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The Role of the Home Environment and Routinization in ART Adherence

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Abstract

Previous research suggests that routinization of medication-taking behavior promotes ART adherence. The current study explored the nature of medication-taking routines in the home environment, where medication is most often taken, to identify home-based cues for taking ART. Qualitative interviews were conducted in the homes of 31 HIV-positive adult males in the U.S. with varying levels of adherence problems. Interviews were audiotaped and transcribed. Content analysis was performed to elicit themes from the text and further categorize responses. Patients with more routinized medication-taking behavior reported fewer adherence problems. Home-based medication-taking triggers that were especially common among patients who reported fewer adherence problems included meals, pillboxes, time of day, and visual cues. Findings characterize the nature of home-based medication-taking routines and suggest the potential utility of the home environment as a setting for adherence interventions.

Keywords

antiretroviral therapy; adherence; strategies; routinization

Introduction

Adherence to HIV antiretroviral therapy (ART) is critical for optimizing virologic, immunologic, and clinical outcomes^{1–4}. However, despite the importance of adherence, only a minority of patients (20–40%) achieve optimal levels of adherence (i.e., take at least 90% of prescribed doses) when assessed by objective measures^{5–7}, indicating that adherence is inadequate for a concerning proportion of patients. Moreover, adherence may decline over time⁸. Thus, there is a need for interventions that can effectively and efficiently bolster and maintain adherence.

Several interventions to promote ART adherence have been developed and tested, but research has demonstrated that most interventions produce only modest effects at best⁸. Drawing from a learning theory perspective⁹, one aspect of extant interventions that may help to explain this lack of success is the mismatch in the context in which training for adherence or pill-taking takes place (i.e., typically the clinic) and the context in which pill-

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taking is typically carried out (i.e., the patient's home). A key tenet of a learning theory perspective is that new behavior is most successfully learned when the training and practice occur in the same setting in which the behavior will be routinely executed and maintained⁹. In this way, effective retrieval cues can be developed in the setting where learning originally occurs to trigger the behaviors after the initial learning has taken place and training has ended, thereby facilitating maintenance of the behavior (adherence) over time. One way to improve on existing interventions may be to align the contexts for learning and maintenance of behavior. As pill-taking most often occurs at home, interventions that take advantage of the contextual cues in the home to increase adherence may be more effective than interventions conducted in other settings (e.g., the clinic).

To design a home-based adherence intervention, it is first necessary to elucidate the facilitators of and barriers to adherence in the home environment to target in the intervention. Past research has identified routinization of medication-taking behavior as critical to optimizing adherence¹⁰⁻¹². However, this research has been conducted outside of the home and so may have overlooked important home-based cues or characteristics that contribute to routinization. In contrast, research on adherence that has been conducted in the home, which is scarce, has not sufficiently explored the nature of medication-taking routines. For example, although the feasibility of home-based research has been demonstrated in one study¹³, there was little emphasis on how characteristics or cues in the home environment contribute to or impede adherence. Similarly, a study of a home-based adherence intervention¹⁴ did not explicitly delineate how specific contextual cues in the home environment may impact adherence.

Given this gap in the literature, the purpose of the current study is to enhance understanding of the role that the home environment and routinization may play in promoting adherence by exploring the nature of medication-taking routines in the home environment. To this end, we conducted semi-structured qualitative interviews of HIV-positive patients on ART in their homes. It was expected that interviewing patients in their homes, where pill-taking most often occurs, would yield richer, more accurate information on the patient's pill-taking behavior, and the contextual cues in the home environment that act either as barriers or facilitators of adherence.

Methods

Selection and Description of Participants

Study participants were 31 HIV positive adult males recruited from a major metropolitan area clinic that specializes in HIV care for gay and lesbian individuals; 95% of patients seen in this clinic are gay men. Inclusion criteria for participating in the study (in addition to being HIV positive) were that patients had to be taking ART, at least 18 years old, and fluent in English. Recruitment mechanisms included referrals from clinic providers (e.g., physician, pharmacist) and flyers posted at the clinic. Interested patients contacted study staff and were screened for study eligibility and asked about the average number of missed doses of ART per week to gauge their level of self-reported adherence. A purposive sampling strategy was followed to select eligible patients with varying levels of self-reported adherence into the study. This strategy was intended to permit examination of differences in the routines of participants with different levels of self-reported adherence. Absolute rules for selecting patients according to self-reported adherence were not applied, but an effort was made to ensure that several patients from both the higher and lower ends of the self-reported adherence spectrum would be represented. For example, when a sizable proportion of the targeted sample size had been met with patients who had no adherence problems (missed less than one dose per week), enrollment of patients who reported adherence problems (missed one or more doses per week) was prioritized.

The majority of participants were white (n = 17, 57%), and the remainder were black (n = 8, 26%) or Hispanic (n = 6, 17%). The majority of participants were unemployed (n = 25, 81%), and participants' average age was 49 years old (SD = 9 years; range = 26 – 61). Participants reported having been on ART for an average of 12.0 years (SD = 6.3 years; range = three weeks to 22 years). Seventeen participants (55%) were on twice-a-day ART regimens, 13 were on once-a-day regimens (42%), and one was on a thrice-a-day regimen. Morning doses were reported by the majority of participants (81%), as were evening doses (74%). Mean self-reported CD4 count was 503 cells/mm³ (SD = 269) and 77% reported undetectable viral load. Based on the self-reported number of missed doses over the last week or month, participants were divided into categories of high and low self-reported adherence. Participants were considered high adherers if they reported having missed less than four doses per month (i.e., one dose per week) and low adherers if they reported having missed one or more doses per week, potentially indicating significant problems with adherence. The majority of participants were in the high self-reported adherence category (22, 73%), and eight participants were in the low self-reported adherence category (8, 26%). One participant was unable to recall how many doses he had missed during the past week or month, so his data were not included in this analysis.

Procedures

All participants were administered a semi-structured qualitative interview for which they were compensated \$30. Interviews were administered by a single interviewer in the study participant's home and took approximately one hour to complete. Interviewers were two clinical psychologists who received training in the conduct of qualitative interviews from an expert in qualitative methods prior to study onset.

The interview protocol covered the following general areas: background information, regimen information (e.g., medication type, number of daily doses), number of missed doses in a typical week or month, challenges and facilitators of adherence, prescription refills, provider communication about the timing of doses and the participant's understanding of the importance of timing of doses.

Another key area of inquiry was the description of the process and sequence of events surrounding recent (last two) dose taking, including contextual cues for taking medication (e.g., mealtimes, waking/sleeping, TV shows), other strategies used by the participant to enhance adherence (e.g., pillbox), and routinization of and disruptions to the pill-taking process. To promote recall of their pill-taking behavior and allow the interviewer to observe the pill-taking process in detail, participants were asked to re-enact the events of the last two doses that they took (without actually swallowing the pills) from when they first remembered that it was time to take their medication to after taking the medication. This was also intended to help uncover aspects of routinization of pill-taking, such as retrieval cues, of which the participant may not be conscious.

Analysis

All interviews were audiotaped and then transcribed verbatim. Text management software (*ATLAS.ti*) was used to mark text that pertained to the major sections of the interview (e.g., description of last dose taken and the dose before that, process of refilling prescriptions). Text responses in each section or block of the interview were then printed out on pieces of paper and pile sorted to elicit themes. The research team then met to discuss and reach consensus on categories of themes. A programmer trained in qualitative methods subsequently matched each quote or text response within each interview section with a specific category and developed a codebook to summarize thematic categories and typical exemplars. Another study staff member assigned participants to categories of self-reported

adherence, as described above, and then examined the degree to which some key themes were distributed across these categories.

Results

Findings on the themes elicited from the text analysis are described in greater detail below.

Challenges and facilitators of adherence

Challenges—Participants reported a wide variety of challenges to medication adherence, as summarized in Table 1. The most commonly cited barrier to adherence was ‘being busy’, which often led to forgetting the dose. For example, one participant stated, “You know, it’s not, oh, gee, I don’t feel like taking it. It’s more like I’m rushing to go somewhere and oh, I didn’t take my meds.” Other challenges that were notable but less commonly reported included a lack of motivation, side effects, and too many doses.

Facilitators—As shown in Table 1, the most commonly reported facilitator of adherence was the use of a pillbox for storing medication. Participants cited its utility in helping them to keep track of whether they had taken a dose or not. For example, according to one participant, “The thing that really serves me well is a pillbox so I know what day I’m on.” Other, less commonly cited factors reported to promote adherence included having a positive outlook, having a routine for taking medication, not having to take as many doses, and heightened awareness/self-education about the importance of adherence.

Routinization

Triggers—As displayed in Table 2, there were several cues or triggers on which participants routinely relied to remind them to take their medication. Several participants reported that medication-taking behavior had become so automatic or deeply ingrained in their routine that they simply remember to take their medication when the time arrives for morning and evening doses. According to one participant asked to indicate how he remembers to take his medication, “I don’t really even think about it. You know, it’s a... how can I say it? It’s a routine so I don’t think about it.” Similarly, another participant responded, “So it’s just like automatically at 10:00 I know.”

One particularly salient medication-taking trigger that enhanced routinization of medication-taking for many participants was meals or food, as many participants took their medication immediately before or after eating. This cue was cited by more than twice as many participants as a reminder for taking morning as compared to evening doses. Other less commonly cited triggers for pill-taking included visual cues (e.g., placing the pills in a location where the participant is likely to see them at the intended time of pill-taking), other medications or vitamins taken regularly, being reminded by others, television shows that air regularly at the intended time of pill-taking, getting ready for bed, and use of a chart or notes to remind oneself.

Extent of routinization of medication-taking behavior—Participants described their process for taking their last two doses and indicated whether this process was typical. This information was used to categorize patients’ medication-taking behavior as “routine” vs. “not routine.” Medication-taking processes were considered “routine” if the participant described a sequence of events surrounding medication-taking that characterized nearly every dose taken. The majority of participants (21, 68%) described medication-taking behavior suggestive of a well-established routine. One example of a “routine” morning dose is as follows: “I’m in bed, I get up, my cat walks me to the bathroom...and I go in the bathroom ...and then I open up the medicine cabinet and on one shelf of the medicine

cabinet I have all my medications that I need to take for that day. And I open up the cabinet door here [showing interviewer], like this, and I put the cap down and I put each of my medications in the cap and then I take them immediately; my routine does not vary.”

For the remaining 10 participants, it was not clear that medication-taking behavior occurred in routine fashion. For example, one participant described a medication-taking process for his evening dose that was not sufficiently consistent to be considered routine: “It varies. You know, sometimes before dinner, sometimes during dinner, sometimes after dinner, and sometimes at nine o’clock.”

Routinization characteristics by level of self- reported adherence problems

To ascertain whether there were aspects of the medication-taking routine that were more common among participants with high relative to low levels of self-reported adherence, participants with high and low levels of self-reported adherence were compared on some of the more commonly cited contributors to and triggers of medication-taking behavior, as well as the extent of routinization of pill-taking. As depicted in Table 3, participants with high self-reported adherence more commonly reported the use of a pillbox as a facilitator of adherence relative to participants with low levels of self-adherence. In addition, participants with high self-reported adherence more commonly reported automaticity/time, meals/food, and visual cues as medication-taking triggers than participants with low self-reported adherence. As would be expected, medication-taking behavior was more clearly routinized among participants with high levels of self-reported adherence as compared to those with low levels of self-reported adherence.

Pocketed doses

Disruptions to participants’ medication-taking routines were the rule rather than the exception in this sample, as only a few (7, 23%) participants indicated that their routine is never disrupted. The strategy of pocketing doses to overcome adherence challenges related to disruptions in routines was explored. Pocketed doses were defined as “when you take a dose from your pill container in advance of when you plan to actually swallow the dose, because you won’t be home when it’s time to take the dose and you don’t want to carry the pill container with you.” The majority of participants (22, 71%) reported having pocketed doses at some point. However, as shown in Table 4, there was considerable variation in the frequency with which these participants reported pocketing doses. In addition, some participants reported forgetting or taking their pocketed dose later than intended. Of the participants who pocketed doses more often than rarely, several indicated that they do not use any strategy to remind them to take their pocketed dose. Other participants referred to strategies such as meals/food, visual aids, use of a pill box, and notes placed in strategic locations.

Prescription refills

The majority of participants reported having run out of medication before getting a prescription refill from the pharmacy at least once since they began taking ART. Having run out of medication before obtaining a refill was reported by a greater proportion of participants with low levels of self-reported adherence (6 of 8, 75%) relative to the proportion of participants with high levels of self-reported adherence (12 of 22, 55%).

As shown in Table 5, participants described several different prompts or cues to order a refill. Most participants reported that they were prompted to order a refill when they noticed that only a few pills remained in their pill bottle. Other, less commonly reported prompts to order refills included written reminders (e.g., appointment book, calendar, list), time of the month, external reminders such as automatic delivery of medication to one’s home (without

the participant having to take any steps to order a refill), phone calls from the pharmacy, and one's partner.

Automated systems commonly played a role in the procurement of refills, such that participants could call and order their refill through a computerized system (without talking to a person) or the pharmacy automatically refilled the prescription and called the participant to inform him that his medication was ready to be picked up. Of the participants who indicated the use of such technology to obtain a prescription refill, three were indifferent, and the rest were nearly evenly divided into those who expressed positive attitudes toward technology and those who expressed negative attitudes. Participants with a positive attitude generally found automated systems to be convenient and efficient; as one participant stated, "It's computer automated, so I don't talk to another human being, but I can order it...It's great." A commonly cited source of frustration of participants with a negative attitude toward technology was that the computerized systems sometimes malfunction, thus preventing them from getting their prescription on time.

Provider information on timing of doses

Participants were asked about their understanding of when doses should be taken and if there was any importance to a specific time interval between doses, as well as their recall of communication with their provider about the optimal timing of doses. A few participants recalled (7) that their health care provider had communicated with them about or provided instructions regarding the timing of their doses, but most (20) did not. Despite most participants reporting an absence of provider communication about the importance of consistent time intervals between doses, roughly half of participants (16) conveyed an understanding that doses should be evenly spaced.

Participants who reported that their providers had not communicated with them about the timing of doses often recalled that their provider told them to take their doses in the morning or evening. However, patients did not recall their provider noting or explaining the importance of evenly spacing intervals between doses. As one participant said, "I don't remember being told to take it at the same time [every day], but it was suggested that I take it in the evening." Another participant described the ambiguity of his communications with his providers about the timing of doses: "It was like they'd have to say, 'Are you taking the pills?', they'd say, 'Regularly?' And I'd say, 'yeah,' because, to me, regularly meant every day, not every 12 hours or every 8 hours, depending on how the pills were..."

Discussion

The current study is the first to explore and characterize the nature of medication-taking routines of HIV-positive individuals in the home environment. Participants' descriptions and recreations of their home-based medication-taking routines collectively demonstrated a wide array of pill-taking triggers in the home environment (e.g., meals/food, visual cues, going to bed, watching a specific TV program). The consistency with which participants referred to routines and the "automatic" nature of remembering to take their medication suggests that many clients who have been on ART for a lengthy period of time (as most participants in this study had been) may have highly routinized medication-taking behavior.

Certain characteristics of home-based medication-taking routines were observed to be more typical of individuals with high self-reported adherence relative to low self-reported adherence. As expected, participants with higher levels of self-reported adherence described more highly routinized pill-taking behavior than participants with lower levels of self-reported adherence. These findings converge with earlier findings suggesting the importance of routinization in promoting adherence^{10, 11, 15}. However, the nonexperimental design of

the current study precludes inferences regarding the causal impact of routinization on adherence.

Participants with higher levels of self-reported adherence also more commonly reported triggers such as automaticity/time of day, visual cues, and meals/food and the use of a pillbox to keep track of medication than did participants with lower levels of self-reported adherence. It is not clear whether these characteristics may contribute causally to greater adherence. However, these findings suggest that a potentially fruitful direction for future research might be to experimentally manipulate and examine the causal contributions of these characteristics of medication-taking routines to adherence.

Medication was typically taken at home, though most participants did have occasional disruptions to their routine that necessitated taking medication elsewhere. It was also typical for participants to pocket doses in preparation for taking medication when they knew they were going to be away from home. The pattern of findings on pocketed doses highlights this medication-taking behavior as an important focus of future interventions to improve ART adherence. Specifically, the findings that pocketed doses were reported by most participants; that several participants reported sometimes forgetting to take pocketed doses or taking them later than intended; and that several participants don't use any strategies to remember to take pocketed doses collectively suggest that this aspect of medication-taking behavior may leave clients vulnerable to adherence lapses and thus warrants additional attention in efforts to increase adherence.

Procurement of prescription refills in a timely manner (i.e., before running out of medication) was also explored. Most participants reported that they had run out of medication before getting a refill at least once since they began taking medication. Recent technological innovations in the systems for ordering prescription refills, which are increasingly common, would be expected to enhance timely procurement of prescription refills. Most participants reported that technology played a role in obtaining prescription refills. However, several participants reported that these systems were vulnerable to malfunction and unreliable, which interfered with timely procurement of prescription refills. These findings suggest the need for pharmacies to monitor the success of their automated systems in providing prescription refills in a timely manner and to identify and remedy problems soon after they emerge. If this is not possible, then, minimally, patients should be alerted to the problem so that they can keep track of the need for and order prescription refills through alternative means until the problem has been corrected.

Most patients in the current sample did not recall their providers having communicated with them about the importance of timing of doses, and many patients' responses conveyed limited understanding of the importance of timing of doses. While dose timing is rarely measured in studies of adherence, a few studies have highlighted the importance of dose timing to achieving virologic suppression^{1, 16, 17}. In particular, patients need to know the ideal interval in between doses and the window of time around the ideal timing of doses during which doses can still be taken without increasing the risk for development of resistance or drug toxicity. As the current findings represent patients' recall of provider communication, rather than actual provider communication, it is unclear whether the findings reflect providers' deficits in communication or patients' faulty recall of provider communication that did occur. Nonetheless, the poor understanding of the importance of dose-timing expressed by many participants underscores a critical gap in patient education. As the nature of deficits in patient education efforts cannot be inferred from this study, more research is needed to determine the nature of improvements that are best suited to close this gap.

In interpreting the findings of the current study, some caveats should be considered. First, given that the sample consisted exclusively of men, most of whom were unemployed, the generalizability of the current findings to other populations, such as HIV positive females and employed individuals, is unclear. In particular, barriers to and facilitators of adherence may differ for employed and unemployed individuals, as unemployed individuals typically lead more unstructured, unstable lives. Past research has indicated that individuals with more unstructured, unstable lives have greater difficulty establishing and adhering to medication-taking routines^{10, 11}. The current findings would need to be replicated in a more demographically diverse sample to determine how barriers to and facilitators of adherence may differ for women and employed individuals.

In sum, the current study expands our understanding of the nature of home-based medication-taking routines. Medication-taking behavior in the home environment was found to be highly routinized for the majority of participants, and several characteristics of home-based medication-taking routines were observed. Findings illuminate areas of inquiry for future research that may be propitious for identifying modifiable targets of home-based interventions to promote ART adherence.

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Table 1

Challenges and Facilitators of Medication Adherence Among HIV-Positive Participants (n = 31)

	Number of Persons (%)
Challenges	
Being busy	14 (45)
Lack of motivation	7 (23)
Side effects	6 (19)
Too many doses in regimen	5 (16)
Facilitators	
Use of pillbox to store medication	13 (42)
Positive outlook	11 (35)
Having a routine for taking medication	8 (26)
Not having to take as many doses	6 (19)
Heightened awareness/self-education about the importance of adherence	6 (19)

Table 2

Triggers for Taking Medication Among HIV-Positive Participants (n = 31)

	Number of Persons (%)
Automaticity/time	
Morning dose	14 (56)
Evening dose	10 (43)
Meals/food	
Morning dose	15 (60)
Evening dose	6 (26)
Visual cues	13 (42)
Other medications or vitamins	10 (32)
Being reminded by others	8 (26)
Television shows	5 (16)
Getting ready for bed ^a	5 (22)
Use of a chart or notes	2 (6)

Note. For the triggers “automaticity/time” and “meals/food,” which are broken down by morning and evening doses, the denominator for percentages is the number of participants with morning (n = 25) and evening (n = 23) doses. For other triggers, unless otherwise indicated, the denominator is the total sample of 31 participants.

^aThe denominator for this percentage is the number of participants who took doses in the evening (n = 23), as getting ready for bed could serve as a trigger only for evening doses.

Table 3

Characteristics of HIV-Positive Participants With High (n = 22) and Low Levels of Self-Reported Adherence (n = 8)

	Number of High Adherers (%)	Number of Low Adherers (%)
Facilitator: Use of pillbox	11 (50)	2 (25)
Triggers		
Automaticity/time	17 (77)	4 (50)
Meals/food	12 (55)	3 (38)
Visual cues	10 (45)	2 (25)
Clear medication-taking routine	17 (77)	4 (50)

Note. "High adherers" were participants who reported missing less than one dose per week; "low adherers" were participants who reported missing one or more doses per week.

Table 4

Frequency of Pocketing Doses and Strategies for Remembering to Take Pocketed Doses Among HIV-Positive Participants Who Reported Ever Having Pocketed Doses (n = 22)

	Number of Persons (%)
Frequency of pocketing doses	
Rarely	8 (36)
Always or frequently	5 (23)
Occasionally	7 (32)
Doesn't recall	2 (9)
Sometimes forgets to take pocketed doses	5 (23)
Sometimes takes pocketed dose later than intended	3 (14)
Strategies for remembering to take pocketed doses ^a	
No strategies used	7 (50)
Meals/food	8 (21)
Visual aids	2 (14)
Pill box	1 (7)
Notes placed in strategic locations	1 (7)

^aThe denominator for percentages of patients who reported each strategy for remembering to take pocketed doses is 14, the number of patients who reported pocketing doses more than rarely; strategies for pocketing doses weren't explored among patients who reported pocketing doses only rarely. For all other themes, the denominator is 22, the number of patients who reported ever having pocketed a dose.

Table 5

Obtaining Medication Refills on Time, Prompts for Obtaining Medication Refills and the Role of Technology in Refill Procurement in HIV-Positive Participants (n = 31)

	Number of Persons (%)
Has ever run out of medication before getting a refill	19 (61)
Prompts for ordering medication refills	
Noticing only a few pills left in bottle	22 (71)
Written reminders	6 (19)
Time of the month	3 (10)
Medication is automatically refilled and sent to patient	3 (10)
Phone calls from the pharmacy	3 (10)
Reminder from one's partner	2 (6)
Uses an automated system to obtain a refill	21 (68)
Positive attitude towards automated system	10 (48)
Negative attitude towards automated system	8 (38)
Indifferent to automated system	3 (14)

Note. The denominator for the percentage of interviews that included the themes "positive attitude towards automated system," "negative attitude towards automated system," and "indifferent to automated system" was 21 (the number of patients who reported using automated technology to get refills). For all other themes, the denominator for percentages was 31.