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Routledge
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Simple, illustrated medicines information improves ARV knowledge and patient self-efficacy in limited literacy South African HIV patients

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Few studies have investigated antiretroviral (ARV) knowledge and self-efficacy in limited literacy patients. Using a randomized controlled study design, we investigated the influence of a simple pre-tested patient information leaflet (PIL) containing both text and illustrations on HIV- and ARV-related knowledge and on self-efficacy over six months in a limited literacy African population. The recruited patients were randomly allocated to either control (standard care) or intervention group (standard care plus illustrated PIL). HIV and medicines-related knowledge was evaluated with a 22-question test at baseline, one, three, and six months. Self-efficacy was assessed using a modified version of the HIV Treatment Adherence Self-Efficacy Scale. Two-thirds of the patients were female, mean age was 39.0 ± 9.6 years and mean education was 7.3 ± 2.8 years. Patients who received the PIL showed a significant knowledge increase over the six-month period (62.0–94.4%), with improvement at each subsequent interview whereas the control group showed no improvement. At baseline, side effect knowledge was the lowest (50–56%) but increased in the intervention group to 92%. Similarly, other medicine-related knowledge at baseline (57–67%) improved significantly (93%) and was sustained over six months. Cohen's *d* values post-baseline ranged between 1.36 and 2.18, indicating a large intervention effect. Self-efficacy improved significantly over six months in intervention but not control patients. At baseline, patients with ≤3 years of education had lower knowledge and self-efficacy but this was not observed post-intervention, which we attribute to the PIL mitigating the effect of limited education. Knowledge and self-efficacy were significantly correlated in the intervention group. In conclusion, a low-cost intervention of a well-designed, pre-tested, simple, illustrated PIL significantly increased both ARV knowledge and self-efficacy in HIV patients with limited education.

Keywords: knowledge; self-efficacy; low literacy; written patient information; pictograms

Background

Approximately 1.8 million people are taking antiretrovirals (ARVs) in South Africa (Johnson, 2012). The resource-limited setting presents many challenges to retaining patients in care and maintaining adherence to treatment (Mills et al., 2006). Self-efficacy, a predictor of adherence to ARVs in HIV patients (Johnson et al., 2007; Wolf et al., 2007), is associated with literacy and health-related knowledge, which influence adherence and retention of HIV/AIDS patients in care (Potchoo et al., 2010; Wolf et al., 2007).

Low literacy/health literacy skills contribute to a poorer knowledge of HIV-related terms and of HIV treatment, lower self-efficacy, and poorer adherence to ARVs (Kalichman, Ramachandran, & Catz, 1999; Wolf et al., 2005). Written medicines information in the form of a patient information leaflet (PIL) can supplement verbal information, much of which is forgotten almost immediately post-consultation (Kessels, 2003). Unfortunately, lack of user-friendliness, poor readability, and inadequate presentation results in poor uptake and lack of perceived PIL value and usefulness (Mwingira & Dowse, 2007; Raynor et al., 2007).

Including visuals/pictograms in patient information improves comprehension, recall, and acceptability (Dowse & Ehlers, 2005; Houts, Doak, Doak, & Loscalzo, 2006; Katz, Kripalani, & Weiss, 2006). The objective of this study was to investigate the influence of simple, illustrated PILs on knowledge and self-efficacy in limited education HIV/AIDS patients taking ARVs.

Methods

The study was conducted in two clinics in the rural Eastern Cape province, where 78.8% have isiXhosa as the first language, and 35% have ≤7 years of schooling (Statistics South Africa, 2011).

Illustrated PILs were designed for the four 2009 South African first-line ARV regimens, evaluated for comprehension in ARV-naive individuals (Dowse, Ramela, & Browne, 2011) and modified for current use (Figure 1).

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(a)

ANTIRETROVIRAL THERAPY (ARV)

Patient information leaflet for Regimen 1a

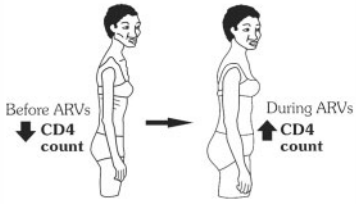
The information in this leaflet will help you take your ARVs properly and stay as healthy as possible.

WHAT YOUR ARVs DO

ARVs fight HIV/AIDS :

- they stop the growth of HIV virus
- they help you become stronger
- they increase the CD4 count (good cells)
- they lower the amount of HIV virus in the blood

ARVs do not cure AIDS



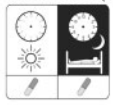
BEFORE TAKING YOUR ARVs

Tell your doctor, nurse or pharmacist if you…

- are taking any other medicines
- have any allergies
- are pregnant or trying to fall pregnant
- are breast-feeding
- are on oral or injectable contraceptive
- have anything else wrong with you.

HOW TO TAKE YOUR ARVs

Stavudine (d4T)



Take 1 tablet in the morning and 1 tablet at night

Lamivudine (3TC)

Take 1 tablet in the morning and 1 tablet at night

Efavirenz (EFV)

Take 1 tablet at night

Take your ARVs with or without food

You must not stop taking any of your medicines. Carry on taking all 3 of your ARVs.

WHILE TAKING YOUR ARVs

Are you taking other medicines?
You must tell your doctor, nurse or pharmacist if you are taking other medicines, herbal remedies or traditional remedies from the:

If you forget to take your medicine…

- take it as soon as you remember.

Do not share your medicines…

- with friends or family.

(b)

SIDE EFFECTS

- Side effects are unpleasant effects that occasionally appear when taking ARVs, but they can be well managed and treated.
- You may not get any side effects. However if you experience any of the following tell the doctor or sister at the clinic.

In the first 6 weeks after starting ARVs:

- abnormal dreams
- dizziness
- headache
- nausea
- diarrhoea
- skin rash

After 3 - 6 months of taking ARVs:

- tingling, burning, numbness or pain in the hands or feet (pins and needles)

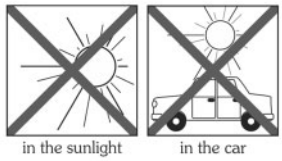
Go to the clinic AS SOON AS YOU CAN if you experience:

- stomach pain, nausea and vomiting

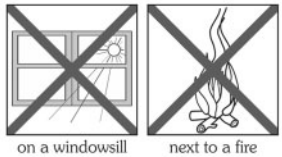
- severe rash on the body or in the mouth and a fever (hot)

HOW TO STORE YOUR ARVs

Do not keep your ARVs…



in the sunlight | in the car



on a windowsill | next to a fire

Keep all medicines…

where children cannot reach them | in a safe, cool, dry place

IMPORTANT !

Go to the clinic AS SOON AS YOU CAN:

- if you are pregnant when taking Efavirenz

- if you experience fever (hot) with or without chills (cold)

USE A CONDOM

You can still spread HIV/AIDS by having unprotected sex, even if you are taking ARVs.

You must use a condom every time you have sex to protect yourself and others.

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July, 2009

YOU MUST TAKE ARVs FOR THE REST OF YOUR LIFE

Figure 1. (a) Page 1 and (b) page 2 of the two-page PIL (Regimen 1a).

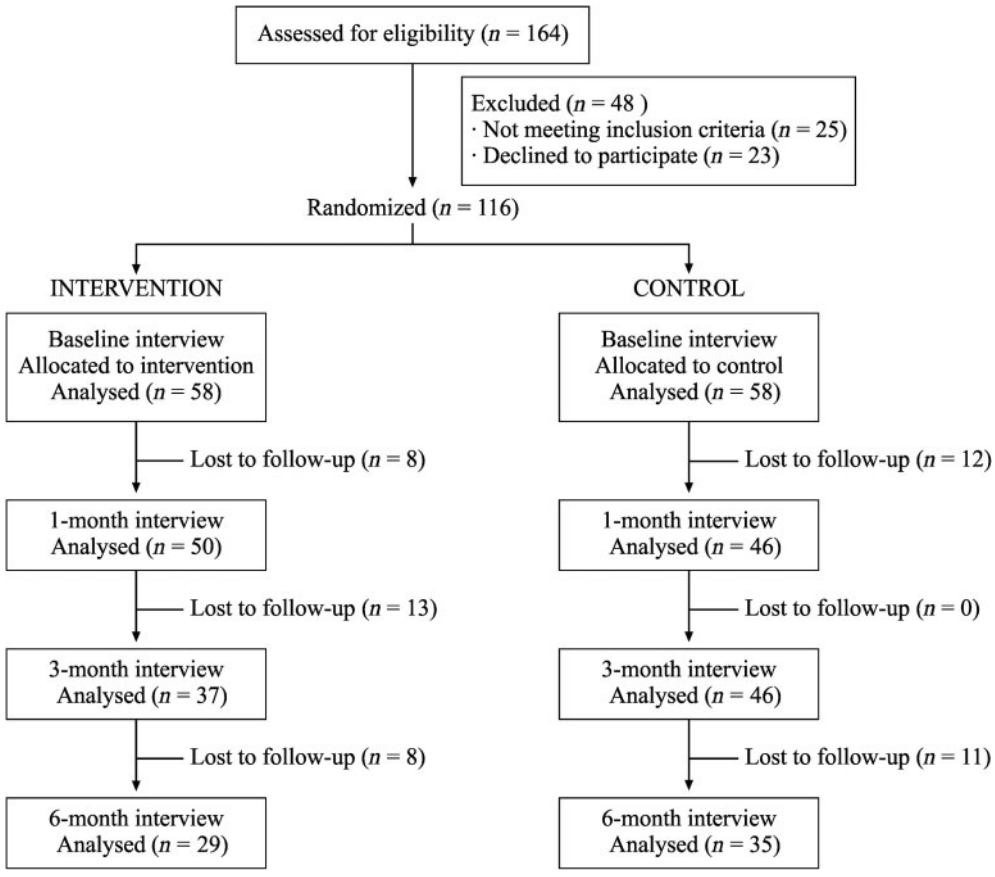

Figure 2. Flow chart of study participants and data collection points.

Ethical approval was obtained from all associated institutions. The study employed a randomized controlled design. HIV/AIDS patients were eligible to participate if they had been taking a first-line ARV regimen for less than three months, were 18 years or older, had isiXhosa as their home language, and had a maximum of 10 years of schooling. Signed informed consent was obtained. Patients were randomized via a computerized random number generator to either control (standard care) or intervention (standard care plus a PIL) groups, stratified by education.

A 22-question knowledge test evaluated three knowledge areas: ARV side effects, additional ARV information, and HIV/AIDS information. Self-efficacy was assessed using a slightly modified version of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES; Johnson et al., 2007). During interviews, conducted with a trained interpreter, demographic, knowledge, and self-efficacy data were collected after which intervention patients were given a PIL (choice of either isiXhosa or English), and a brief verbal description of section contents. Patients were encouraged to read it at home and to return for one-, three-, and six-month follow-up interviews, where the same knowledge and self-efficacy tests were administered.

A knowledge score was obtained by summating correct responses. *t*-tests and chi-square tests were used to investigate differences between groups. One-way analysis of variance (ANOVA) and chi-square tests were used to investigate associations between knowledge and self-efficacy with gender, age, and education at the 5% level of significance. The association between knowledge and self-efficacy was analyzed using multivariate linear regression. To calculate sample size, it was predicted that "knowledge" was predicted to increase from 60% (baseline) to 85% (post-intervention). Based on $p = 0.05$ and statistical precision of 10%, 53 patients were required in each group. Repeated measures ANOVAs over the four interview times were used to calculate the effect size. Cronbach's α was used to test for internal consistency of the knowledge test.

Results

Of 174 patients approached, 116 patients were interviewed at baseline and 64 at six months (Figure 2). The demographics of those lost to follow-up over six months did not differ significantly from those who completed.

At baseline, 67.0% were female, mean age was 39.0 ± 9.6 years, mean education was 7.3 ± 2.8 years, >90% were unemployed. No significant differences were found between groups.

Table 1. Knowledge results (%) for the three knowledge areas over the four interview times.

	Baseline			1 month			3 months			6 months		
	Control (n = 58)	Intervention (n = 58)	p	Control (n = 46)	Intervention (n = 50)	p	Control (n = 46)	Intervention (n = 37)	p	Control (n = 35)	Intervention (n = 29)	p
ARVs	66.6	56.3	<0.001*	65.0	84.7	<0.001*	70.4	90.7	<0.001*	70.7	93.1*	<0.001*
HIV/AIDS	87.9	85.9	0.504	89.5	95.7	0.019*	91.3	98.2	0.007*	100.0	98.3	0.052
Side effects	55.9	45.9	0.020*	52.2	88.0	<0.001*	56.1	95.7	<0.001*	59.4	92.4*	<0.001*
Total score	70.0	62.0	0.001*	68.8	88.5	<0 001*	72.8	93.9	<0.001*	76.1	94.4	<0.001*

*Significant difference ($p < 0.05$) between intervention and control group.

Table 2. Mean score (± SD) for self-efficacy (0–10 scale).

	Baseline			1 month			3 months			6 months		
Self-efficacy	Control (n = 58)	Intervention (n = 58)	p	Control (n = 46)	Intervention (n = 50)	p	Control (n = 46)	Intervention (n = 37)	p	Control (n = 35)	Intervention (n = 29)	p
Score (SD)	9.65 (0.74)	9.11 (0.46)	0.013*	9.84 (0.63)	9.60 (0.88)	0.130	9.70 (0.01)	9.62 (0.89)	0.087	9.73 (0.89)	9.71 (0.72)	0.916

*Significant difference ($p < 0.05$) between intervention and control group.

Evaluation of knowledge

Cronbach's α was 0.65, indicating acceptable internal consistency of the knowledge test. From Table 1, baseline knowledge scores were higher in control group (70%) than intervention group (62%, $p < 0.001$). Post-intervention, the intervention group had consistently significantly higher knowledge scores ($p < 0.001$). Cohen's d values post-baseline ranged between 1.36 and 2.18, indicating a large intervention effect. No significant change in knowledge was found in the control group over six months ($p = 0.258$) whereas knowledge in the intervention group increased significantly from 62% to 94% ($p < 0.001$).

ARV knowledge

At baseline, most knew ARV names and dosing instructions (>85%) and knew not to share ARVs or use traditional medicine (98–100%). Intermediate results (40–50%) were achieved for storage conditions, taking concomitant medicines with ARVs, and what to tell the provider before starting ARVs. Poorest knowledge (<20%) was related to acceptability of taking ARVs without food and action to take regarding a missed dose. At six months, control patients scored <50% for 5 of the 11 questions, whereas intervention patients scored between 79% and 97%.

HIV/AIDS knowledge

Knowledge was high throughout in both groups: need for lifelong ARVs and spread of HIV while taking ARVs (>90%), effects of ARVs on viral load, CD4 count, possibility of curing AIDS (75–85%). By six months these scores approached 100%.

Side effect knowledge

Poor knowledge at baseline revealed only 5.2% able to describe some late side effects, whereas 40–50% were able to describe general and early side effects. Control patients showed no improvement, whereas intervention patients sustained significant improvement over six months.

Self-efficacy results

At baseline, the self-efficacy score was lower for the intervention group ($p = 0.013$), but thereafter remained similar between groups (Table 2). Over six months, no change was evident in control patients, whereas intervention patients displayed an overall significant improvement in mean score ($p = 0.008$).

Associations and correlations

Only education influenced knowledge in both control ($p = 0.027$) and intervention ($p < 0.001$) groups, with patients having ≤Grade 3 displaying lower knowledge than other education groups. Interestingly at six months, intervention patients with ≤Grade 3 displayed superior knowledge to Grade 4–7 patients ($p = 0.001$), evidence of the positive effect of the PIL in mitigating the effect of low education.

A significant correlation of higher knowledge with increased self-efficacy was seen at baseline for combined group data ($r = .487$, $p < 0.001$), control patients ($r = 0.281$, $p = 0.033$), and intervention patients ($r = .587$, $p < 0.001$), but only for intervention patients at six months ($r = .430$, $p = 0.022$).

Discussion

ARV-related knowledge and self-efficacy were improved by a PIL containing pictograms and simple text. A dramatic effect on knowledge occurred at one month and this was sustained over the following five months indicating excellent retention and recall of newly acquired information. Improving patient knowledge and understanding at the individual level improves health literacy, which is central to enhancing self-care in patients. Interestingly, although education did influence baseline knowledge, this effect appeared to be mitigated at six months due to the PIL, with lower educated patients displaying better knowledge than more educated patients.

A South African study concluded that local PILs are not an efficient communication medium as they contained difficult words, had an unappealing layout, and were user-unfriendly (Krige & De Wet, 2009). All pictogram and text components for our PIL were designed in consultation with the target population using a multi-stage iterative process, and pre-tested for comprehension and acceptability (Dowse et al., 2011). Study patients (97%) liked the PIL appearance and inclusion of pictograms, and despite limited education, found it easy to read and comprehend.

Side effects are a major factor in adherence to ART (Chesney, Morin, & Sherr, 2000) but, disconcertingly, patient reports indicated that providers did not routinely offer this information and it was the area that generated the poorest baseline results (46–56%). Improved post-intervention knowledge appeared to contribute to higher self-efficacy in patients who received the PIL. Risk factors for lower self-efficacy were lower education and older age (>50 years). Knowledge and self-efficacy in our study were significantly correlated, supporting other studies where associations between disease-related knowledge and self-efficacy have been reported

(Macabasco-O'Connell et al., 2011, Mancuso, Sayles, & Allegrante, 2010). As low health literacy is associated with reduced self-efficacy (Wolf et al., 2007), an intervention that improves knowledge in patients with low literacy should therefore have a relatively higher impact on self-efficacy, possibly helping patients avoid unintentional nonadherence. Our intervention was deliberately designed to fit seamlessly into current practice in under-resourced settings with the PILs requiring only a brief content description as they are easily comprehended by most patients. However, best-practice is to use information materials as a tool to facilitate the counseling/education process.

Limitations of the study include the high attrition rate over six months. The study was conducted in one town in a limited study population and therefore generalizability of findings is limited. Future research should investigate the effect of a knowledge intervention on adherence and health outcomes in HIV/AIDS patients.

Conclusions

Patient knowledge of ARVs and self-efficacy was improved and sustained over six months by a simple PIL developed with the target population using good design practice that included pre-tested pictograms. Well-designed medicines information such as ours may be useful to include as a component of programs to support and sustain ART adherence, or as an aid to community-based adherence support workers.

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