

14th Annual Conference of the
National HIV Nurses Association (NHIVNA)



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University of Brighton

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HIV Healthcare in the Future: Where do nurses fit in?

Please note that the findings of this research are currently undergoing a verification process. This presentation covers a snapshot of mid-term results and does not include final results or conclusive recommendations at this stage.

Please contact e.nixon@brighton.ac.uk if you wish to discuss any aspect of the presentation or current findings.

HIV Healthcare in the Future: Where do nurses fit in?

MID-TERM RESULTS UNDERGOING VERIFICATION

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Aim of Research

To explore HIV healthcare provision with a view to informing future models of HIV healthcare in the UK

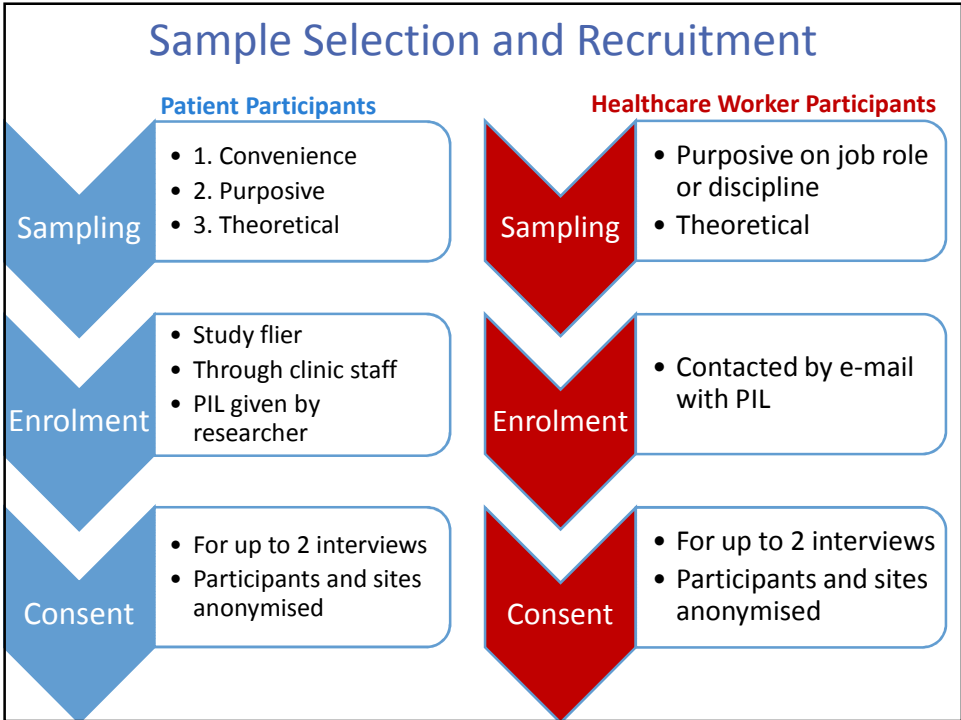
Research Questions

- 1. How do HIV patients view their changing and progressive healthcare needs?*
- 2. How do healthcare workers in HIV adapt the way they provide care to meet the changing needs of HIV patients?*
- 3. What is the role for HIV nurses in response to the on-going needs of people with HIV?*

Methodology

- Inductive, grounded theory approach ¹
- Semi-structured interviews with patients and healthcare workers across 3 HIV service sites ²
- Constant comparative analysis of data ^{1.2.3.4.5}
- Naming of emergent patterns in the data and development of abstract concepts ^{1.2.3.4.5}
- Researcher effect minimized through reflexive dairy, abstraction, analytical memos and use of Patient Advisory Group

1.Glaser and Strauss 1967; 2.Strauss and Corbin 1990; 3.Schatzman and Strauss 1973; 4. Schatzman 1991; 5.Charmaz 2006



Overview of Study Sites

Springfield
Small HIV Unit in low prevalence area



Metropolis
HIV Centre in high prevalence urban area



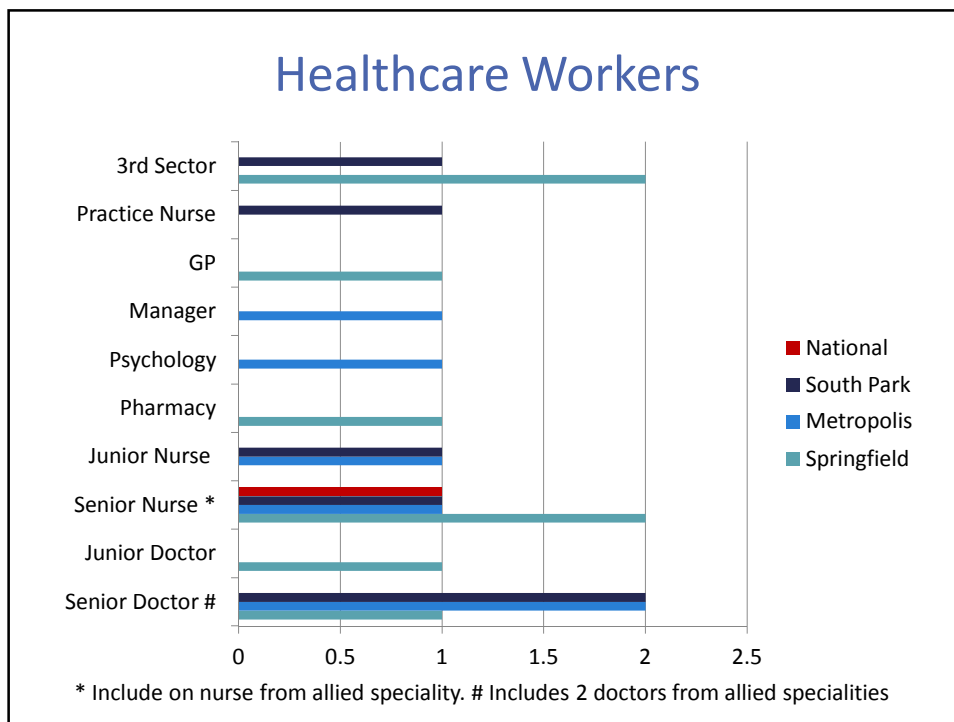
South Park
HIV Centre in lower prevalence urban area



Overall Study Population 4500 patients

Participant Distribution

Site	Springfield	Metropolis	South Park	National	Total
Patient Participants	5	8	0	0	13
Healthcare workers	6	6	5	1	18
3rd sector	2	0	1		3
	Total 13	Total 14	Total 6	Total 1	Total 34
Second Interviews to date	2	1			Total Interviews 37



Demographics of Patient Participants

	Springfield	Metropolis	Total
Male	4	5	9 (69.2%)
Female	1	3	4 (30.8%)
MSM	4	3	7 (53.8%)
Heterosexual	1	5	6 (46.2%)
White UK	5	4	9 (69.2%)
Black African	0	2	2 (15.4%)
Black Caribbean	0	1	1 (7.7%)
White European	0	1	1 (7.7%)
Age (yrs)	Range 27-56 Mean 42.4 Median 39	Range 34-70 Mean 50.5 Median 52	Range 27-70 Mean 47.3 Median 52
Time since diagnosis (mean)	5.2 years	12.87 years	9.92 years
On ART	5/5	7/8	(92.3%)

HIV Healthcare as “Special”

Relationships

It's completely different from going to your doctor (GP) you've got more of a relationship it's like an HIV family

Sally, Age 27, Springfield

there was an equivalence between the treating clinicians and the patient which meant there was a degree of mutual respect and often still in other areas of disease treatment that's not the case

Morgan, Age 45, Metropolis

we have great longevity of relationship with patients and you may have seen them through various sick periods when they are very unwell and they may have seen you as a saviour or integral to their health

Mary, Senior Doctor, Metropolis

HIV Healthcare as “Special” (2)

Pervasive Nature of HIV infection

I think with HIV one of the biggest problems is not the illness itself but the depressions that go with it they are really..depressions you really do go into a deep decline

Michael, Age 70, Metropolis

I suppose in some sense I guess everything from now on is going to be related in some way because it affects my immune system

Stewart, Age 39, Springfield

It's sexually acquired you can give it to someone else and you can die from it does make it different

Melissa, Psychologist, Metropolis Area

HIV Healthcare as “Special” (3)

Feeling Accepted

they (HIV Clinic) always ask me how I feel and have I had any problems and things like that but most of the time the way I have always been treated is that I even forget that I'm HIV-positive it's like I'm just a patient who has come to the doctor
Malcolm, Age 55, Metropolis

For example I went to physio to have a massage, I had the massage with latex gloves which I found horrible
Martha, Age 40, Metropolis

The shame goes very very deep..you can be criminalised for it you can be cast out for it..so there is something about HIV that goes to the heart of shame
Penelope, 3rd Sector Worker, South Park Area,

Illness Experience

- 11/13 described Uncertainty
- 11/13 described HIV affecting different aspects of their lives
- Treatment continuing to work
- Having children
- How HIV would manifest itself
- New relationships
- Planning for the future
- Employment
- Community integration

Patient factors that influence views on future healthcare provision			
Advocate new models of HIV care			
HIV minimal impact on rest of life			
Report no illness experience			
No / minimal negative experiences of other services			
3 (23%)			
SELF-RELIANT			

Patient factors that influence views on future healthcare provision			
Advocate new models of HIV care	HIV services viewed as central to maintain health		
HIV minimal impact on rest of life	HIV has some impact on rest of life		
Report no illness experience	Current or previous health issues		
No / minimal negative experiences of other services	All use GP but have low confidence in knowledge		
3 (23%)	6 (46.2%)		
SELF-RELIANT	CONFIDENT WITHIN CURRENT MODEL OF CARE		

Patient factors that influence views on future healthcare provision			
Advocate new models of HIV care	HIV services viewed as central to maintain health	HIV services viewed as key support mechanism	Dependence on HIV healthcare
HIV minimal impact on rest of life	HIV has some impact on rest of life	HIV has some impact on rest of life but tend to be more isolated with diagnosis	
Report no illness experience	Current or previous health issues	Current or previous health issues	
No / minimal negative experiences of other services	All use GP but have low confidence in knowledge	2 report overt discrimination from other services 2 use GP selectively	
3 (23%)	6 (46.2%)	4 (30.8%)	None
SELF-RELIANT	CONFIDENT WITHIN CURRENT MODEL OF CARE	STABLE WITHIN CURRENT MODEL	

HIV Nursing Roles

Influenced by number of doctors and volume of patients but structure also seemed to play a part

If we do have to set up (another) HIV clinic (session) we would probably try and make that nurse-led if I could get a suitably interested and qualified nurse team to actually do that but unfortunately it's almost impossible to create a new nursing post in the current climate

Seth, Senior Doctor, HIV Unit, Springfield

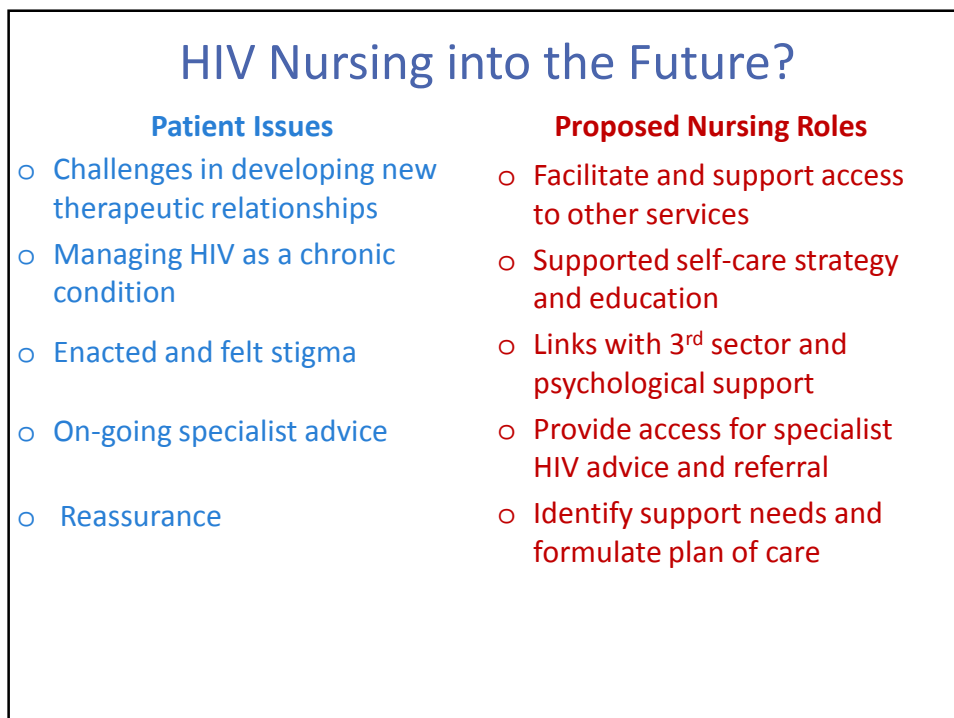
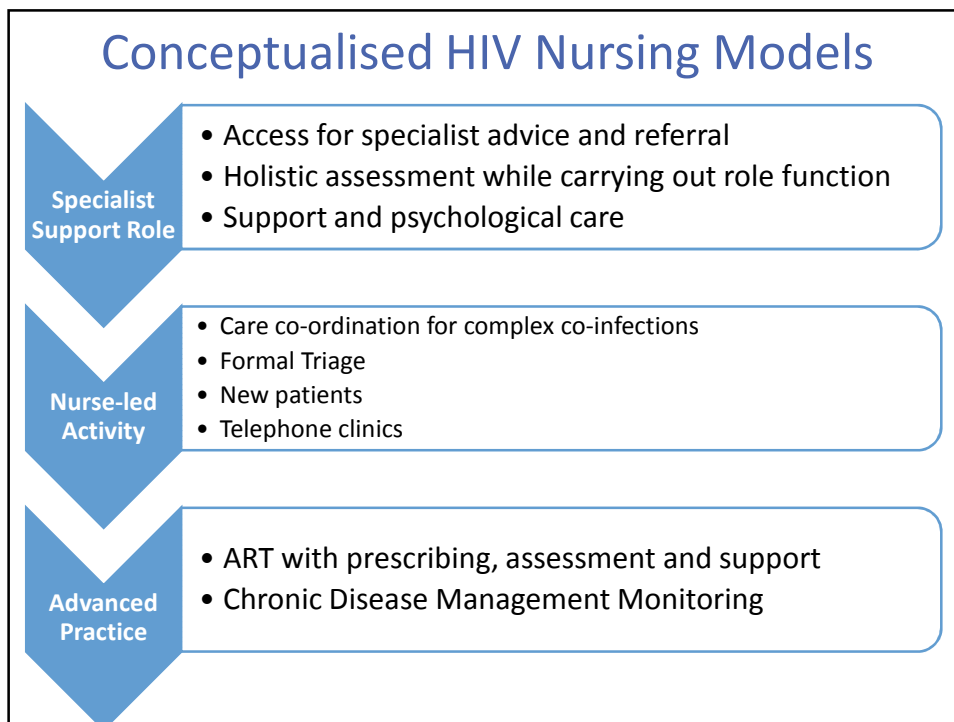
Nurses have been cut to the bone here

Shirley, Senior Nurse, HIV Unit, Springfield

Some role tensions

it took a long time to negotiate (nurse-led clinics).it was very much a case of trying to allay the fears of the doctors that we weren't suddenly going to steal their patients

Marcus, Senior Nurse, HIV Centre, Metropolis



Limitations

- Mid-term results undergoing verification
- Largely stable group of patients who are very happy with services
- Most HCW are clinic based doctors and nurses at this stage

Conclusion

- HIV healthcare is not just about CD4 and viral load monitoring
- High level of patient concern about moving away from secondary care specialist services
- Nursing roles are key in responding to the illness experience of HIV patients and in supporting appropriate utilisation of other healthcare services.
- Theoretical sampling from e-mail clinics, complex patients and community services is required to further develop this research

Thanks to:

Study participants in 3
study sites

Local Site Hosts

Patient Advisory Group

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- Robert Fieldhouse
- Robert James
- Angelina Namiba

Supervisory Team

- Professor Julie Scholes
- Dr Martin Fisher

Critical Friends

- Anna Bamford
- Catriona Bellingham
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- Gary Seaton