UNDERSTANDING THE EXPERIENCES OF SERONEGATIVE PARTNERS IN HIV DISCORDANT COUPLES

Dr Sanjay Naran

A research report submitted to the Faculty of Health Sciences,
University of the Witwatersrand,
Johannesburg,
in partial fulfillment of the requirements for the degree of
Master of Family Medicine

Johannesburg 2007
DECLARATION

I, Sanjay Naran declare that this research report is my own work. It is being submitted for the degree of Master of Family Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signed ________ On____________ day of ______________ 2007 at Johannesburg.
Thank you to my Father, Mother, Wife and daughter

for putting up with me

as I battled to complete this research.

I love you all.
Abstract

Introduction

HIV serodiscordant couples are presenting more often to their doctors as the epidemic continues to spread. There have been various theories as to why some couples remain discordant, but none have yielded a conclusive answer as yet. The negative partners in discordant couples have previously been ignored. However, more of them are now presenting with psychosocial problems of their own. They are increasingly being recognized as ‘hidden’ patients and as potential resources. The researcher would like to discover what issues and problems these negative partners have so that we can understand and help them.

Aims

To explore seronegative partners’ experiences and emotions in HIV discordant couples.

Methodology

Using qualitative interview methods to explore the range of emotions and experiences that seronegative partners in discordant relationships experience at the time of disclosure of the different results and thereafter.

Results

Three main themes emerged from the research. These were:

1) Emotional problems-These were further sub-divided into expected responses and unexpected responses, based on the researchers own views and from literature reviews.
2) Coping strategies- these were further sub-divided into positive and negative coping strategies based on the beneficial or harmful effects on the individual, family or the relationship as well as the increase in risk behaviour associated with each action.

3) Future plans- these were according to the participants and included what they wanted for their future.

Conclusion

Negative partners in discordant couples have been ignored for too long. They face many challenges and problems but they can also assist in the management of their partners. This was explored in more detail. From the research, a host of experiences and reactions were noted and based on these, recommendations for doctors were drawn up. The recommendations include the following:

1. Doctors should not ignore the negative partner in discordant couples. They are also patients and in need of help and support. They can in turn help the doctor in future treatment of the positive partner. By just acknowledging them and that they are also going through difficult times, allows them to bring out their problems and assist in future management.

2. Always discuss the possibility of discordant results before testing a couple. This possibility can be a source of immense stress and confusion to the couple if they have not been alerted to the fact that it can occur.

3. Both partners in the discordant couple must be screened for depression as there is a high rate of this illness in both groups. Too often, this depression is not actively looked for in the negative partner. Doctor’s who fail to do this, will be neglecting the wellbeing of the family unit.

4. All discordant couples should be offered ongoing counseling sessions, either separately or together as a couple. This will give the often ignored negative partner an opportunity to air their views and problems, not only to the doctor, but if they participate in the sessions as a couple, they may be able to speak to their partners, indirectly, by speaking to the doctor.
5. When faced with a discordant couple, the topic of future parenthood should be raised by the doctor. If this is ignored, it may force some couples to engage in high risk behaviour without them knowing the repercussions of it. The doctor must present all the options available to the couple, including adoption and assisted reproductive techniques as well as the role of antiretroviral medication.

6. Doctors must keep abreast of the latest developments in HIV and treatment as patients expect them to provide answers. This would include the doctor improving his/her computer skills as well as learning and practicing the art of critical reading so that he/she can access valid information for patients when the need arises.

7. Doctors must pay attention to the setup at their surgeries so that they always ensure privacy and confidentiality. This includes the position of the waiting room in relation to the consulting rooms so that what is discussed cannot be heard by others. The doctor must also not leave patient records where subsequent patients can see them. Lastly, the doctor must ensure that his staff members, who do see patient records, are informed of their obligations to patient confidentiality.

8. Doctors should avoid using the term undetectable when reporting on the positive partner’s viral load. This term may be misunderstood by both partners to mean that the virus was no longer present and thus safe sex practices were on longer needed. A better word to use would be “further reduced” or “in the acceptable range showing good compliance”.

Acknowledgements

I would like to thank Dr Claire van Deventer for her assistance as my supervisor. I would also like to thank Miss Rakhi Kasanjee for her assistance with the transcription of the audio tapes.

I truly appreciate your help.
Consent Form

I _________________________ hereby agree to participate in an interview carried out by Dr Sanjay Naran for the purpose of research.

I agree that my participation in this research project is voluntary but not binding and that I may withdraw from the project at any time if I wish to do so without any penalty and this will not jeopardize my future treatment by my doctor who will not be informed of my decision.

I have been informed of the purpose of the study and have received an information pamphlet.

I have been informed that participation in the study is voluntary and every attempt will be made to keep my details confidential.

I agree that my interview will be recorded onto an audio tape and this will later be transcribed to paper, after which the tapes will be destroyed. I have been informed that my responses will only be used for this research project.

I have been informed and assured that whether I choose to participate or not in the research, my doctor will not be informed of my decision.

I also agree that I will not be allowed to change my doctor to the doctor doing the interview for at least one year after the interview but that I can change to another doctor if I wish to do so.

Signed at ________________on ________day of _____________ (Month) _______Year

For queries or information call me
Dr Sanjay Naran (MBBCh) WITS
0721267748
To The Doctor in Charge

My name is Dr Sanjay Naran. I am a General Practitioner currently doing my third year of study towards my Masters in Family Medicine at The University of the Witwatersrand. As part of my studies, I am required to do a research project. I have selected to do research looking at serodiscordant HIV couples. These are couples who have one partner HIV positive and the other HIV negative. I would like to do a qualitative study to gain a deeper understanding of what the negative partner feels and experiences. From my literature review, this topic has never been looked at from the negative partner’s perspective.

I require your help to do the following.

1) To identify any serodiscordant couples in your practice who would be willing to participate in this study and who know each other’s HIV status.
2) These participants must speak fluent English
3) I will personally interview the participant who will be asked one single question. The participant will be allowed to say whatever they want about the topic. The interview will last about 1 hour and only the negative partner will be present and participate in this interview.
4) All participants will remain anonymous
5) I will do the interviews at a time and place suitable to the patient but only the negative partner will be involved.
6) I will ask you to provide those who agree to participate with my cellular phone number so that they can contact me – this will prevent them from feeling pressurized to participate. I will not inform you of their refusal to participate so as not to pressurize them. The patient can leave a missed call on my cell phone so that I can call them back.
I request that if a patient expresses a will to participate that you call me to let me know that a patient may call my phone.
7) After the interview, in the following month, the patient can attend a debriefing session with a HIV and marriage/relationship counselor at no cost.

I will not take your patients from your practice. None of the participants will be allowed to attend my practice for a period of at least one year following the interviews.

Thanking You
Dr Sanjay Naran (MBBCh) WITS
0721267748
Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Declaration</td>
<td>ii</td>
</tr>
<tr>
<td>Dedication</td>
<td>iii</td>
</tr>
<tr>
<td>Abstract</td>
<td>iv-vi</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>vii</td>
</tr>
<tr>
<td>Consent form</td>
<td>viii</td>
</tr>
<tr>
<td>Information sheet</td>
<td>ix</td>
</tr>
<tr>
<td>Table of contents</td>
<td>x</td>
</tr>
<tr>
<td>Copy of Ethics Clearance Certificate</td>
<td>xi</td>
</tr>
<tr>
<td>1) Chapter 1-Introduction</td>
<td>1</td>
</tr>
<tr>
<td>2) Chapter 2 -Literature Review</td>
<td>9</td>
</tr>
<tr>
<td>3) Chapter 3 -Methods</td>
<td>17</td>
</tr>
<tr>
<td>a) Aims</td>
<td>17</td>
</tr>
<tr>
<td>b) Objectives</td>
<td>17</td>
</tr>
<tr>
<td>c) Design</td>
<td>17</td>
</tr>
<tr>
<td>d) Site of Study</td>
<td>18</td>
</tr>
<tr>
<td>e) Sampling</td>
<td>19</td>
</tr>
<tr>
<td>f) Inclusion Criteria</td>
<td>19</td>
</tr>
<tr>
<td>g) Exclusion Criteria</td>
<td>19</td>
</tr>
<tr>
<td>h) Data Collection</td>
<td>20</td>
</tr>
<tr>
<td>i) Bias and Validity</td>
<td>21</td>
</tr>
<tr>
<td>j) Ethical Considerations</td>
<td>22</td>
</tr>
<tr>
<td>k) Data Analysis</td>
<td>23</td>
</tr>
<tr>
<td>l) Limitations</td>
<td>24</td>
</tr>
<tr>
<td>4) Chapter 4 –Results</td>
<td>26</td>
</tr>
<tr>
<td>1. Emotional Problems</td>
<td>27</td>
</tr>
<tr>
<td>2. Coping Strategies</td>
<td>36</td>
</tr>
<tr>
<td>3. Future Plans</td>
<td>47</td>
</tr>
<tr>
<td>4. Participant suggestions</td>
<td>48</td>
</tr>
<tr>
<td>5) Chapter 5 -Discussion</td>
<td>54</td>
</tr>
<tr>
<td>6) Chapter 6 –Conclusion and Recommendations</td>
<td>75</td>
</tr>
<tr>
<td>7) Chapter 7 - References</td>
<td>78</td>
</tr>
</tbody>
</table>
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49  Naran

CLEARANCE CERTIFICATE
PROJECT
discordant couples - a qualitative study
UNDERSTANDING SERONEGATIVE PARTNERS IN HIV

PROTOCOL NUMBER MO60628

INVESTIGATORS
Dr S Naran

DEPARTMENT
Family Medicine

DATE CONSIDERED
06.06.30

DECISION OF THE COMMITTEE*
APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE
06.07.23

CHAIRPERSON
(Professor A Dhai)

cc: Supervisor: Dr C van Deventer

*Guidelines for written 'informed consent' attached where applicable

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and ONE COPY returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Dr S Naran