

# Attitude of patients with HIV infection towards organ transplant between HIV patients. A cross-sectional questionnaire survey

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**“Attitude of patients with HIV infection toward organ transplant between HIV patients. A cross- sectional questionnaire survey”**

**Key words** : Organ transplant, HIV patients, Attitude, antiretroviral therapy.

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**Abstract**

This study examined HIV patients' attitude towards the practice of organ transplant between HIV patients using a cross-sectional survey design. In total, 206 patients participated with a mean age of 42 (+/- 8.8) years. The majority (70%) were black African and female (54%), and 83% described themselves as heterosexual. Most participants (n=171, 83%) were on treatment and 159 (93%) had viral load less than 40 copies/ml. Mean duration of illness and mean duration of treatment were 77 (+/-42.7) and 68 (+/-41) months respectively. Of all participants, 128 (62%) reported that they would consider donating either any organ or a specific organ/s to an HIV patient, 33 (16%) would not consider it and 45 (22%) were unsure about donating their organs. Furthermore, 113 (55%) participants would consider receiving an organ from an HIV patient, 37 (18%) would not consider it, and 56 (27%) were unsure. Ninety eight participants (42%) reported that they would consider both donating and receiving an organ. Multinomial logistic regression analysis found that significantly more Black African than Caucasian participants were unsure about organ donation (p=0.011, OR=3.887). Participants with longer duration of infection were significantly less likely to consider receiving an organ from an HIV patient (p=0.036, OR=1.297). Overall the study findings indicated that the majority of participants were in favour of organ transplant between HIV patients. Use of HIV infected donors could potentially reduce current organ waiting list among HIV patients.

## **Background**

In the era of Highly Active Antiretroviral Therapy (HAART), the spectrum of HIV disease has changed dramatically [1, 2]. Non-AIDS defining illnesses are becoming more common causes of HIV related mortalities and morbidities compared to AIDS defining illnesses [2, 3]. Key examples of non-AIDS defining illnesses include End-stage Kidney Disease (ESKD) and End-stage Liver Disease (ESLD), both of which have multi-factorial origins [1, 4-7]. Kidney transplant and liver transplant could be an attractive proposition for patients who present with end-stage disease [8-10]. Recent results from a series of cases in the UK in which HIV patients have received organ transplants from HIV negative donors are encouraging [11]. Transplants between HIV positive patients however is not a current practice, significantly reducing the pool of available organs. The American federal law has recently lifted the ban on organ donation between HIV infected individuals, a move that offers hope to thousands of HIV patients on transplant waiting lists [12]. This procedure is however yet to be performed in the USA. Instead the only country to have allowed this to happen is South Africa. Here, outcomes to date have been largely positive for the organ recipients [13]. The changing circumstances in the USA and South Africa, and tentative evidence of successful outcomes for HIV patients, may have implications for UK practice. In anticipation of a possible change in UK law in the future, the aim of this study was to explore the attitude of UK HIV patients toward organ transplant between HIV infected patients.

## **Methodology**

This study had a cross sectional survey design. Over a period of 3 months, all HIV patients attending for a routine follow-up at a HIV outpatient clinic within a large city centre Genitourinary Medicine (GUM) department, were invited to participate. A sample size of 150 to 200 participants was aimed for. This was judged to be sufficiently large to provide reasonably robust estimates of effect sizes. Participants completed a questionnaire written in simple English, with largely fixed response questions (appendix 1). The questions were initially developed by two GUM doctors and then piloted with 15 patients to identify their suitability and ease of comprehension. Some minor changes to the wording were made as a result. Informed consent and completion of questionnaires took place in a private room.

Participant's Demographic data including age, gender, ethnicity, sexual orientation, duration of HIV infection and both clinical and treatment history were collected. Ethical approval was obtained from a regional ethical committee. Patients were eligible to participate if they had a documented positive HIV antibody test according to the standard of HIV diagnosis, provided informed consent, and were age 18 years or over. Participants were also required to have a reasonable grasp of the English language or were alternatively able to communicate adequately with the help of an interpreter. We excluded patients with primary HIV infection, who didn't consent, had poor knowledge of English and declined to use an interpreter, or were known to suffer from a mental health problem.

Responses to the questionnaires and information from the case notes were entered into SPSS (version 15.0) for analysis. Frequency analysis and multinomial logistic regression were performed.

## Results

### Sample description:

308 patients attended the clinic during the study and 206 chose to participate giving a response rate of 67%. The mean age of the participants was 42 (+/-8.8) years. Most reported that they were black African (n= 145, 70%, CI= +/- 6.26) and heterosexual (n= 171, 83%, CI= +/- 5.13). There were more females (n=111, 54%, CI= +/-6.81) than males (n=95, 46%, CI= +/-6.81). Mean Cd-4 cell count was 486 (+/-231) cells per dl and most participants (90%, CI= +/-4.1) were on treatment. Viral load was undetectable in 93% of the participants. The mean duration of illness was 77 (+/-42 .7) months and the mean length of time on HAART was 68 (+/-41) months (table 1) Seventy one (34%, CI= +/-6.47) participants had a history of opportunistic infection. One hundred and four (50%, CI= +/-6.83) participants had co- morbidities (table 2) including diabetes mellitus, hypertension, impaired renal function (defined as e-GFR below 60 ml/min/1.73m<sup>2</sup> at the time of the study), ischemic heart disease, peripheral vascular disease, deranged liver function, auto-immune hepatitis, anaemia, and osteoarthritis. Five participants (2%, CI= +/-1.91) had a history of cancer. Twelve (6%, CI= +/-3.24) participants had Hepatitis B and/ or C infection. Alcohol related problems were documented in 7 (3%, CI= +/-2.33).

### Attitude towards donating organs to HIV infected patients

Participants were asked whether they would consider donating an organ to another HIV infected patient. One hundred and twenty eight participants (62%, CI= +/-6.63) indicated that they would donate an organ. Another 33 (16%, CI= +/-5.01) indicated they would not and 45 (22%, CI= +/-5.66) were not sure (figure1). Those who would consider donating an organ to another HIV infected patient (n=128), were asked to indicate whether this was specifically their liver, kidney, heart or other organ. Eighty two (70%, CI= +/-7.94) participants indicated they would consider donating their liver, 96 (81%, CI= +/-6.80) their kidney, 75 (63%, CI= +/-8.36) their heart, and 17 (14%, CI= +/-6.01) another type of organ. Sixty eight (58%, CI= +/-8.55) participants responded that they would consider donating all three specified organs. Multinomial logistic regression was performed to examine whether there was an independent effect of any of the demographic and HIV characteristics on attitude towards organ donation. Findings indicated that an individuals' attitude towards organ donation to HIV infected patients was not associated with their age, gender, duration of infection or duration of HAART. However there was a significant effect of ethnicity. Black African participants were more likely than Caucasian participants to indicate that they were not sure if they would consider organ donation (compared to those who would consider donation) ( $p=0.011$ , OR=3.887, CI=1.36-11.08) (table 3).

### Attitude towards receiving an organ from HIV infected patients

Participants were asked whether they would consider receiving an organ from a HIV infected patient. One hundred and thirteen (55%, CI= +/-6.79) participants indicated that they would, 37 (18%, CI= +/-5.25) participants reported that they would not, and 56 (27%, CI= +/-6.06) participants were not sure (Figure 1).

Of the 113 participants who would consider receiving an organ, 103 participants indicated their preferred type of donor. Fourteen (14%, CI= +/-6.70) participants reported that they would prefer a live donor, 6 (6%, CI= +/-4.59) reported that they would prefer a deceased

donor, and 83 (80%, CI= $\pm$ 7.82) participants reported 'either'. Participants who reported that they would not consider receiving an organ from an HIV infected individual were asked what their main concerns were (participants could endorse more than one response). The proportion who endorsed each response was as follows: confidentiality 26% (CI= $\pm$ 14.13), infection 23% (CI= $\pm$ 13.56), quality of organ 23% (CI= $\pm$ 13.56), and 'other' 33% (CI= $\pm$ 15.15). Multinomial logistic regression was performed to examine whether there was an independent effect of demographic and HIV characteristics on attitude towards receiving an organ. There were no variations in response for the following factors: age, gender, ethnicity, or sexuality. Duration of infection however did have an effect and there was a borderline effect of duration of HAART. Specifically participants with a higher number of years of infection were more likely to indicate that they would not consider receiving an organ compared to those with a lower number of years of infection ( $p=0.036$ , OR=1.297, CI=1.02-1.61). This suggests that as the length of infection increases, HIV patients become less willing to consider accepting an organ transplant from another HIV patient. Participants with a higher number of years on HAART were more likely to indicate that they would consider receiving an organ compared to those with a lower number of years of HAART (borderline significance,  $p=0.052$ , OR=0.804, 0.65-1.00). (Borderline significance) (Table 4).

### **Whether participants' motivation to accept an organ donation is to stay alive/ improve quality of life (QOL)**

Participants were asked whether they would accept an organ to stay alive and/or improve their quality of life (Responses were yes, no or other). Out of the 206 participants, one hundred and thirty five participants (66%, CI= $\pm$ 6.47) indicated that they would accept an organ transplant from an HIV infected patient to stay alive and/or improve their quality of life (QOL). Multinomial logistic regression was performed to examine the association between demographic and HIV characteristics, and responses to the above question. An individual's age, gender, ethnicity, sexuality, duration of infection or duration of HAART was not associated with whether they would accept an organ to stay alive and/or improve their QOL.

### **Discussion**

There is a strong case for organ transplant between HIV patients to prevent unnecessary death and improve quality of life. This study aimed to examine the attitude of HIV patients towards organ transplant between patients and as far as the authors are aware, is the first study of its kind. Out of 206 participants, 62% indicated they would consider donating an organ to another HIV patient. Fifty-five percent of participants indicated that they would consider receiving organ from HIV infected patient. Of those who would not consider receiving a donated organ, approximately a quarter indicated that they were concerned about infection, quality of organ, and confidentiality.

The Euro SIDA study has shown that the death rates from HIV/ AIDS have fallen eight-fold between 1994 and 2001 [14]. Studies have shown that non-AIDs related disease including drug related toxicities is becoming more common in HIV patients [3]. HIV patients may have relatively higher risk of organ failure. HIV patients with end-stage organ disease are likely to derive benefit from accepting organs from HIV infected donors. Researchers at the Johns

Hopkins University School of Medicine estimate that there are approximately 500-600 potential deceased HIV infected kidney and liver donors per year in the United States [4]. Transplants between HIV positive patients could therefore potentially reduce or even eliminate the current waiting list for organs among HIV-positive people needing transplants this may also shorten waiting times for non-HIV infected patients. Muller and colleagues have pioneered positive-to-positive kidney transplants since 2008. They have demonstrated that transplanting HIV-infected patients with ESKD with kidneys from HIV-positive donors represents a significant advance, benefiting patients with ESKD due to HIV associated nephropathy and could be cost effective [13].

One potential concern relating to organ transplants between HIV positive patients is the possibility of super- infection with a different HIV clade or a recombinant virus carried by a donor organ. In theory, this could accelerate HIV disease progression in the patient, particularly if that strain is resistant to antiretroviral drugs. However, some studies have suggested that in patients with well-established HIV infection on HAART, there may be a smaller number of host cells that are susceptible to the new HIV strain, hence, low risk of super/ dual infection [15]. However, the HIV status of would-be donors should not be considered as disadvantage for HIV patients who are living with end organ failure. Doing so significantly restricts the pool of potential organ donors to the relatively small HIV positive cohort.

Further trials are needed to investigate positive-to-positive transplants which will yield valuable clinical insights into the functioning of HIV and the human immune system [4]. In the UK, the imbalance between donor supply and organ need is growing. In conjunction with high quality trials to examine clinical risk [4], there is a need for social science research to examine attitudes towards organ donation between HIV patients. This is needed to ascertain the level of support for a future HIV organ donation programme, specifically whether patients are likely to register as donors, be willing to accept an organ donation, and also whether receipt from a live or deceased donor is more acceptable. It is also needed in order to identify whether there are any particular groups who hold less favourable opinions and why. Our survey has shown that HIV patients are largely in support of both donating and receiving organs, and that the majority of patients in favour of this are happy to receive an organ from either a live or a deceased donor. A significant proportion of participants however indicated that they would not want to do this or were unsure. Concerns of participants who would not consider receiving an organ include confidentiality, infection and quality of organ. Further research is required to explore these concerns in more detail and to understand their basis, both for those who are against receiving an organ or unsure. This is particularly important in order to develop future patient education about organ donation between HIV patients. This study identified some potentially important associations between organ donation attitudes and demographic and HIV characteristics. Firstly, attitudes towards organ donation were associated with ethnicity. Black African participants were more likely than Caucasian participants to indicate that they would not consider donation. This may be due to cultural or religious beliefs and further research is required to explore this. Also of interest are the findings that participants with higher number of years of infection are less likely to consider receiving an organ, but those with higher years of HAART are more likely to consider this. Reasons for these apparent inconsistent findings are unknown. Caution should be taken in drawing strong conclusions given that the relationship between years of HAART and receipt of organ was of borderline significance. Future survey research with a larger sample size is

required to interrogate this. Qualitative research to further explore these beliefs would also be beneficial.

### Limitations

Limitations of this study should be considered when interpreting the results. These include the small number of participants, drawn from a single centre, and mostly of black African ethnicity. These factors reduce the external validity of the results. Furthermore the survey design meant that there were limits to the conclusions which could be made. As discussed above, further research is required, specifically in the first instance a qualitative study, to fully explore beliefs underlying attitudes towards organ donation between HIV patients. Ideally this would be followed by a further cross-sectional study using a larger, more representative sample and more refined questions capable of measuring the strength of these beliefs and their association with direct measures of attitude. This would enable us to better understand which beliefs are drivers of positive and negative attitudes towards organ donation, and to identify any misperceptions which could be addressed through patient education.

### Conclusion

This study indicates that the attitude of HIV patients towards the practice of organ transplant between HIV patients is broadly favourable. Patients with HIV infection should have every opportunity to express their views and needs. It is suggested that an organ donation registry for patients with HIV infection is instituted and further studies conducted at a national level as outlined above. Furthermore, transplantation networks and disciplinary teams will be needed to develop ethical and clinical standards to guide medical research on positive-to-positive transplants.

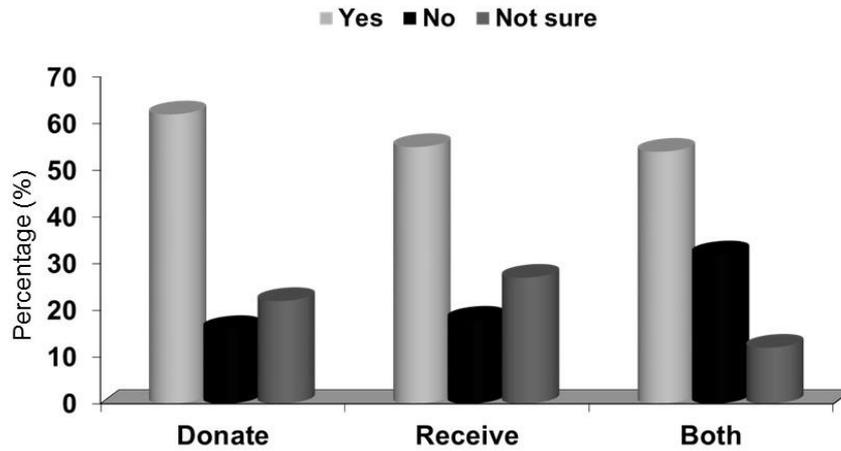
Category	N (%)
Mean age (+/-SD)	42 (8.8)
Female Gender (%)	122 (59)
Black Africans (%)	145 (70)
Heterosexual (%)	171 (83)
Mean CD-4 count (+/-SD)	486 (231)
On HAART (%)	185 (90)
Mean duration of illness (+/-SD) months	77 (42.7)
Mean duration of ARV (+/-SD) months	68 (41)
Co- morbidities (%)	104 (50%)
Alcohol use (%)	7 (3)

**Table 1: Participants baseline results (n=206)**

<b>Co- morbidity type</b>	<b>N (%)</b>
Cardiovascular diseases & Hypertension	22 (11)
Renal problems	7 (3)
Respiratory illnesses	12 (6)
Gastro intestinal / liver/ pancreatic illnesses	4 (2)
Peripheral vascular disease	8 (4)
Diabetes Mellitus	5 (2)
Auto immune skin illnesses	3 (1)
Gynaecological illnesses	5 (2)
Mental illnesses	10 (5)
Hepatitis B and or C infection	12 (6)
Previous CA	5 (2)
Musculoskeletal illnesses	4 (2)
Alcohol related illnesses	7 (3)
<b>Total</b>	<b>104 (50)</b>

**Table 2: List of co- morbidities (n=104)**

## Consideration for donate or Receiving organ



**Figure 1- Consideration for donating or receiving organ**

	Not sure would consider organ donation			Would not consider organ donation		
	OR	95% CI	P value	OR	95 % CI	P value
Age	0.98	0.93- 1.04	0.48	1.00	0.94-1.06	0.96
Gender	1.51	0.64- 3.54	0.34	0.48	1.31 -1.53	0.20
Ethnicity	3.89	1.36- 11.08	0.01	1.51	0.64- 3.56	0.35
Duration of infection	1.02	0.82- 1.26	0.90	0.95	0.73- 2.24	0.70
Duration of ARV	0.95	0.76- 1.18	0.61	1.00	0.77- 1.30	0.99

**Table 3: Multinomial logistic regression model to predict attitude toward organ donation by demographic variables.**

	Not sure would consider receiving organ			Would not consider receiving organ		
	OR	95% CI	<i>P</i> value	OR	95 % CI	<i>P</i> value
Age	0.99	0.95- 1.04	0.65	1.03	0.98- 1.10	0.27
Gender	1.55	0.67- 3.62	0.31	1.05	0.35- 3.15	0.93
Ethnicity	2.15	0.69- 6.68	0.18	1.37	0.46- 4.08	1.37
Duration of infection	0.96	0.78- 1.18	0.67	1.28	1.02- 1.61	0.04
Duration of ARV	1.02	0.83- 1.26	0.86	0.80	0.65-1.00	0.05
Sexuality	2.43	0.23- 25.40	0.46	0.63	0.05- 8.16	0.73

**Table 4: Multinomial logistic regression model to predict attitude toward receiving organ by demographic variables.**

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