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Experiences of participating in an antiretroviral treatment adherence club

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Abstract

In an effort to streamline the management of large numbers of patients receiving antiretroviral therapy (ART) in South Africa, adherence clubs were introduced in some districts in the Western Cape since 2008. Adherence clubs are group clinic visits of approximately thirty ART users who receive group adherence counselling and obtain a supply of medication. We sought to document the experiences of patients attending adherence clubs and health care workers at clinics where clubs were operating. Participants were six ART adherence club members and seven health care workers, which included HIV nurses, medical doctors, pharmacists and counsellors. Data in the form of one-on-one interviews were collected at the Infectious Diseases Clinic of a large district hospital in a peri-urban area in the Western Cape region of South Africa. The interviews covered ART users' experiences of the clubs, advantages and challenges that arose in the context of the club-based method of providing treatment, and the concerns facing ART users and health care workers (HCW's) with regard to the clubs. The data were analysed using thematic analysis. There were clear benefits to the introduction of adherence clubs, most importantly the reduced amount of time ART users needed to spend at the clinic. Yet, various problems also emerged, the most important one being the logistical problems associated with the timely and correct delivery of drugs. These benefits and disadvantages are discussed in the context of providing ART services to large numbers of patients in post-apartheid South Africa.

Keywords

adherence clubs; antiretroviral therapy; adherence; South Africa

Approximately 2.4 million South Africans are currently receiving antiretroviral therapy (ART) (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu et al (2014), a country with an estimated 12.2% of the population living with HIV. High levels of adherence are required for ART to function optimally (Tam, Pharris, Thorson, Alfven, & Larsson, 2011). Adherence clubs were introduced in some areas over the last five years to streamline the management of treatment. Adherence clubs are group clinic visits in which only highly adherent patients are eligible to participate. A typical club involves approximately thirty patients attending the clinic simultaneously at a given time every two months, where they would receive group adherence counselling and a two-month supply of medication. Club meetings typically last no more than one hour, compared to the up to six hours that is common in usual individual clinic visits (Coetzee et al 2010). The chief purpose of adherence clubs is to reduce the time patients spend waiting for services. Health care personnel usually make decisions about patients' eligibility to be part of an adherence club.

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In order for patients to be eligible to join an adherence club, their CD4 count is required to be 200 cells/mm3 or above and their viral load is required to be at a lower than detectable level (40 copies per ml). Patients are required to attend the clinic every two months and have their blood drawn once a year.

The experiences of club participants have not been recorded. We sought to document the experiences of patients and health care workers (HCW's) at a clinic in the Western Cape province of South Africa.

Methods

Setting and Sample

Participants were ART users attending an adherence club, HIV nurses, medical doctors, pharmacists and counsellors. Sampling was conducted to saturation (Kelly, 2006). Six ART users and seven health care workers were recruited into the study. Data were collected at the Infectious Diseases Clinic of a large South African hospital.

Procedures

A research assistant associated with the study asked clinic nurses to hand out information leaflets to club members and HCW's. The interviews were conducted over a period of three weeks and took place in one of the clinic consulting rooms that was made available to the researchers. Participants received a grocery voucher as a token of appreciation for their participation. Ethical approval for the study was obtained by the Stellenbosch University Health Ethics Committee.

The interviews covered ART users' experiences of the clubs and the advantages and challenges of club participation. Interviews were then were tape recorded, transcribed, and entered into the Atlas.ti 4.2 computer programme. The analysis of the data focused on the manner in which the narratives were structured and the content of the participants' experiences and concerns. The analysis was conducted using the categorising process involving open coding, selective coding, comparison and categorisation, and re-reading and modifying (Silverman & Marvasti, 2008). The issue of trustworthiness of the data was considered using the criteria developed by Lincoln and Guba (1985). These were credibility, transferability, dependability, and neutrality. Credibility was addressed by ensuring the participants were indeed clinic employees and adherence club members. Transferability was not addressed as the data pertained only to the participants at the hospital where the data were collected. Dependability was addressed by examining the consistency of the data and determining that the responses from the participants were similar when questions were asked in different ways. Confirmability was addressed by ensuring that the interviewers were appropriately trained in conducting qualitative interviews and in reducing or acknowledging bias.

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Results

Rationale for the adherence clubs

When asked about the rationale for the club, a HCW stated "… the number one reason is to decongest the clinics so we have more time to spend with the really sick patients or the new patients." The purpose of the adherence clubs from the HCW's point of view was to streamline clinic functioning and create conditions for faster processing of already adherent patients. The HCW's appeared to have a clear rationale for implementing the adherence clubs, namely, the ease of service delivery in the context of large numbers of patients seeking treatment.

Benefits of adherence clubs

Participants were unanimous about the benefits of adherence clubs. One HCW stated "The actual day of the club also is quite great. Patients are in and out in less than fifteen minutes, and they don't have to spend the whole time at the clinic." Another ART user stated "because most of the people are working so the… club is fantastic for the working people. Then they come here, pick up and go."

The shorter waiting time was cited as the most important benefit of the club, as was the fact the clinic system was now fitting in with the lifestyle of the patients who no longer needed to miss days off work. A HCW similarly stated that before joining the club most patients were required to take a sick day from work every time they attended the clinic. She stated "the patients are very excited. For them it's firstly their job, they're not in trouble in their work place anymore." Participants stated that those patients who were paid on a daily basis would no longer need to forgo a day's wages as they no longer had to spend several hours at the clinic waiting for a nurse to see them.

Another HCW stated:

> "We used to have more than a hundred patients every single day… So now with the adherence clubs we managed to drop the number to about seventy, eighty per day".

The mood of the patients was referred to by several HCW's, for example, "it's a very happy…positive experience, so for once you are actually seeing healthy, happy, patients, who just literally come in there to pick up their pills." An ART user reflected on the way the club influenced her perspective of her community, stating "I enjoy being in the club because sometimes you see different people. You see… people from your community that you never know… are positive."

Cohesion among patients

Cohesion among club members emerged as a strong theme. A HCW stated "they all come on that date and they know each other and they know where who lives and so that if that person didn't come they're like, 'Okay, we know where he lives maybe they'll take his medication there or whatever.'" Thus when one club member did not collect his/her medication, others would offer to drop it off at the person's house. Another HCW stated "people feel… there's somewhere they can belong… and people that really care for them".

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Relationships appeared to play an important role in maintaining the cohesion of the club. However, one ART user had the opposite experience, stating “You can’t actually make friends in the club because at that time of the day they just come and take their pills and go. There is no time to sit down and talk to each other.” For this participant the shortness of the club meetings did not allow for relationship-building among club members. When asked about contact with club members outside of the club meeting times, one participant said that contact was minimal because they resided far from one another. Thus, it appeared that cohesion among club members did not extend beyond club meeting times.

Different patient identity

A HCW commented on the way in which patients’ identities changed as a result of joining an adherence club. She stated “patients are… promoted out of the sick role in which they have to see the nurse and the doctor and collect their pills. Now they are healthy patients, who literally just need to go pick up their pills.” The abandonment of the sick role was an important way of redefining the way ART users view themselves as active rather than passive participants in their care.

Challenges associated with adherence clubs

Despite the benefits associated with the innovation of adherence clubs, several challenges also emerged. A HCW noted “the delivery of medication was not on time for the clinic. It was a nightmare. The CDU (Central Dispensing Unit) failing to deliver the medication on time… scripts being lost at CDU after they have been issued.” Another HCW stated that scripts were routinely lost “in some silo”, reflecting that the bureaucracy of the health care system did not allow for networks of communication between its various parts. She stated “so for six months we did not have medication and yet there was proof… and then our pharmacy has to issue the medication”. It appeared that the logistics of administering the club were problematic to such an extent that it placed a greater burden on clinic functioning than might have been the case without the existence of the club. The CDU, whose responsibility it was to ensure delivery of the medication to the clinic, often failed in this regard. Another HCW stated “There were times, especially initially when we started, when we got incomplete packets.” Other problems that emerged were the late delivery of scripts to the CDU and reports from the CDU of the expiration of scripts.

A HCW expressed concern about the poor communication between the clinic and the CDU, stating “it’s not like you are sitting with someone that’s next to you or you can walk to the CDU and you get an answer. They will always be passing the buck.” This HCW expressed impatience at the fact that the logistics of the dispensing system were taking too long to work themselves out. It also became problematic when the need arose to inform patients that their medication did not arrive and the patients could not be reached. When patients were without medication they defaulted on treatment. Such problems were exacerbated in the context of structural barriers such as poor transport infrastructure and the lack of money to pay for transport, as patients would then need to travel to the clinic on another day to collect their medication.

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Another problem expressed by HCW's was understaffing, which placed pressure on the existing nurses. One participant stated "so imagine having to suddenly redo thirty plus scripts of four months medication over and above your normal work duties and to work overtime. It's hectic." ART users stated that the club regimen did not consider individual patients' needs. For example, the way the club was organised did not permit patients to see a doctor at the time of a club meeting. They were required to make an appointment at another time.

The issue of stigma emerged as a problem in the context of adherence clubs. A HCW stated "a patient who enlisted for the club… actually turned around and went back home because he didn't want to be known by fellow community members." Being identified as an ART user even by another patient was unacceptable to this patient. On the other hand, another HCW stated that ART adherence clubs might serve a destigmatising function. She stated "once patients start owning their conditions, you know, we start treating it like diabetes. In most city health clinics… there's a club for such conditions. So why not HIV?" For this HCW, adherence clubs were a possible way to normalise and integrate HIV treatment within the public health care system in ways that placed an emphasis on de-stigmatisation of the condition.

The need for more clubs

Participants indicated the need for more adherence clubs, including the need for dedicated clinic staff to administer the clubs as the sheer volume of patients was a challenge to managing the clinic. One HCW stated "There's no way… that we can actually manage all the patients or the way the clinics will run, unless you really have almost 24 hour clinics."

Consequences of poor adherence among club members

HCW's stated that club members whose adherence was suboptimal expressed concern when they were asked to leave the club. One HCW reported "it was for them really not a good thing because now they're used to coming in and going out in about 10 or 15 minutes. So they felt like (having to leave the club was) punishment." As blood tests were only conducted once a year, HCW's indicated that they did not really know the current levels of adherence of patients. On the other hand, there were also cases in which non-adherent ART users were not asked to leave the clubs. A HCW spoke about such challenges, stating "… they can be quite evasive because they obviously want to be, they want to please the medical staff, they want to please the doctors; they don't want to admit that they're not managing well." Inherent in the system were challenges in identifying sub-optimal adherence among patients. For example, a HCW stated:

> "You really need to spend a lot of time teasing out the individual issues and actually getting them to run through the week with you. Like what do you do on a Monday morning when you take your pills, and really go into quite a lot of detail."

Working with patients in such a detailed manner was time-consuming and the adherence club context did not allow for this extended time with patients. A HCW reflected on the minority of club members who were non-adherent, stating "they sometimes really genuinely… don't realise how non-adherent they are. I don't think they are lying

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necessarily; they just actually just don't realise how often they forget." One HCW expressed her difficulty in applying the rules to non-adherent participants, stating "the problem is that we are like… soft hearted and all of that… you accommodate them because you don't really want to have them back into the mainstream clinic." In many cases non-adherent patients were not dismissed from their clubs because nurses were reluctant to apply the rules in a rigid manner. Personal relationships developed between HCW's and ART users making it difficult to exclude the ART users from the clubs when they no longer met the criteria for membership in terms adherence levels.

Discussion

There were clear benefits to the introduction of adherence clubs, most importantly the reduced amount of time ART users needed to spend at the clinic. Previous research indicated that the long periods of time spent at the clinic was a barrier to adherence (Kagee & Delport, 2010; Kagee et al. 2012). The introduction of adherence clubs created conditions where ART users were processed more rapidly, thus creating fewer tense interpersonal experiences between HCW's and patients than in the general clinic.

For employed ART users, the clubs represented a viable option to taking a whole day off work to attend the clinic. Kagee et al (2012) found that work commitments were a major barrier to clinic attendance among employed ART users. The clubs were a solution to this difficulty as ART users would only needed to spend one hour at the clinic, typically before the working day commenced.

Another benefit of adherence clubs was the opportunity for cohesion among patients. Many ART users typically do not disclose their status to others and Kagee and Delport (2010) found that ART users actually hid their medicines from family members to avoid being identified as living with the virus. Thus, the fact that adherence club members by definition knew that each member was an ART user created the potential for them to provide support to each other.

The logistical difficulties associated with the adequate supply of medication is a systemic problem characteristic of a health care system undergoing numerous changes. The supply of medication is an individual treatment issue for patients, a group concern for adherence clubs, an institutional matter for the health care clinic, and also fundamentally a bureaucratic matter that has its roots in a health system still struggling to function optimally, even twenty years after racial segregation of public health care was eliminated. The compromised ability of the CDU to adequately supply clinics with medicines is a consequence of under-investment in the resource base of health systems such as personnel and infrastructure (Schneider et al 2006). Solutions to these problems are beyond the scope of the present paper and require interventions at political and administrative levels. Yet, as more patients are enrolled in the national ART programme, more clubs will undoubtedly become necessary, but they are only likely to be successful if optimal supply chain management can be assured. It is unlikely that club members will continue to meet on a long-term basis if medication is not available for collection, a situation that will in turn have implications for

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ART adherence. In such circumstances, the original intention of forming adherence clubs is at risk of not being realised.

Concluding comments

It is apparent that adherence clubs are a potentially important and useful innovation in ART care in the South African public health system. The resolution of logistical problems requires research at a health systems level, rather than at an individual personal level. Nonetheless, the experiences of adherence club members in other parts of South Africa where such innovations are being tried await investigation.

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