?
Contexts / Behavioral skills	Which are the situations when it is easy or difficult for you to take the pills? What solutions are there for particular situations?	What are some situations when it is easy/ hard for service users to take their pills? Could you name some examples of solutions that service users have found in order to adhere better to their medication?
General	Imagine you are in the waiting room, and you meet a young person who just found out he/she is HIV-positive, and needs to decide whether he/she should take the treatment or not. What advice would you give him/her for or against taking medication? What issues would you alert him/her to?	Could you give some examples of situations when service users have told you something in relation to taking their medication which you have found shocking, dysfunctional, prejudiced?