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Where we are now and how we can improve: a qualitative study of practitioners’ perspectives on providing ART adherence support in Romania

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Abstract

Supporting medication adherence is a priority in HIV care worldwide as low adherence threatens the effectiveness of antiretroviral treatment (ART). While evidence on adherence causes and consequences has steadily accumulated, investigating current practice and relevant determinants of practitioners' behaviors has only recently been highlighted as essential for developing effective and sustainable interventions. In Romania, ART adherence is low despite universal access to HIV care, and improving support services is a priority. We report a qualitative exploration of practitioners' experiences and views on ART adherence support, guided by current behavioral theory.

Semi-structured interviews were performed with 10 practitioners from 6 HIV centers, aiming for maximum variation sampling on professional experience, location and organization type. Questions addressed practitioners' views and experiences on assessing patients' adherence behaviors and determinants, content and format of adherence support, and perceived influences on their capacity to deliver support. Verbatim transcripts were analyzed via template analysis.

Results show that adherence support is provided in Romania by trained psychologists in multidisciplinary teams that operate flexibly and perform multiple HIV care activities. Assessment of adherence behaviors and determinants is primarily interview-based, and practitioners use mostly psychotherapeutic techniques and theories with a degree of intervention tailoring. Practitioners' descriptions covered a broad range of common determinants and behavior change techniques, but showed limited use of behavioral theory. Participants also described difficulties to cope with limited resources, and lack of support for managing practical and emotional challenges. Several opportunities for improvement were

identified, such as standardizing patient profiling and intervention delivery, conceptualizing and recording active intervention content based on behavioral theory, and actively monitoring intervention effectiveness.

This qualitative inquiry provided valuable information for improving adherence support in this clinical context. Understanding practitioners' perspectives based on behavioral theory-informed analyses can help intervention developers increase intervention fidelity by integrating current practice information in program design.

Keywords: adherence; antiretroviral therapy; qualitative research; implementation; service providers

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Introduction

Adherence to antiretroviral therapy (ART) remains a challenge (Ortego et al., 2011). In Romania, people living with HIV (PLWH) have universal access to treatment and care but specialized psychosocial services are limited and improvement of adherence support is needed (UNAIDS, 2014).

Intervention developers increasingly use evidence on causes and consequences of ART adherence from the perspective of PLWH (Langebeek et al., 2014; Mills et al., 2006; Ortego et al., 2011) and effective interventions (Nieuwlaat et al., 2014). In contrast, understanding how practitioners provide adherence support in routine care has only recently been acknowledged as an important source of practice-based evidence (Amico, 2011). Intervention success commonly depends on adapting protocols to fit local settings, and practitioners' feedback on current care and feasibility of changes is central to achieving high intervention fidelity (Cohen et al., 2008). In Romania, evidence accumulates on patients' perspectives (Buzducea, Lazăr, & Mardare, 2010; Dima, Schweitzer, Amico, & Wanless, 2013; Dima, Schweitzer, Diaconiță, Remor, & Wanless, 2013) but no information is yet available on practitioners' views of adherence support.

We conducted a qualitative study of practitioners' views and experiences of ART adherence support to understand the context of care, how practitioners assess adherence, what adherence determinants they target, what interventions they use, and what factors influence their activity.

Methods

Within a project on improving ART adherence support in Romania, approved by the Romanian Institutional Review Board, we developed a guide for semi-structured telephone

interviews targeting key adherence issues (Table 1). We used purposive maximum variation sampling on geographical location, clinical setting, and professional experience to select practitioners providing ART adherence support. No additional inclusion criteria applied. Three psychologists trained in interviewing and study objectives collected data. They sent written invitations to 13 practitioners, provided study information, and obtained informed consent. No incentives were provided for participation. Three refusals were recorded stating concerns about sharing information. Ten interviews (mean duration 45 minutes) were conducted, recorded, anonymized, transcribed, and translated to English.

Insert Table 1 here

Transcripts were analyzed via template analysis (Brooks, McCluskey, Turley, & King, 2014) using Atlas.ti7.1.8 (Friese, 2014). The coding template followed the interview guide and behavioral theory. Adherence determinants were coded following the WHO taxonomy (World Health Organization, 2003). Patient-related factors were further classified according to an adherence support taxonomy (de Bruin et al., 2010). Descriptions of intervention content were coded using a behavior change taxonomy (BCTTv1; Michie et al., 2013). Adherence support barriers were classified into context- and practitioner-related (see Supplemental online material 1). Two bilingual researchers coded the English text and reviewed regularly the Romanian text. Each statement (meaning unit) was examined in relation to existing or new relevant codes. The coding template was reviewed iteratively and codes were summarized narratively and discussed within the research team to achieve consensus.

Results

ART adherence support is provided in Romania by psychologists working within multidisciplinary HIV care teams that may include doctors, nurses, social workers, teachers, and vocational counselors collaborating via a flexible and iterative system of referrals. Team members' roles partly overlapped; tasks were usually allocated to the relevant specialty but sometimes performed at a basic level by others. Participating psychologists described their role as involving numerous activities, some targeting adherence. Participants' background characteristics are presented in Table 2.

Insert Table 2 here

Adherence assessment

Participants described adherence assessments as following referrals by doctors or nurses for suspected non-adherence, or as standard procedure within flexible follow-up schedules (1-, 3- or 6-monthly). Mostly clinical interviews, medication refill records, medical tests results, and doctor's opinions were used for adherence and determinants assessment, and less frequently pill counts and self-report questionnaires. Participants mentioned that corroborating information qualitatively from several sources helped obtain higher accuracy, e.g. by identifying inconsistencies between methods. Categorizing patients as (non-)adherent was based on method-specific thresholds (e.g., 75-80% missed doses for pill count).

Adherence determinants

Participants mentioned numerous adherence barriers and facilitators, mostly patient-related (representative excerpts in Table 3). More extensively discussed were patients' **attitudes**, e.g. therapeutic fatigue and medication necessity beliefs and concerns, and **self-efficacy**, i.e. their

perceived ability to cope with schedule changes, side effects, or medication shortages. Having accurate **knowledge** was considered necessary but insufficient for high adherence.

Participants also mentioned the role of **awareness**, **action control** (e.g. social support or cues), **facilitation** (e.g. social and professional support), or **intention/action planning** (e.g. daily routines), and of more generic determinants, such as optimism, emotional distress, diagnosis acceptance and disclosure. *Health care system-related factors* mentioned were the limited financial resources, time constraints due to work overload and reduced staff numbers, and recent medication stock-outs considered detrimental to patients' motivation. The importance of good interdisciplinary collaboration was highlighted. *Socio-economic factors* mentioned were patients' education and social integration levels, financial and professional status, living conditions, and distance from treatment center. The parents' encouraging medication intake was noted as a negative social influence. Medication side effects, physical characteristics of the medicines (size, taste), and regimen complexity were the main *therapy-related factors* mentioned, and being asymptomatic as a *condition-related factor*.

Insert Table 3 here

Adherence interventions

Participants reported using mainly psychotherapeutic approaches (e.g., cognitive-behavioral, rational-emotive, experiential) and motivational interviewing. The transtheoretical model of change was the only behavior change model mentioned as guiding practice. Interventions were described as less structured, delivered either in one-to-one or in group formats, consisting of health education or personal development activities), and targeting multiple topics: knowledge, motivation, skills, diagnosis acceptance, and emotional balance. The

intervention content described could be classified in 11 of the 16 BCTTv1 categories (Table 4). Practitioners underlined the importance of tailored interventions, considering patients' feedback and shared decision-making. Intervention effects were irregularly evaluated using routine adherence and health outcomes assessments and patient and doctor feedback. Intervention follow-up was described as an informal and ongoing process involving the family or medical staff.

Insert Table 4 here

Determinants of intervention delivery

Context-related barriers to adherence support concerned limited resources: poor access to medication, reduced staff numbers affecting service continuity, and insufficient access to medical tests causing irregular monitoring. The quality of interdisciplinary communication was mentioned both as a facilitator (i.e. satisfaction with the local communication processes) and as a topic for further improvement. They mentioned several personal resources for successful interventions, such as their long-term professional relationships with patients and their tailoring skills, several specific difficulties (examples in Table 5), and their need for training and emotional support.

Insert Table 5 here

Discussion

Our findings highlight several current strengths and opportunities for improvement of ART adherence support in Romania (Figure 1). First, services are delivered by trained psychologists within multidisciplinary teams providing comprehensive HIV care and tailored support. As flexible procedures and overlapping responsibilities may lead to gaps in care, better role definition and standardization may improve case management, as advised broadly for chronic conditions (Beaglehole et al., 2008). General communication training has proved valuable for improving adherence (Zolnierek & DiMatteo, 2009). Adherence-specific training should be provided to allow evidence implementation in routine care (Simoni, Amico, Smith, & Nelson, 2010). Second, assessing adherence is integrated in routine care and practitioners use multiple methods, which facilitate adequate monitoring. Using validated tools and updated regimen-specific adherence thresholds would further improve care, as relying on unstructured clinical interviews often leads to inaccurate assessment (Bangsberg et al., 2001), and evidence-based thresholds for adherence to some regimens are higher than participants' descriptions ($\geq 95\%$ versus 80% ; Kobin & Sheth, 2011). Third, practitioners mentioned numerous adherence determinants consistent with research literature (Kardas, Lewek, & Matyjaszczyk, 2013), but they assessed determinants mainly via clinical interviews. Identifying determinants via self-report tools would allow more systematic and comprehensive patient profiling (Dima, Schweitzer, Diaconiță, et al., 2013). Fourth, practitioners reported using psychotherapeutic techniques and theories and described active intervention content covering most behavior change categories. Nevertheless, standardizing intervention protocols, recording intervention delivery, and monitoring results based on behavioral theory is needed to facilitate evaluation of routine care (Oberjé, Dima, Pijnappel, Prins, & de Bruin, 2015). Fifth, practitioners relied on their long-term experience, the good local set-up in some settings, and their tailoring skills, but were constrained by limited

resources, training, and practical support, barriers often encountered in implementation research (Wensing et al., 2014) and highlighting the need to allocate resources on continuity of service provision, and develop practitioner training and support programmes.

Insert Figure 1 here

These findings should be interpreted in light of their strengths and limitations. By linking behavior theory with qualitative data, we interpreted practitioners' discourses within the current global endeavors for cumulative evidence based on a common behavior change language (Michie, Fixsen, Grimshaw, & Eccles, 2009). We provide a method of bridging practice and research that could be implemented in other settings. However, our study targeted psychologists as main adherence support providers, and collected self-reports which may differ from performance in consultations. Results therefore need corroboration with research on other professional groups (e.g. doctor, nurses) and complementary methods (e.g. in-depth face-to-face interviews, consultation records).

Our study identified concrete action points for improving adherence support in Romania which should be implemented within the nationwide efforts to improve ART adherence. Intervention developers may find such theory-based qualitative inquiry useful in other settings to understand practitioners' perspectives on current capacity and needs, and adapt interventions to routine care.

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Table 1. Topics included in the interview schedule

Topic	Questions
Professional background and experience	number of years working with HIV patients; experience with other health conditions; professional training (general and adherence-related); type of organization currently working in; size of team and clinical specialties of members; process of HIV care and roles of members; number of patients registered at their centre; patient workload per year (in general, and on adherence)
Assessment of adherence	own definition of adherence; assessment process and methods; objectives of adherence assessment; assessment tools available & used; how a patient is categorized as (non-)adherent
Adherence determinants	most common adherence barriers described by patients and how patients (try to) overcome them; patient characteristics associated with non-adherence
Adherence interventions	status of adherence-related activities among other tasks; theoretical models used more or less frequently, or not at all; objectives targeted in adherence support; types of interventions used more frequently, found most effective, or least effective;

effective interventions not (yet) translated to own practice;
intervention follow-up;
assessment of intervention results

Determinants of adherence support factors that would make adherence interventions more effective (organizational, training, etc.);
most common barriers that affect the results of adherence interventions;
type of support needed;
most important lessons learned from their experience

Table 2. Background characteristics for the 10 participating practitioners (women, undergraduate psychology training, working in multidisciplinary teams in 6 regional centers)

Characteristics		N or M (SD)	Range
Age		38.3 (5.90)	31- 47
Years of experience in HIV care		10.8 (4.4)	2-17
Working in...	Public hospitals	5	
	Non-profit organizations	5	
Number of professionals in the multi-disciplinary teams		6.2 (3.2)	3-12
Number of PLWH currently in care		437.2 (363.4)	100-1000
Number of consultations per year	Total	156.6 (116.1)	55-420
	Adherence	96.9 (61.6)	12-173
Postgraduate training	Psychotherapy	7	
	Adherence	2	

Table 3. Adherence determinants mentioned by practitioners and representative excerpts

Patient-related factors

Attitude

Medication not needed when asymptomatic. “Others lose their motivation [...] because they rely on the idea that it’s ok without [the medicines], they don’t feel anything physically, they don’t have any pain, they don’t feel any weakness, “I am fine as long as I feel fine.”” (*Maria*)

Concerns about treatment. “How they feel after they take their treatment and the fact that sometimes they think [...] that as soon as they feel unwell their treatment should be changed.” (*Dana*)

Misinterpreted side effects. “Or it happens that they have all sort of physical symptoms or discomfort, which are many times not side effects of the pills, [...] and then they say: “I felt ill and I thought it’s from the pills, I have not taken them anymore.”” (*Irina*)

Therapeutic fatigue. “For some of them it is the therapeutic fatigue, after so many years, they got tired.” (*Maria*)

Self-efficacy

Changes in daily schedule. “They are saying that different changes interfered in their life, for example they were away from home and they forgot to take their medicines with them.” (*Irina*)

Managing side effects. “They find small tricks, they are telling me: “you know, I cannot take them like this and I take them with juice”, or they are saying: “I don’t feel well after I take them, so I try to rest a bit after taking them.”” (*Ina*)

Coping with medication shortages. “They have managed to form a group of 3-4 people when

medicines were given once every 3-5 days and they needed to come regularly and couldn't afford to come [...] they agreed with each other "I go this week, you go next week." (Crina)

Knowledge - About condition and medication. "It's very important for them to understand also what a certain level of test results means, be it CD4, be it VL, and to understand what is the role of the treatment, what happens with the treatment after they took it." (Irina)

Awareness - Disease progression "Those who feel really ill [...] suddenly become adherent 100%, they would do anything, they would swallow anything, just not to feel like this anymore and most of the times it does work, but unfortunately for some it's too late." (Maria)

Action control - Cues. "Regarding forgetfulness they are saying: I set the alarm on my phone." (Irina)

Facilitation - Social support. "The kids from the cohort, who don't have [...] social integration, and are not supported by their family." (Olga)

Intention/action planning - Daily routines. "I think there are aspects related with personal life, the way they manage their life [...] those who have a disorganized schedule, this disorganization impacts also on following the treatment." (Dana)

Other factors

Optimism. "If he is centered on the future and if he has plans, for me this is an indicator that he wants to be healthy in order to achieve his plans. If he talks to me about optimism." (Crina)

Depression. "There are personal failures, periods of depression, which also leave a mark on adherence." (Dana)

Acceptance. "Some of them have not integrated the diagnosis, even now after so many groups, we are sometimes stuck in the support group meetings on this thing: tell me how did you find out?" (Olga)

Disclosure. "It's harder for the person who is not disclosing the diagnosis to be adherent, if he

has to hide from other persons.” (*Irina*)

Health care system-related factors

Limited resources

Probably more personnel should be available, clearly; the social worker to go on site and count the pills, a doctor to be in the centre all the time, who can chat with them.” (*Olga*)

Medication stock outs

“The period when medication supply was disrupted has contributed to their non-adherence and to their relapses and worsening health.” (*Dana*)

Quality of multidisciplinary collaboration

“Our interventions on adherence could be even more efficient, if there would be a better collaboration with the hospital.” (*Irina*)

Socio-economic factors

Education

“The fact that they are not educated and they couldn’t build a future for themselves, somehow they don’t have what to hold on to.” (*Olga*)

Social influences

“Those who continue to live with their parents, and their parents nag them [are less adherent].” (*Ana*)

Therapy-related factors

Medication side effects

“Some tell me they have side effects and at most of them I have noticed this at [brand name] that it gives them dizziness and even if it’s taken for a long time.” (*Maria*)

Medication size and taste

“They say that they cannot take [the pills] because they are too small, too big, too bitter.”
(*Irina*)

Medical regimen complexity

“Some tell me [as reason for non-adherence] that the combination is very complex.” (*Maria*)

Condition-related factors

Being asymptomatic

“They don’t see an improvement or a deterioration of the health condition on a long or a short term [following adherence]. Their asymptomatic condition is another obstacle.” (*Irina*)

Note: Names are fictional to maintain anonymity.

Table 4. Behavior change technique (BCT) categories mentioned by practitioners (of N=10) and representative excerpts

Goals & planning (4/10). “If what prevents him to take his treatment is a particular state - he feels sick physically or sad, depressed - then we can see what situations create these states and find together alternatives or solutions to cope with these.” (*Irina*)

Feedback and monitoring (2/10). “Then we have sessions in which we discover a method to help him become adherent, by offering him the possibility to choose how he can monitor his adherence, [for example] charts for pill intake.” (*Irina*)

Social support (6/10). “The family takes part actively in this adherence intervention, because on site we discuss with the family aspects regarding the therapy, administration, procurement, support.” (*Tina*)

Shaping knowledge (6/10). “Clarifying small things, such as [taking] two tablets instead of two times two, because sometimes they don’t understand. Very clear and tangible things, because it’s being said very fast and abstract.” (*Olga*)

Natural consequences (1/10). “we explain to him more what happens after he swallows the pill, why is it important for him to take them at fixed intervals or after a meal.” (*Irina*)

Comparison of behavior (1/10). “If the problem is swallowing the pills, we can use a short movie in which we can show to the patient what the correct method of swallowing the pills is.” (*Irina*)

Associations (2/10). “For some it works with the mobile phone, because [organization x] has a program through which they receive a message that they have to take their dose.” (*Maria*)

Reward and threat (1/10). “[It is important to] focus a lot on what they are doing well, on encouraging: “this you have done well.”” (*Ana*)

Regulation (1/10). “In denial, in depression, in rage there is nothing I can do; he cannot see his life and I insist on medication; that’s not helping him. First I have to get him out of there, to help him. [...] Until he is not emotionally stable, I cannot work on adherence, although is part of the treatment maintenance.” (*Ana*)

Antecedents (1/10). “We had at some point some pill organizers per week / month [we gave to patients] – it was a small box.” (*Ina*)

Covert learning (1/10). “Positive models. If I brought someone who succeeded, they were amazed – ‘but how did you succeed?’ People that went to a job interview and nobody asked them about HIV and they got hired, or who could have children.” (*Ana*)

Note: Names are fictional to maintain anonymity.

Table 5. Difficulties encountered in providing adherence support and representative excerpts

Feeling they have tried all possible methods. “It has already been discussed many times with them, so sometimes you don’t know what arguments to bring and what attitude to take on so that these patients adopt a positive attitude.” (*Tina*)

Supporting patients with irregular attendance to appointments. “They don’t come regularly, not even once per month and you cannot work like that. [...] This should be a sustained initiative; initiatives that happen so rarely don’t have any effect.” (*Ana*)

Organizing adherence support for patients located in broad geographical area. “There is a bigger area around [the city] where they live, [in different] towns, the date does not correspond with the date of picking up the treatment, which implies an additional trip for them on their own accord, on top of picking up the therapy; [...] I never manage to form a group.” (*Maria*)

Working with patients with low motivation for adherence. “I am in a phase when I realize that it’s important to be there for them, when they will want to be adherent. Maybe it doesn’t seem very ambitious, but now I am at that point. There are also those who do not want to see it anymore, to hear about it, there are those who refuse to come, they were coming so rarely that I bombarded them with information. Now I don’t know...” (*Ina*)

Setting realistic objectives for adherence improvement. “Any intervention I heard of, I have tried to apply it myself and I don’t believe there is a magic intervention, which can make all the patients take their treatment exactly as it was prescribed to them, at the prescribed times, as many times as it was prescribed, non-stop. I think there are methods to patch here and there, to rebuild.” (*Clara*)

Managing emotionally intervention failure. “I have learned that even if you are good specialist and you are doing everything to the letter and you also do it with passion, that doesn’t necessarily mean a guarantee of success in working with a non-adherent, because somehow the responsibility is shared and the largest part belongs to the patient and not to you, as a professional, [...] I am in a process in which I am trying to tell myself that not everything depends only on me and to stop blaming myself if a non-adherent patient dies.” (*Maria*)

Note: Names are fictional to maintain anonymity.

Professional context
Figure 1 Strengths of current practice and opportunities for improvement
 Flexible procedures in multidisciplinary teams
 Postgraduate training in psychology
 Clarification of team members tasks
 Adherence-specific training

