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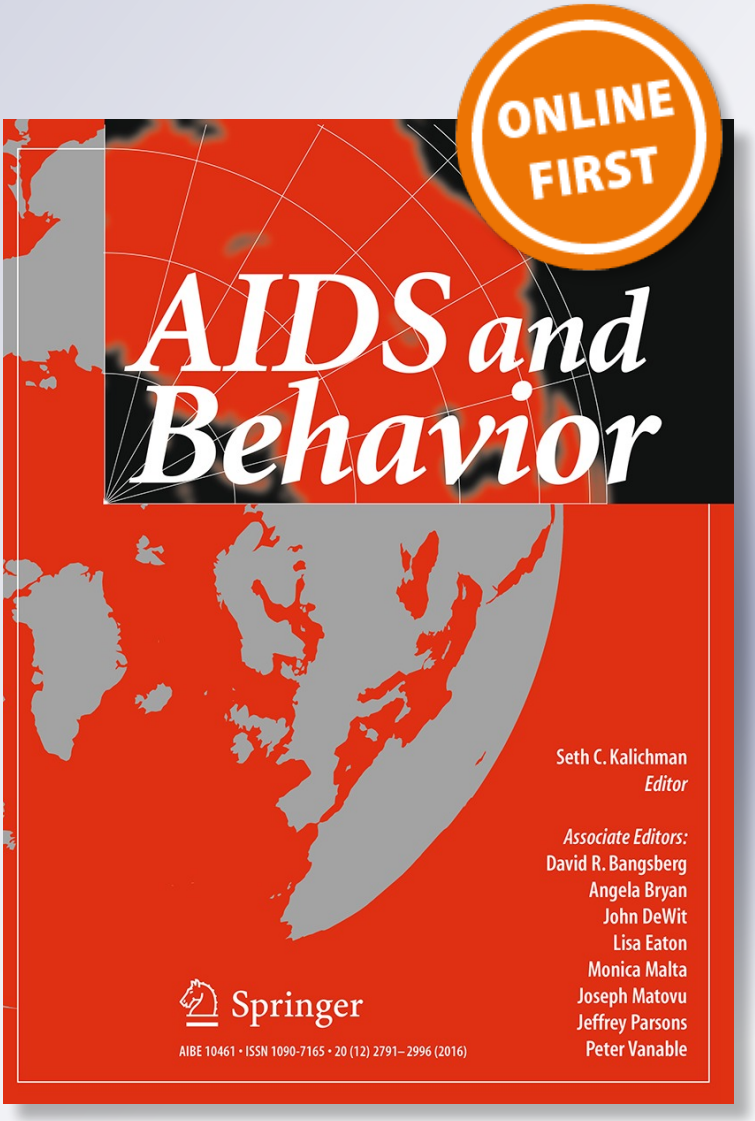

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GUEST EDITORIAL

I Can See Clearly Now: Using Active Visualisation to Improve Adherence to ART and PrEP

Annie S. K. Jones[1] · **Keith J. Petrie**[1]

Abstract Non-adherence remains a perplexing issue in HIV treatment. After decades of research supporting the efficacy of antiretroviral therapy, non-adherence to medication remains an important issue. For patients who are non-adherent to anti-retroviral therapy (ART), there appears to be a mismatch between their model of illness and the necessity for ART treatment. We propose that 'active visualisation' is a technique that could be utilised to improve understanding of treatment and subsequently adherence for both individuals living with HIV and those at-risk of infection. We discuss the theoretical background and highlight the initial evidence suggesting the utility of active visualisation. We then discuss how active visualisation could be utilised in a live demonstration to improve adherence to ART and pre-exposure prophylaxis medications.

Keywords Adherence · PrEP · HIV · Antiretroviral medication · Visualisation · Illness perceptions · Medication beliefs

Advances in HIV treatment have transformed the management of the illness but have increased the importance of improving adherence to treatment. Consistently high levels of adherence to anti-retroviral therapy (ART) provide direct clinical benefits for the patient through preventing increases in viral load and disease progression, while also substantially reducing the risk of HIV transmission [1]. Despite the benefits of adherence to the individual and population, low adherence to ART is the most common reason for treatment failure [2].

While a small proportion of long-term non-adherence and treatment failure is related to non-intentional factors, such as forgetting to take medicines, the most common reasons for why patients do not take their ART lie in how they make sense of their illness, the judgements they make about the usefulness or harmful effects of the treatment, and the lack of immediate visible consequences for non-adherence. Maintaining high levels of adherence requires a cognitive model of the illness and treatment that appreciates the necessity of taking ART consistently in order to control the virus.

For most patients, their previous experience with medication is that the treatment works when you take the medicine and fails to work when you stop. However, when you start the medication again it generally works just as well as before. Unlike hypertension medication, analgesics, or indeed most other types of medication, ART adds a new element to treatment that patients have likely not seen previously: if you do not take your medicine regularly the medicine may fail to work at all, and second or third line treatment options may be limited. Indeed, the scarcity of treatment options for ART is something that patients are largely unaware of [3]. Thus the challenge is to provide patients with a simple model for how ART is working on the inside of the body and a clear rationale for why consistent medication is critical for controlling the virus. We propose that 'active visualisation' could be used to improve adherence for individuals living with HIV or those at risk of infection.

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Why Might Visualisation Work?

There is evidence to suggest that visual information may be an effective format to deliver information about illness and treatment processes. A certain level of abstract thinking is required in order for a patient to understand the cause of their illness and how treatment helps to control their condition. Visual information may therefore make these intangible processes easier to understand. Additionally, visual information is easier to attend to and remember compared to more traditional forms of information [4]. Visual information is more uniquely encoded into our memory, which makes the information easier to remember, retrieve, and therefore utilise [5]. Research further suggests that visual information is highly accepted by patients as a form of conceptualising their illness. Patients are believed to develop their own mental images of what their illness "looks like" inside themselves [6–8]. These images provide vital insight into patients' understandings of their condition. Patients also acknowledge the value in being able to "see" what is going on inside [9].

Visual information may also result in increased motivation for positive health behaviours, in comparison to standard forms of information. Visualisation can transform previously intangible concepts into concrete representations of health threats. Emotions research suggests that the increased anxiety brought about by the presence of a concrete threat should provide strong motivation to take actions that alleviate this unpleasant feeling [10]. Of course, extreme levels of anxiety may result in maladaptive coping strategies such as avoidance. Therefore, to motivate adherence while avoiding high levels of anxiety, it is crucial to visualise both the health threat itself as well as how treatment works to increase perceived personal control over the illness threat.

Finally, visualisations have high clinical applicability as they can be adapted to a wide range of different illnesses, treatments, and patient demographics. Visualisations can be tailored to a specific patient (which is likely to increase the power of that information) or be made so they are suitable for an entire patient group. Visualisation mediums can also be made to suit particular patient demographic profiles and the relevant clinical context. For example, physical demonstrations or models may be more suitable for use in under-resourced areas as they can be low-cost and easily transportable options. In contrast, animations presented on mobile devices will presumably be more appropriate in areas where that technology is available and familiar to patients. This suggests that visualisation interventions are highly transferrable into diverse contexts, illnesses, and conditions.

What We Know So Far

Although there is sufficient theoretical support for the use of visualisation in promoting adherence, there is limited empirical work investigating this concept. Early studies utilised existing images from diagnostic testing, which were shown to patients and at-risk individuals to try and increase motivation for health behaviours. Showing smokers ultrasound images of their own atherosclerotic plaques has been found to increase their motivation for smoking cessation and increase quit rates [11, 12]. Similarly, arterial imaging has been used to improve adherence to statin medication and reduce risk behaviours in individuals with coronary calcification [13, 14], and to increase exercise levels and reduce cholesterol in patients with cardiac disorders [15, 16]. Showing personal retinal images has also been associated with greater blood glucose control in patients with diabetic retinopathy [17]. The premise of these studies is that presenting patients with a visual image of their own personal risk influences their illness beliefs and motivation to adhere to treatment.

In contrast to showing patients existing images from diagnostic testing, visualisations can also be created using more abstract, non-personalised methods. Three-dimensional, anatomical animations have been utilised to improve colorectal cancer screening literacy [18], to improve recall in periodontitis patients [19], and to reduce anxiety and increase understanding regarding thyroid surgery [20]. 3-D printed, physical models have also been utilised to represent biopsies of osteoporotic versus healthy bone and encourage preventative treatment [21]. These more abstract forms of representation are underutilised and under-researched, particularly in regards to their ability to improve adherence.

Active Visualisation

Active visualisation interventions are created to specifically represent the internal processes of an illness or treatment in a more dynamic way. Active visualisation can be animations, computer modelling, or even live, physical demonstrations of an illness process or treatment mode-of-action. Advances in technology, particularly in regards to the availability of mobile devices, means that animated active visualisation can be easily incorporated into everyday life for patients in an on-demand, open format.

The earliest work investigating what we classify as active visualisation was a pilot study by Karamindou et al. [22] which used a live, physical demonstration to improve end-stage renal disease patients' understanding of phosphate-binding medication. The demonstration explained

the mode-of-action of phosphate-binding medication by showing how the 'medication' (a phosphate-binding solution) worked inside the patient's 'body' (a plastic container) after they had eaten their favourite high phosphate food (represented by a phosphate solution). The demonstration focused on simplifying what can often be perceived as a difficult concept for patients by showing them what is actually going on inside the body and why they need to take their medicine. Seeing this intervention resulted in improved renal knowledge and treatment coherence, and increased treatment efficacy beliefs at 4 months following the intervention compared to the control group.

A recent study with myocardial infarction patients utilised active visualisation to explain both the aetiology of a heart attack, as well as how statin medication works to reduce subsequent risk [23]. Animations demonstrating these processes were shown on an iPad to patients hospitalised following an acute coronary event. At 7 weeks following discharge, patients who saw the intervention, compared to those who received standard care alone, reported more accurate perceptions of their illness and treatment, reduced levels of cardiac anxiety, as well as improved exercise levels and shorter return times to normal activities. Although limited in number, the initial research suggests that active visualisation appears to be a powerful intervention for improving patient understanding.

Theory would suggest that active visualisation may be most useful for illnesses which are typically asymptomatic, for treatments that do not result in obvious symptom reduction for patients, or for medications that work differently from others the patient may have used previously. This is true for patients taking PrEP as a preventative treatment to reduce infection risk, as well as for many early-stage patients living with HIV who are often asymptomatic. Active visualisation could increase perceptions of treatment necessity for patients taking PrEP and ART by presenting illness and medication mode-of-action information which is otherwise difficult to conceptualise.

There is evidence to suggest that active visualisation may improve adherence to ART from an initial study using mobile technology [24]. Participants (patients living with HIV) received two versions of a smartphone application: one with a standard 24 h medication clock, or an augmented version that included an animated representation of how their personal adherence levels affected their viral load activity and t cell protection within the body in real-time. Patients who saw the augmented version of the application (which included active visualisation) were found to have greater self-reported levels of adherence and decreased viral loads at 3 months follow-up when compared to participants who received the standard version. Furthermore, those participants who reported greater engagement with the augmented application had greater perceived understanding of their HIV infection and greater necessity beliefs regarding their ART. Although limited by a small sample size, this preliminary evidence suggests that being able to visualise the biological process of ART appears to be more effective in improving adherence when compared to interventions that address non-intentional aspects (e.g. forgetfulness) alone.

Using Active Visualisation for HIV and PrEP

We have recently developed an active visualisation device that can be used to demonstrate the necessity of consistent adherence to ART and PrEP therapy. This active visualisation device uses a clear Perspex outline of the body and dynamic changes in colour to illustrate the action of the medication (see Fig. 1). The device uses the changing colour of a liquid to represent two states; one where the virus is able to replicate (pink colour) and one where the presence of medication controls this from happening (clear colour). The device uses a diluted solution of sodium hydroxide, water, and a pH indicator, so that the addition of more acidic or basic solutions can change the colour accordingly. A demonstration using the device can be seen in a video for adherence demonstration and non-adherence.

In the demonstration, the acid is an effervescent tablet representing the patient's ART (actually an aspirin tablet) that when added to the pink solution looks potent as it fizzes and changes the pH balance to result in a clear liquid. The second solution is a sodium hydroxide basic solution which represents the HIV virus. This solution is added to the body each 'day' during the demonstration. The demonstration takes the participant through a series of days to convey the message that their ART needs to be taken every single day. This is achieved by showing patients that when they take their medication (and the solution becomes clear) on day one, on day two the virus is still in their body, meaning that they need to again take their medicine to control the risk of their viral load increasing (see Fig. 1). This message and the demonstration are repeated several times to the patient.

The device also demonstrates to patients what happens if they repeatedly miss doses of their medication and how this affects the body's ability to control the viral load. In this part of the demonstration the participant sees that each day the 'virus' is inside of their body, but this time there is no medication being taken to control the virus from replicating. The solution becomes pinker as the level of virus within the body is increasing. When the participant eventually 'remembers' and medicine is added to the device, this time the solution does not change back to clear (see Fig. 2). The message here is that if the patient does not

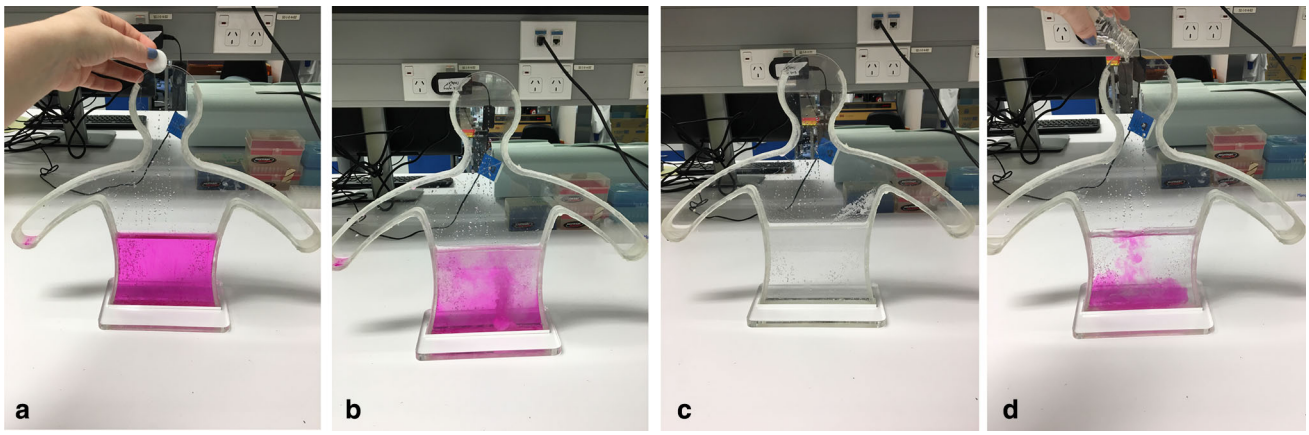

Fig. 1 The active visualisation device demonstrating the need for adherence to ART. **a**–**c** show the medicine controlling the virus inside the body, and **d** shows the 'virus' still being present the next day (indicating that medication needs to be taken once again) (Color figure online)

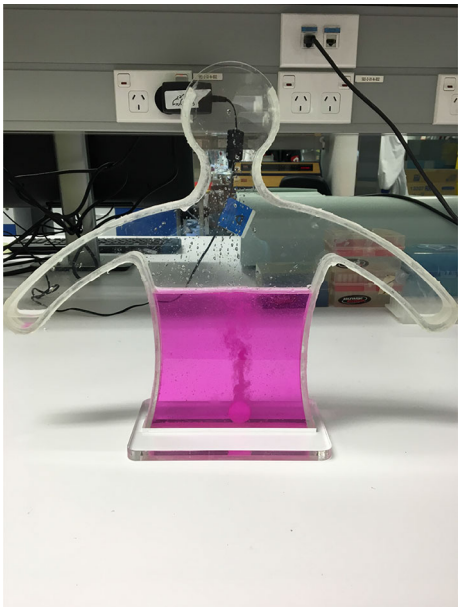

Fig. 2 The active visualisation device demonstrating what happens when a patient is not adherent to their medication. Medicine is added but the solution does not change to clear (Color figure online)

consistently adhere to their medication, the viral level is not controlled within their body and so they will become resistant to their medication.

There is also an application for using the active visualisation device to explain how PrEP works preventatively to lower the risk of HIV infection. In this version of the demonstration, PrEP medication (aspirin tablet) is continuously added into a water solution, which actively dissolves and leaves a clear mixture. Following this, a vial with a purple coloured solution representing the HIV virus is poured into the liquid but the mixture remains clear (see Fig. 3). The message here is that consistent adherence to PrEP maintains the level of the medicine within the body, meaning that the risk of contracting an HIV infection is greatly reduced. This demonstration can be contrasted with a solution where no medication or irregular medicine is taken. In this version, when the purple liquid is added to the solution it does turn the whole body purple, representing the higher risk of contracting an HIV infection when PrEP is not taken consistently.

Future Applications

Our device has the potential to increase understanding regarding the necessity of consistent adherence to both ART and PrEP, meaning that it could be a powerful intervention to improve adherence to both of these medications. The device has key features that make it a promising tool for use within this disease population. Firstly, the use of a simple, visual representation should make the concept of consistent adherence to PrEP and ART easier for patients to understand. The device could therefore be especially useful as an educational tool for specific populations, such as children and adolescents, or other individuals with low health literacy. Second, the device is a highly portable and low-cost resource. This makes it ideal for use within hard to reach, under-resourced areas where other formats of active visualisation (such as mobile technology) may not be as suitable. The next step forward in attempting to understand the utility of active visualisation in improving adherence to ART and PrEP is to therefore conduct more research using larger and more diverse samples.

There are also future applications for using active visualisation with other chronic illnesses. There are many conditions where adherence does not always directly relate to a change in symptom experience (e.g. hypertension, asthma). Relatedly, active visualisation may be particularly useful for patients to comprehend the need for

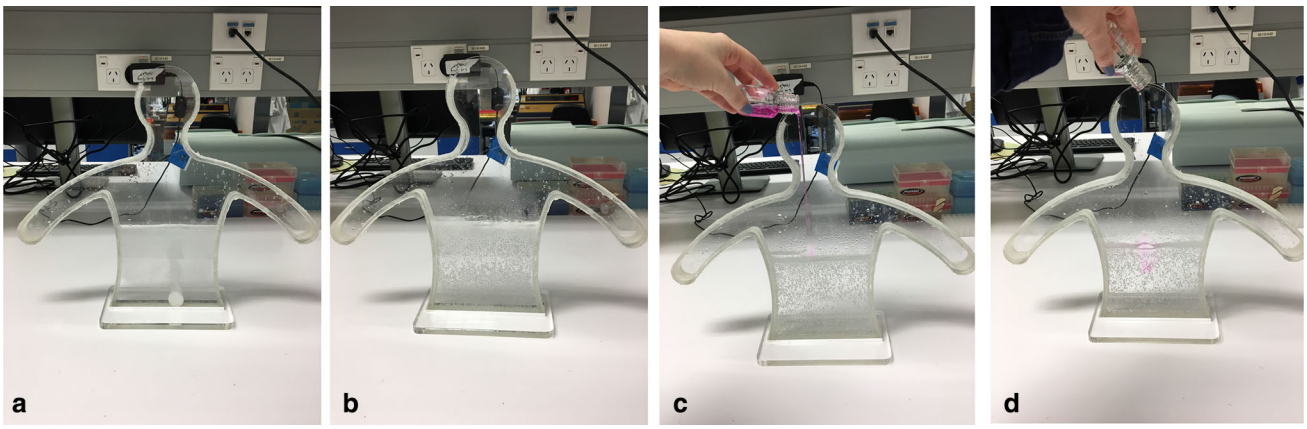

Fig. 3 The adapted active visualisation device demonstrating how adherence to PrEP lowers risk of HIV infection (**a**, **b**). When the virus is added into the device (**c**) the solution remains clear (**d**) (Color figure online)

a preventative medicine, such as statins prescribed to patients with angina or high cholesterol. In addition, active visualisation may be a useful tool for explaining the biological process of particularly complex treatments, where other methods of communication may be insufficient. The dynamic nature of active visualisation means that there are many contexts within which it could be applied to provide a clearer explanation and, more importantly, to fit the purpose of treatment to the patient's model of illness.

Active visualisation presents a new frontier in patient education. Using visual information may seem like common sense, but active visualisation is about more than simply drawing a picture or creating a model. Visualisation interventions need to be carefully considered, and must be created based on the theoretical approaches that we have discussed above. They must be presented in the context of the clearly defined "problem", and subsequently highlight how treatment can be used to try and control or cure the health threat. Active visualisation must create a fit in the patient's mind between their illness model and the purpose of their treatment. The initial evidence and considerable background theory suggests that visualisation could be an immensely useful tool in helping patients to 'see' what is actually going on inside.

Compliance with Ethical Standards

Conflict of interest Annie Jones and Keith Petrie declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual study participants.

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