

# The psychological impact of caring during the covid-19 pandemic on HIV nurses

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March 2022

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## Executive summary

### Background

The World Health Organization declared the novel coronavirus (COVID-19) outbreak a global pandemic on 11th March 2020. Over the next twelve months, successive waves of infection created unprecedented challenges for healthcare providers as they responded to the dual challenges of maintaining core services whilst also caring for the large number of people hospitalised with severe infection. The psychological impact of working during the pandemic has been largely considered in relation to those working in front line services and far less so on those working in non-acute services. To date, there has been no systematic examination of the impact of the Covid-19 pandemic on the HIV nursing workforce who were involved in both maintaining essential HIV care and in contributing to frontline acute care.

### Aim

To establish how caring during the covid-19 pandemic has impacted on the professional quality of life of HIV nurses in the UK and develop evidence-based recommendations for addressing adverse impact and safeguarding psychological wellbeing.

### Objectives

- To determine the levels of compassion satisfaction and compassion fatigue within the HIV nursing workforce as determined by completion of the ProQOL 5 questionnaire
- To identify how compassion satisfaction and compassion fatigue are distributed across the HIV nursing workforce in relation to demographic and professional characteristics and Covid-19 related factors.
- To provide detailed insights into the experiences of those reporting compassion satisfaction and compassion fatigue, and those factors which have contributed positively or negatively to their professional quality of life.
- To develop evidence-based recommendations that can contribute to supporting and improving psychological wellbeing of HIV nurses and other healthcare professionals.

### Methods

This was a sequential mixed methods study design with two stages. Stage one comprised a national online survey which was distributed to HIV nurses in England, Scotland, Wales, Northern Ireland, and The Republic of Ireland. The survey ran for a three-week period in May 2021. It collected demographic

information and details of working patterns during two periods of high infection rates and national lockdown (March – June 2020 and October 2020 – February). It incorporated PROQOL 5 to measure compassion satisfaction and compassion fatigue. Stata v15.1 was used to generate basic descriptive statistics for all variables. We conducted a regression analysis of the PROQOL data.

Stage two was a qualitative phase involving semi-structured interviews with 28 survey respondents to establish detailed insights into the experience of working during the pandemic. The interviews took place October – November 2021 and were all conducted using remote communication. They were digitally recorded and fully transcribed. Data were analysed using a thematic analysis approach supported by the software package Quirkos.

## Findings

The survey generated 132 responses for the descriptive analysis, 99 of which were available for the final analysis. The overall survey respondents were primarily white, working in England, and female with more than one-half qualified for more than 20 years. Just over 1 in 3 were redeployed in the first pandemic wave dropping to 1 in 6 in subsequent waves. Two in five reported a greatly increased workload in the first wave, which was still reported by 1 in 4 in subsequent waves. In the PROQOL questionnaire 76% had medium levels of compassion satisfaction and 23% high levels, 32% and 67% indicated low and medium levels respectively of burnout. 48% and 52% indicated low and medium levels respectively for compassion fatigue. One person had a high level of compassion fatigue. In multivariate analysis, redeployment in both waves increased burnout scores by nearly 10 points and decreased compassion satisfaction scores by nearly 5 points, with no effect on secondary traumatic stress scores.

Analysis of the qualitative data identified four overarching themes, each of which contained several subthemes. Collectively they provided detailed insights into the complexity of challenges generated by working during the pandemic and their immediate and longer-term impact on the participants. The first theme explored the reality and the associated challenges of ‘working through the pandemic’ through five subthemes. Initially of *closing the clinic doors* of the HIV service and then continuing the work of the clinic *behind closed doors*. Redeploying the workforce and *working at the frontline* focused on *redeployment experiences*, whilst *restoring the HIV service explored the resumption of services*. The second theme focused on the ‘Emotional and physical demands’ through the five sub themes of: *Infection anxieties*, *Caring for covid patients*, *Caring for HIV patients*, *Preparing for the storm*, and Physical exhaustion. The third theme ‘Sources of help and support’ explored the role of *Daily routine*, *Support networks* and *Trust-wide initiatives* as sources of

immediate support and finally what was supporting recovery in the aftermath of the acute phase of the pandemic. The final theme 'New directions' focused on the *Career decisions and Changes to HIV services* that had been triggered by working during pandemic.

## Discussion

HIV nurses were confronted by unprecedented challenges as they worked through the pandemic, collectively responding to the two-fold challenges of maintaining an HIV service and contributing to the covid-19 effort. The ever-present threat of infection permeated everything. It shaped and determined every behaviour and interaction and was a major source of anxiety. Everyone was navigating uncharted territory and managing the uncertainties of the situations they frequently found themselves in.

Redeployment experiences were largely negative for many and in some cases, they were highly traumatic. Those who remained spent a large proportion of their time providing psychological support to HIV patients, many of whom experienced a deterioration in mental health, which carried a heavy emotional toll.

it is essential that HIV nurses are able to access the support they require to recover from the impact of the pandemic and to ensure that this support is available on a long-term basis given the emotional demands of the role.

Many services have capitalised on the opportunity created by the pandemic and made a substantial shift towards greater remote management of HIV care and the indications are that this is welcomed by many patients. However, ongoing monitoring and evaluation of wider roll out will be essential to ensure acceptability and effectiveness.

## Conclusion

HIV nurses had a key role to play during the covid-19 pandemic which involved both contributing to the redeployed workforce and maintaining essential HIV services. Ensuring all HIV nurses have access to workplace support and supervision will be important for emotional recovery and ongoing mental wellbeing. The temporary ways of working introduced during the pandemic has created conditions for long term service improvements within which nurses should have a major role.

## Acknowledgements

We gratefully acknowledge the contribution of the following people:

Dr Michelle Croston for making the project possible and for her ongoing support, particularly in helping Matt to develop his interview skills and in providing constructive comments and suggestions for the final report.

All the members of the advisory group whose input and support over the course of the project was invaluable: Dr Michelle Croston, Gillian Farrell, Dr Matthew Grundy-Bowers, Liz Foote, Jennifer Kendrick, Linda Panton, Jonathan Roberts, Dr Sarah Rutter, Peter Tovey, Jason Warriner.

All the study participants and particularly those who willingly shared their experiences with us in phase two of the study.

## Funding

This project was funded by the National HIV Nurses Association.

## Introduction

This is the report of a two-phase mixed method research project examining the effect that caring during the covid-19 pandemic had on HIV nurses and the services they worked in. The study focused on the period March 2020 - February 2021 and was conducted April 2021 – March 2022. In phase one we surveyed the HIV nursing workforce in England, Scotland, Wales, Northern Ireland and The Republic of Ireland to establish working conditions during the pandemic and assess professional quality of life. In the second phase we interviewed a sample of survey respondents to understand in detail their individual experiences and the conditions and circumstances that had shaped those experiences. The methods and findings of the two phases are reported separately and the findings from both phases are then synthesised in the discussion leading to a series of evidence-based recommendations for consideration by individual nurses and the National HIV Nurses Association (NHIVNA).

## Background

The World Health Organization declared the novel coronavirus (COVID-19) outbreak a global pandemic on 11th March 2020 (World Health Organization 2020) and called on nations around the world to take action to reduce transmission of infection. In the UK, as part of the national response, a letter issued by the chief executive of the NHS on 16th March 2020 set out the actions that NHS Trusts should put in place to redirect staff and resources in order to free-up the maximum possible inpatient and critical care capacity and to prepare for, and respond to, the anticipated large numbers of COVID-19 patients needing respiratory support (Stevens 2020).

This marked the beginning of an extended period of major upheaval and unprecedented challenges to the health care services that played out over the next 12 months as successive waves of covid infection spread across the nations and health services. Health services faced a double burden of maintaining core services whilst also caring for the large number of people hospitalised with severe infection. Intensive care and high dependency provision were expanded to cope with the increasing demand, with nurses, doctors and other healthcare workers being redeployed from other clinical services to work in those areas. Redeployed staff were expected to rapidly upskill and function effectively in unfamiliar surroundings without their usual professional support networks whilst coping with personal anxieties about risk of infection to self and family (Alharbi, Jackson et al. 2020, Nelson, Lee-Winn 2020, Que, Shi et al. 2020). Many were exposed to high risk of infection with inadequate protection whilst coping with increased volume and intensity of work (Iacobucci 2020).



## National lockdowns

The first national lockdown was imposed on 23rd March 2020 in response to rapidly increasing levels of hospital admissions of critically ill patients and numbers dying from covid-19. In all outpatient facilities, including HIV services, routine work was scaled down at the beginning of the first lockdown to reduce the burden on hospitals. Services were required to cancel clinics and move to remote consultations using telephone or video calls wherever possible to reduce the amount of social mixing and reduce the spread of infection manage (Willan, King et al. 2020). The staff who continued to work in those areas had to manage the changes and adjust rapidly to new ways of working.

As the first wave receded at the start of the summer period, hospitalisation rates fell and restrictions began to be lifted in early June. A second wave of infection in the autumn again saw hospitals coping with huge numbers of critically ill patients and thousands of covid related deaths. A second period of lockdown was imposed on 5th November and was eased after a month, only to be reimposed on 6th January when the highly transmissible delta variant arrived and rapidly spread across the country. December 2020 and the roll out of the vaccination programme marked the beginning of the end of the pandemic, dramatically reducing the link between infection and severe morbidity.

## Professional quality of life

Professional quality of life has been defined as 'the quality one feels in relation to their work as a helper' (Stamm 2010) and is made up of the positive and the negative elements of compassion satisfaction and compassion fatigue respectively (Stamm 2010). Compassion satisfaction (CS) relates to the pleasure that individuals derive from being able to do the job well. For example, the pleasure derived from being able to help others, feel positively about colleagues or being able to contribute to the work setting or the greater good of society.

Compassion Fatigue (CF) is characterized by emotional and physical exhaustion as a result of frequent exposure to trauma and complex patient stories which leads to desensitisation, diminished empathy or compassion for others (Joinson 1992). It is considered a specific consequence of the caring relationships with patients and families and considered to develop over time; a product of the prolonged effect of providing care for others (Stamm 2010). CF is understood as encompassing the two components of Burnout, and Secondary Traumatic Stress (STS). Occupational burnout generally refers to a response to a broad range of occupational stressors and chronic tediousness in the workplace. It is often characterized by symptoms such as emotional exhaustion, depersonalization, or a lack of personal accomplishment which usually have a gradual onset (Maslach, Schaufeli et al. 2001).

The relationship between burnout and work-related factors has been demonstrated consistently with meta-analyses indicating significant relationships between job burnout and risk factors such as high job demands (e.g., workload, role conflict) or low job resources (e.g., control, autonomy at work) (Alarcon 2011, Lee, Ashforth 1996). Secondary Traumatic Stress is a negative feeling driven by fear and work-related trauma which may be direct (primary) or it may be secondary trauma caused by indirect exposure to traumatic events. The negative effects of STS may include fear, sleep difficulties, intrusive images, or avoiding reminders of the person's traumatic experiences.

The psychological impact on healthcare professionals of working during the pandemic has focused primarily on those working in front line services, caring for covid patients. For example, a cross-sectional web-based survey conducted in China in February 2020, approximately two months after the virus was first reported in that country, reported prevalence of psychological problems in physicians, medical residents, nurses, technicians and public health professionals as 60.35%, 50.82%, 62.02%, 57.54% and 62.40%, respectively (Que, Shi et al. 2020). Similar results have been reported elsewhere (Shechter, Diaz et al. 2020). Those who continued to work in non-acute services have received less attention. We have limited insights into their experiences of working through the pandemic and the impact of those experiences.

## Aim

To establish how caring during the covid-19 pandemic has impacted on the professional quality of life of HIV nurses in the UK and develop evidence-based recommendations for addressing adverse impact and safeguarding psychological wellbeing.

## Objectives

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- To identify how compassion satisfaction and compassion fatigue are distributed across the HIV nursing workforce in relation to demographic and professional characteristics and Covid-19 related factors.
- To provide detailed insights into the experiences of those reporting compassion satisfaction and compassion fatigue, and those factors which have contributed positively or negatively to their professional quality of life.
- To develop evidence-based recommendations that can contribute to supporting and improving psychological wellbeing of HIV nurses and other healthcare professionals.

## Methods

This was a sequential mixed methods study design with two stages. Stage one comprised a national online survey of HIV nurses incorporating PROQOL 5 to measure compassion satisfaction and compassion fatigue. Stage two was a qualitative phase and involved semi-structured interviews with a sub sample of those who completed the survey to provide an in-depth understanding of their experiences of working during the pandemic and to generate detailed explanatory accounts of those factors that had contributed negatively or positively to individual PROQOL scores.

### Phase one

#### Determining the study population

Stage one consisted of a national online survey of nurses employed to work in HIV services in England, Wales, Scotland, Northern Ireland and Republic of Ireland. We used a range of approaches to calculate the size of the population because information on the number of nurses employed to work in HIV services is not routinely collected at national level. We consulted NHIVNA and co-ordinators for regional HIV nursing networks to establish details for as many services as possible. Using this information, the average number of nurses per HIV service was estimated to be three. The number of HIV services was determined to be approximately 183, based on previous information relating to services in England (Piercy, H., Bell et al. 2015) and local knowledge for the other four countries. These calculations gave an estimated total of 550 HIV nurses in the UK and Ireland combined.

#### Survey design

The survey was administered using Qualtrics SP and consisted of three parts. The first part collected personal, professional and demographic information. The questionnaire began with demographic questions on age, gender and ethnicity, then collected number of years qualified, and number of years as an HIV nurse (*Table 1*). The next section collected workplace information: NHS pay band, number of hours worked per week, country within the UK, English region, type of HIV service, size of the HIV cohort, and number of HIV nurses in the service (*Table 1*).

The second part asked about working patterns and redeployment during two peak periods of infection: February to June 2020 and November 2020 to February 2021 when levels of hospital admissions and COVID-related mortalities triggered national lockdowns. For each peak period, it asked

about redeployment: where redeployed, nature of redeployment and length of redeployment. For those not redeployed, it asked about changes to HIV workload. The last part of the survey assessed professional quality of life using ProQOL 5.

ProQOL is a validated tool that measures the three domains of compassion satisfaction, burnout and secondary traumatic stress (the latter two are the two elements of compassion fatigue) by means of responses to 30 statements in a self-completed questionnaire (Stamm, 2010). Each question asks about experiences, both positive and negative, and respondents select how frequently, within the last 30 days, they have experienced the thing being described, on a five-point scale ranging from 'never' to 'very often'. Each domain consists of 10 questions with a possible score ranging from 10 to 50. The ProQOL instruction manual (Stamm, 2010) details the scoring process and provides cut off scores for 25th and 75th percentiles of accumulated testing results based on a database of responses. For each domain: low is a score of 22 and below, medium a score of 23-41, and high for a score greater than 41.

#### Piloting the survey

The survey was piloted with five health and social care professionals who had worked through the COVID-19 pandemic and who were not HIV nurses. Their feedback confirmed that the survey was easy to complete and straightforward, that the questions were clear with a good logical flow and that they had no problems with interpretation. The researchers made no changes to the survey in response to the feedback, other than slight formatting adjustments.

#### Administering the survey

The survey ran for a 3-week period over 14 June to 5 July 2021. It was embedded in an invitation email, which was distributed widely through regional HIV nursing networks and through NHIVNA, who sent it to all its members individually as well as promoting the survey on the website and through its social media presence on both Facebook and Twitter. The email included a request that recipients share the survey link with other nurses in their clinical teams and their HIV nursing networks. Reminders were sent at weekly intervals across all platforms.

#### Analysis

Stata v15.1 was used to generate basic descriptive statistics for all variables. Mean and standard deviation were calculated for each component score along with categories using the low, medium and

high cut-offs. The characteristics of the original 132 respondents along with the 99 who completed the ProQOL scale are presented in *Table 1*.

For the ProQOL descriptive and regression analysis, the scores for each domain were treated as continuous variables. Six respondents were missing the score for one item on the ProQOL and these responses were replaced with the mean of the item calculated from all the other respondents.

For the purpose of analysis, redeployment information was combined to indicate 'redeployed in both', 'not redeployed in either', 'redeployed only once', or 'missing'.

To examine the effect of redeployment on ProQOL scores, the distribution of the domain scores were checked and a separate multivariate linear regression for each ProQOL domain were run. First screening all the explanatory variables individually, running multivariate analysis with all statistically significant variables in the screening, and finally using forward and backward testing to check for interactions. Statistical significance was set at  $P=0.05$ . Small numbers in the ethnicity category meant that it was reduced to white vs 'other than white' for these regressions. Further analysis added the category variables for the other domains to each domain regression.

## Phase 2

### Recruitment

The final question on the survey invited respondents to provide an email address if they would consider participating in an individual interview, to be conducted using remote means. We contacted all 56 who provided contact details, supplied them with a study participant sheet and asked them to reply if they were willing to be interviewed. We sent one reminder response to those who did not respond initially. A total of 28 people responded and were recruited to the study.

### Data collection

Interviews were semi-structured using a topic guide to ensure all relevant issues were covered to meet the study objectives. They were all conducted by one of the research team (MW and HP) using zoom or by telephone and recorded on a separate hand-held device. Verbal consent was taken immediately prior to the interview and separately recorded. All interviews took place between October – November 2021 and lasted between 30-60 minutes.

Interviews were fully transcribed by a commercial company and then checked and anonymised. For reporting purposes, the participants are referred to by their survey response number.

## Data analysis

Data were analysed using a thematic approach (Terry, Hayfield et al. 2017) and supported by QUIRKOS, a qualitative data analysis software programme. This involved familiarization with the entire dataset, inductive coding of all interviews and development of a thematic structure with overarching main themes and sub themes. Both researchers (HP and MW) independently coded the interviews and then compared these to agree a set of codes and an overall analytic structure of themes and sub themes. This was subsequently revised and finalised through iterative analytic processes and regular discussions between them.

## Ethics approvals

The project received ethical approval from the University Research Ethics Committee (Ethic Review ID: ER31499720)

## Results

### Survey results

The survey process provided 143 respondents who started the survey, of whom 6 did not answer any questions and a further 5 stopped before completing the demographics section, leaving 132 for the description of the respondents. A further 36 did not answer the ProQOL questions leaving 99 for the final analysis.

The overall survey respondents were primarily white, working in England, and female with more than one-half qualified for more than 20 years. Approximately 70% worked full time and 80% worked in HIV outpatient services. The ProQOL subsample were essentially similar to the original respondents with only a smaller proportion of those qualified for less than 10 years in those who completed the ProQOL scale.

**Table 1: Demographic and workplace description of the respondents in the initial cohort and the subset that completed the PROQOL**

Variable	Original respondents (N=132)	Respondents that completed PROQUOL (N=99)
Ethnicity (N(%))		
White	118 (89.4%)	89 (89.9%)
Mixed/multiple	3 (2.3%)	3 (3.0%)
Asian/Asian British	2 (1.5%)	0
Black combined	8 (6.1%)	6 (6.1%)
Prefer not to say	1 (0.8)	1 (1.0%)
Male (N(%))	24 (18.2)	18 (18.2%)

Female	107 (81.1)	81 (81.8%)
Non-binary/third gender/Prefer not to say	1 (0.8)	0
Age band (N(%))		
20-29 y	10 (7.6%)	8 (8.1%)
30-39 y	22 (16.7%)	12 (12.1%)
40-49 y	43 (32.6%)	34 (34.3%)
50-59 y	50 (37.9%)	40 (40.4%)
60+ y	7 (5.3%)	5 (5.1%)
Number of years as a qualified nurse (N(%))		
1-10 y	25 (18.9%)	14 (14.1%)
11-20 y	32 (24.2%)	26 (26.3%)
20+	75 (56.8%)	59 (59.6%)
Number of years as a qualified HIV nurse (N(%))		
1-5 y	36 (27.3%)	25 (25.3%)
6-10 y	26 (19.7%)	19 (19.2%)
11-15 y	11 (8.3%)	7 (7.1%)
16-20 y	21 (15.9%)	14 (14.1%)
20+	37 (28.0%)	33 (33.3%)
missing	1 (0.8%)	1 (1.0%)
NHS Payband (N(%))		
5	9 (6.8%)	4 (4.0%)
6	36 (27.3%)	27 (27.3%)
7	76 (57.6%)	61 (61.6%)
8	11 (8.3%)	7 (7.1%)
Number of hours worked per week (N(%))		
full time	97 (73.5%)	71 (71.7%)
< full time	35 (26.5%)	28 (28.3%)
Country (N(%))		
England	108 (81.8%)	81 (81.8%)
Scotland	14 (10.6%)	10 (10.1%)
Wales	3 (2.3%)	2 (2.0%)
Ireland (North & South)	7 (5.3%)	6 (6.1%)
Place of work (N (%))		
HIV Outpatients	104 (78.8%)	84 (84.8%)
In patient with HIV beds	6 (4.5%)	1 (1.0%)
HIV specialist community service	17 (12.9%)	10 (10.1%)
Other – please specify	4 (3.8%)	4 (4.0%)
Size of HIV cohort (N (%))		
< 100	10 (7.6%)	5 (5.1%)
100-1000	64 (48.5%)	53 (53.5%)
1001-2000	14 (10.6%)	9 (9.1%)
2000+	44 (33.3%)	32 (32.3%)
Redeployment (N (%))		
Redeployed in both	21 (15.9%)	14 (14.1%)
Not redeployed in either	62 (47.0%)	58 (58.6%)
Redeployed only once	28 (21.2%)	27 (27.3%)
Missing	21 (15.9%)	0
PROQUOL scores (mean (SD))		
Compassion Satisfaction	N/A	37.6 (6.3)
Burnout		26.2 (5.6)
Secondary Traumatic Stress		22.6 (6.2)

PROQOL categories (N(%))	N/A	
Compassion Satisfaction		
Low		0 (0%)
Medium		73 (73.7%)
High		26 (26.3%)
Burnout		
Low		32 (32.3%)
Medium		67 (67.7%)
High		0 (0%)
Secondary Traumatic Stress		
Low		47 (47.5%)
Medium		51 (51.5%)
High		1 (1.0%)

Just over 1 in 3 were redeployed in the first pandemic wave dropping to 1 in 6 in subsequent waves (see [Table 2](#)). Two in five reported a greatly increased workload in the first wave, which was still reported by 1 in 4 in subsequent waves—although 1 in 8 reported an unchanged workload in the first wave period increasing to 1 in 4 in the subsequent waves.

**Table 2: Redeployment circumstances for those who completed PROQOL (n=99)**

The questions refer to where they were working during the pandemic waves	Period 1 Feb-Jun 2020	Period 2 Nov 20-Feb 21
Continue working in normal place		
yes	62 (62.6%)	81 (81.8%)
No	37 (37.4%)	18 (18.2%)
Situation during the pandemic wave		
deployed elsewhere in usual workplace	32 (32.3%)	13 (13.1%)
shielding/working from home	2 (1.5%)	2 (2.0%)
elsewhere in covid infrastructure	2 (1.5%)	0
Half inpatient HIV, half other	1 (1.0%)	0
Not redeployed	62 (62.6%)	81 (81.8%)
Left the NHS (comment in wave 2)	N/A	1 (1.0%)
Where redeployed		
ITU	5 (5.1%)	2 (2.0%)
High dependency covid ward	4 (4.0%)	2 (2.0%)
Covid ward	18 (18.2%)	8 (8.1%)
Non-covid ward	1 (1.0%)	0
Community service	3 (3.0%)	0
other	1 (1.0%)	1 (1.0%)
Missing	5 (5.0%)	5 (5.0%)
Not redeployed	62 (62.6%)	81 (86.9%)



Screening of explanatory variables found only three to be predictive of the ProQOL domain scores: ethnicity (white vs other than white), redeployment status, and continuing to work in their usual workplace. In multivariate analysis, redeployment in both waves increased burnout scores by nearly 10 points and decreased compassion satisfaction scores by nearly 5 points, with no effect on secondary traumatic stress scores. Being redeployed only once, halved the impact on burnout scores but made little change to compassion satisfaction scores. Being ‘other than white’ decreased burnout scores by nearly 5 points. None of the variables predicted secondary traumatic stress scores in multivariate analysis (*Table 3*). Only burnout was affected by the scores from the other domains (model 2 in *Table 3*).

**Table 3: Linear regression of PROQUOL domains**

variable	Compassion Satisfaction Coeff (SE)	Secondary Traumatic Stress Coeff (SE)	Burnout Coeff (SE)	Burnout model 2
White	Ref	Ref	Ref	Ref
Other than white	2.40 (0.048)	-3.19 (0.124)	-4.89 (0.006)	-3.35 (0.016)
Redeployment				
Not redeployed in either	Ref	Ref	Ref	Ref
Redeployed only once	-4.85 (0.009)	0.34 (0.914)	5.47 (0.039)	3.93 (0.059)
Redeployed in both	-4.92 (0.026)	4.72 (0.211)	9.98 (0.002)	7.88 (0.002)
Continue working normal				
yes	Ref	Ref	Ref	Ref
No	3.17 (0.101)	-0.05 (0.986)	-3.96 (0.152)	-3.68 (0.088)
Compassion Satisfaction				
Medium*	N/A	N/A	N/A	5.47 (<.001)
High				Ref
Secondary Traumatic Stress				
Low	N/A	N/A	N/A	Ref
Medium				3.25 (<.001)
High				6.35 (0.127)
Constant	17.53	25.41		

- \* No one scored low
- % No one scored high

### Phase two findings

We interviewed 28 participants. 23 females and five males. Twenty-five self-identified as white, two as Black/ African /Caribbean/Black British and one as Mixed/Multiple ethnic group. Seventeen had a clinic-based role in services ranging in cohort size from approximately 150 – 5,000. Seven were HIV community specialist nurses. Four had a combined OPD/community role and one worked in an inpatient ward. Thirteen had remained in the HIV service during periods one and two with the

remaining 15 having had been re-deployed, full-time or alongside their HIV role. Periods of redeployment ranged from a few weeks to several months.

Data analysis identified four overarching themes which provide detailed insights into the complexity of challenges generated by working during the pandemic and their immediate and longer-term impact on the participants. Figure 1 provides an overview of the four themes and their respective sub themes.

**Figure 1: Overview of themes**

<b>Themes</b>	<b>Subthemes</b>
Working through the pandemic	Closing the clinic doors Working behind closed doors Redeploying the workforce Working at the frontline Restoring the HIV service
Emotional and physical demands	Infection anxieties Caring for covid patients Caring for HIV patients Preparing for the storm Physical exhaustion
Sources of help and support	Daily routines Support networks Trust-wide initiatives Supporting recovery
New directions	Career decisions Changes to HIV services

### Working through the pandemic

At the beginning of the pandemic, routine HIV outpatient clinics were cancelled, and treatment and care were dramatically scaled back. A substantial proportion of the HIV team were redeployed to other clinical areas. Those who remained provided some level of service to HIV patients to ensure uninterrupted access to medication, care and support. As the first wave receded and the pressure on acute services eased, redeployed staff returned to their HIV service, clinics started to open again, and normal service were largely resumed. The second wave necessitated another period of redeployment for some and placed additional demands on HIV services that largely remained open.

Each of these phases generated a new set of challenges for everyone as they navigated their way through uncharted territory. Each set of new challenges created a new set of work pressures and demands for all the participants which were shaped and influenced by the context and circumstances within which they were operating.

Closing the clinic doors

As the scale of the pandemic crisis became evident, the guidance from trusts to HIV services was *'don't bring people through the door if you don't have to'* (20). Clinics effectively shut their doors to the vast majority of their patients and scaled back the service that continued to provide essential services to keep their HIV cohort safe and well. A large proportion from all staff groups were redeployed to work elsewhere.

Scaling back involved an intense initial period of activity reviewing patient records, cancelling appointments, mobilising remote communication systems, organising medications. In many services, this initial work was done in a timely fashion:

*Our clinic shut its doors and most of the staff were deployed onto covid areas. We had departmental meetings in the weeks leading up to this ... so we had put in place a plan... clinic lists were reviewed; medications were pre-prescribed.'* (10)

*Before we shut in March we did a massive exercise in getting medicines out to patients if we thought they would run out in the next six months. Most of them didn't want to go anywhere near a hospital which was understandable, so we wanted to make sure nobody ran out of medication.* (7)

Not all services however were as well prepared. One participant who worked as the sole HIV nurse in a small service described her experience:

*By the end of that Monday, I heard that the clinic had been shut and that I obviously had to cancel all the appointments and that's what I was working on ... and then we heard that the lockdown was coming that night. But I really had no contact with the doctors that I worked with ... it wasn't coming out very clearly what was going on ... it felt like it was really down to me... and I can remember feeling really deserted, really deserted.* (34)

Alongside this, there was a large volume of essential work keeping patients in the loop, explaining what was happening and providing reassurance to reduce anxiety. Some services had the facility to put information on service websites, but all services were receiving and responding to large numbers of enquires from anxious patients desperate to know what was happening to their HIV care.

*There was a high quantity of calls, and it was really around advising people that it was ok not to come in.* (35)

*The triage were deluged by patients asking what they needed to do and medications etc.* (18)

Working behind closed doors

When the clinic doors closed, the task of delivering an HIV service continued behind closed doors and focused on three things: ensuring patients received uninterrupted supplies of HIV medication, ensuring they had access to the information, guidance and support they required, and ensuring that those with health needs received the treatment and care they needed.

The volume of work was enormous, and the nature of the work was extremely challenging, a source of '*mega anxiety and stress*' (34). People picked up the work of other members of the team who had been redeployed, navigated their way through an array of difficult logistical problems and, even in the larger services, were working in relative isolation.

*I thought it would be a good way of not having the stress of being on a ward but actually it was more stressful because there just seemed like so much to do even though it was quiet in the clinic because nobody was coming in, the amount of background work was just overwhelming. There was just so much unseen work. (28)*

In the early stages of lockdown, there was little clear guidance about what anyone was required to do and conflicting advice about what people with HIV should be doing in terms of shielding. Participants dealt with large numbers of queries and dealt with '*a lot of worried conversations*' (52), trying to ensure that individuals received the latest advice and guidance in the midst of frequently changing information and considerable uncertainties:

*We were fielding a huge amount of calls as well as our own anxieties about how to keep ourselves and staff safe which, you know, for a large part we were unable to answer. BHIVA hadn't put up any information yet, so we were, it felt a bit like we were winging it at the beginning I think, in terms of what is this, what is the risk, you know. (45)*

*We identified people with low CD4 counts straight away and contacted them, told them what they should be doing about shielding. What was harder I think was identifying people who were shielding but didn't need to be. (20)*

The nurses had a major undertaking to ensure that everyone received uninterrupted supplies of antiretroviral medication. Some services had home delivery pharmacy provision in place. Others who didn't set up a temporary collection service for those who could come to the hospital and for those who couldn't were '*coming up with ways to get their medication to them*' (10) which largely involved organising courier services and taxis. In some cases, the nurses did the deliveries themselves, using it as an opportunity to check on those who were elderly or vulnerable. One explained how she had '*dropped medicines off for people, some wouldn't even open their doors, so I had to put it through*

*windows, leave it on doorsteps' (52) and another how 'we did a lot of getting on our bikes and cycling out to people's houses' (10).*

Getting medication to those who had been stranded far away from their HIV services as a result of international travel restrictions created substantial challenges and added to the workload.

*We had an awful lot of patients from other services who were stranded here because they couldn't travel ... So, it was liaising with other services, getting their records, there was a lot of work on the phone, on the email, that sort of stuff. (10)*

*There was another lot who got stuck ... some of them unfortunately were stuck in other countries, which made things really complicated, ... some of them were stuck places that we couldn't courier the medicines to .... Brexit made it really hard to courier stuff out of the country because it all became customs forms and everything and yeh, from 2020, it was easier to courier medication to Nigeria or South America than it was to France, so that became very complicated. (35)*

HIV services were not closed to everyone. Whilst postponing appointments and providing medication was sufficient for the majority of the cohort, it was not enough for a substantial minority with physical or psychosocial needs, who required ongoing care and support. Many health and social care services had stopped face to face visits which increased the isolation of vulnerable individuals and amplified their needs. Some services had worked closely with voluntary sector organisations to ensure those who were isolating received enough social support. They also provided ongoing support themselves through remote means and some community-based HIV nurses had continued to visit patients at home.

Participants also saw and managed those with a range of problems that required assessment and care. They were often making clinical decisions with reduced ready access to clinical support because medical staff were redeployed and, in some cases, reduced access to facilities because their normal clinics were shut or were being used for other purposes. As one explained: *'there was nothing immediate, quite often you had to make decisions very quickly and on your own'* (25). Among this group were a proportion of patients who had previously disengaged from the HIV service and whose anxieties about the pandemic had triggered a decision to re-engage with HIV treatment and care.

*We were inundated with anxious people, one good thing about it was a lot of people who had been difficult to engage with and get them to take their medication well did come out of*

*the woodwork, we had a lot people who were like no I really want to start meds now, I really want to get my supply. (21)*

*At the start we did have a lot of patients who were lost to follow up and they got back into contact, I need my meds, we haven't heard from you in 3 years. It was brilliant but not easy at the time because all the staff had been redeployed so it was a bit of a challenge for the staff who had stayed to try and manage patients. (24)*

#### Redeployment arrangements

Just over half of the 28 participants had been redeployed during the first wave of infection. Those employed by hospital trusts went to work on an acute ward or high dependency or emergency department whilst two who were employed by a community trust were re-deployed to other community services dealing with covid related cases.

Redeployment decisions were made at a trust management level which largely adopted a control and command position. Participants had limited involvement in the process although some who were in management roles contributed to decisions about the nursing workforce in their service and others were able to influence local level decisions about where they were redeployed to. The context within which those decisions were being made, where *'there was so much pressure on nurses to do their bit'* (52) meant that few felt any sense of agency. As one explained:

*I probably could have [refused to be re-deployed] but I don't know, I think it would have been difficult, I probably wouldn't have had a choice, it didn't feel like I had a choice. (47)*

During the first wave of the pandemic, people were redeployed for variable lengths of time ranging from two weeks to approximately four months. Some were redeployed full-time and continued to work there for several months, returning to their normal role in the HIV service over the summer period when infection rates had fallen, and services were beginning to open up. Those people effectively stepped aside from their HIV role during that time. As one explained: *'From a nursing perspective, once we were gone, we were gone, and we were out of the service'* (13).

More commonly, people retained some aspect of their HIV role whilst they were redeployed and managed the competing pressures of both roles. Many of them were either the only nurse or the senior nurse with a managerial role in their service, or they had responsibility for a patient caseload. Stepping away from the HIV service was not an option for them because *'I couldn't just abandon my service'* (14) and they had to ensure that the HIV patient cohort were receiving the care and support they needed and deserved. These people simultaneously helped to keep the HIV service going whilst working elsewhere. In some cases, this was managed with a split working week, working one or two

days in the HIV clinic alongside two or three shifts in another clinical area. Sometimes this arrangement worked well and sometimes it didn't.

*I kept 1 day in clinic and 2 days in Intensive Care .... So, I still felt like I had a bit of ... a foot in my normal job and contact with my colleagues and clinic in the job that I am supposed to be doing. I didn't feel totally and utterly detached from it ... it did feel much better. (45)*

*I wouldn't have done both jobs at the same time. I think at the time it felt like the right decision ... but yeh, with that hindsight I would not have been doing both the jobs at the same time. It was, it was too difficult. (9)*

A more common situation was for people to continue with their HIV role alongside full redeployment, taking calls on their HIV service phone whilst working on the ward, or going back to the HIV unit at the end of a long shift to pick up and deal with the messages that were waiting there.

*When I first went over to be re-deployed, I still had my office phone so I would check it every so often and patients were ringing in looking for help. (24)*

*Sometimes I had to be doing prescriptions while I am in the redeployment, I would go online, screen patients and prescribe and it's like trying to balance – it was just hell. (16)*

*There were times where I would do a shift on the ward and then I would come back to clinic, to check my email and things to ensure there wasn't anything I needed to do to support my patients that I had to try and look after. (44)*

When the 2<sup>nd</sup> wave arrived at the end of summer 2020, HIV services stayed open. There was less justification for staff to be moved out of the HIV service and fewer were redeployed. Patterns of combined roles that had been problematic in the first wave were not repeated and the process of redeployment felt more controlled. One explained that 'we hadn't got the same fears about being redeployed all over the place and places we hadn't got skills to work in and [we had] a bit more knowledge about protection, how to protect ourselves' (34).

For those who were redeployed, whilst there was less uncertainty and fear associated with going back to the front line, the prospect was no less daunting:

*So again, .. it was just the dread and I guess that feeling of, you know, we've done this before and it was less uncertain and less scary, but it was definitely just, yeh, it was more, more like oh s\*\*\*, here we go again, and knowing, just knowing what was going to happen. It should have made it easier, but eugh. (45)*

Working at the front line

Participants who were redeployed worked in a variety of different areas. Some worked in intensive care units, but the greater proportion worked in other areas including accident and emergency units, respiratory wards and infectious diseases wards. Several were well equipped for redeployment because they had fairly recent ward experience and a set of clinical skills that were just *'a bit rusty'* (53). Returning to clinical specialities they were still familiar with meant they were relatively comfortable with the situation although *'it was a completely new job with new people, it was like starting a new job again to be honest'* (25). One had a further advantage because they were able to return to a team they had worked with before and where, *'on a personal level I knew I would be kept the most safe'* (45).

The majority of the participants however were not well equipped for the roles they were redeployed to. They were highly experienced nurse specialists who had worked in HIV services for many years. Some had very little previous experience of acute care and those that did were hopelessly out of date. They were well out of their depth working on the acute wards and, in the early days, unable to do anything other than the most basic aspects of care because everything had changed.

*The last time I was on a ward it was a paper care plan and a fold out drug chart that you had to sign off, now everything's on the computer, I've never used any of it... and then there's just this bank of machines that are keeping this person alive, everything's beeping .... and then little things, you think at least I can empty a catheter bag but no that's all changed because you have to empty it into some kind of silicon gel bag that keeps all the urine in some kind of jelly mould, so it's not like I could even do that unaided. (47)*

*I couldn't, even the most basic medication, I can't give it, I'd not even got the passwords for the system. (1)*

As part of a large supplementary workforce, brought in from a wide range of other non-acute services to work in a clinical situation, there were anxieties about how well they would be received by the ward teams and concerns that their presence would make things harder rather than easier for the acute care workforce who were already under extreme pressure.

*I think that's the biggest fear, you are going there to help out, but in reality, you are making their job a little bit harder. (13)*

Trusts had the daunting task of rapidly preparing this workforce for ward work. Participants described induction programmes that were primarily focused on core aspects of safety and on the covid situation, much of which had been delivered on-line or at a speed that *'wasn't that helpful'*



(13). Those programmes had done little to address the major knowledge and skills deficit or to allay the participants' fears and anxieties. The overall sense from the data was of participants who were ill prepared and out of their depth as they explained:

*We hadn't got the knowledge or the up to date experience and nobody, there was no like kind of breaking in period, there was no training, it was just like, whoosh, you're out. (1)*

*I joined the team I suppose, I think there were a couple of other band 7 nurses who'd been out of ward-based stuff for a while and we all very much shared the same experience, we felt really unsupported and just expected to be exactly the same as a ward-based nurse within seconds sort of thing. (28)*

The beginning of the redeployment period was extremely difficult for everyone. It continued to be difficult for a small proportion who had an extremely negative deployment experience, the pressure of the situation they were working in creating an environment in which they could not function with any sense of satisfaction or confidence:

*There was just so much expectation the first time round, I think everyone was panicking and everybody felt the pressure on themselves, the nurses and team that worked there and I think somebody new coming in was just making them go I can't support them as well, I think it was just too much for everybody. (28)*

For the majority however, initial experiences were moderated over time and became more positive. One acknowledged that 'within a week or 2 .... I picked it up OK' (13) and another that 'I learnt a lot about things that I haven't dealt with for a very, very long time' (14). This was due in a large part to the reception they received from the teams they went to work with and the training and support they received from those teams:

*Support from the ward staff who were brilliant, really really helpful. (23)*

*The staff on the ward, you were going to help them, they were very good and I think they were very appreciative. (13)*

*The new department, A&E, were very good at recognising that they had a lot of new staff so they were very good at education and making you feel part of the team and I learnt an awful lot there as well. I felt I coped with it okay. (25)*

Opening up the service

When the first wave subsided and lockdown eased, redeployed staff gradually returned and normal services started to resume. Clinics opened, initially primarily for blood appointments to deal with the

backlog of monitoring and reviews that had built up over the previous few months and then providing face to face consultations. Those in the community went *'back into the normal community nurse role.'* (47). Risk of infection was a major consideration and created a number of challenges. Although there was a sense of urgency about *'seeing as many patients as we can because .... we don't know what's going to happen in winter'* (52), most services ran with reduced clinics *'because of all the infection control cleaning that had to take place in between patients'* (25).

In some places, there were challenges of running a reduced service when they were trying to clear a backlog and demand was high. One explained that in their service *'there was a difficulty in slotting people in who hadn't been seen for a long time'* (53) and in another that in their service, where they *'didn't have sophisticated systems to be able to [restrict the numbers] it led to a bit of a bun fight, some people got what they wanted, some people didn't'* (35).

When clinics did reopen, participants spoke of the considerable difficulties they had had in persuading patients to attend for face-to-face appointments, some of whom were anxious about the risk of infection and others who questioned why they needed to attend because they hadn't had to during the pandemic. In some services *'they left it up to the patients really whether they wanted, we gave them the choice whether they wanted to see us face to face'* (22). Others were more proactive in their efforts to persuade people to attend in person, managing *'patients' anxiety about coming in and trying to explain that we feel it's safer to see you and get your bloods checked and be safely prescribing'* (52).

There was widespread acceptance of the value of remote consultations and acknowledgement that their role had increased substantially over the past year. Several participants however highlighted the value of face-to-face consultations as an essential component of HIV care and explained what they were doing in their service to encourage patients to return to the clinic.

*I think when you do talk to patients, they do like coming in, that is their space and time of being HIV positive and by denying them that space you're denying them that opportunity.*  
(54)

*We weren't happy to provide them with more than a month's excess medication, we were trying to get them to come in. Most people were happy with that and to be honest I think a lot of people wanted to come in, when you actually saw them in clinic, they were pleased to be seeing someone face to face and they got a chance to talk.* (28)

## Emotional and physical demands

Five sub themes collectively encompass the physical and emotional demands on the participants of working through the pandemic. Firstly, *the threat of infection* that permeated every action and the emotional toll it produced. The second and third subthemes describe the emotional impact of *caring for covid patients* and for *caring for the HIV cohorts* respectively. *Preparing for the storm* focuses on transitional points and the associated uncertainties and anxieties that occurred at those points as the pandemic played out in the workplace. The final sub theme focuses on the *physical and emotional exhaustion* people felt.

### The threat of infection

At the beginning of the pandemic, little was known about the virus, about the routes of transmission and the degree of transmissibility, or about the consequences of infection. There was confusion about how to protect yourself from infection and about the requirements for and availability of personal protective equipment. The threat of infection was an overriding concern for everyone. Those who were redeployed and at high risk of exposure were fearful of contracting covid, of transmitting it within their households and to vulnerable family members they were supporting:

*The anxieties of what if you get COVID, what if you take it home to your family, what if you get ill from it, all those kind of uncertainties and mixed emotions. (44)*

*I think there was always that worry as well that you were going to get Covid yourself, you're working frontline with potential Covid positive people and I wasn't so worried about myself, it was more my family. (25)*

In line with guidance at the time, they were following stringent infection control measures at the end of each shift:

*I remember coming home, we would all strip off next to the washing machine, throw our clothes straight in, it was, we were frightened because you know, we were like, we didn't know anything about it, we didn't know who was going to get ill, who wasn't going to get ill. (1)*

*it sounds really crazy to say all of these things now, but I had to come home, strip off by the door, go upstairs and have a shower. (9)*

Others were particularly fearful of bringing covid into the workplace and the consequences of that for patients and services:

*I live on my own so I wasn't worried that I was going to bring home covid but I was worried that I was going to bring covid into work, pass it onto patients. (24)*

*I was very wary of where I was going and who I was near. I was just fearful of taking anything into work because I just had this in my head, if they're shutting down because they've all had exposure to me and I can't be responsible for that. (54)*

As time passed those fears began to subside, as a result of increased knowledge of the virus, improved and established infection control measures and ultimately, the roll out of the vaccine programme:

*Second time round I think there wasn't the uncertainty and the fear. I think we all just, I think we all just, you know, we just knew what we were doing. You know, I wasn't scared, I wasn't scared about taking COVID home, I was vaccinated, you know. (45)*

Caring for covid patients

As the number of covid cases and hospital admissions rose rapidly, increasing numbers of hospital wards were turned over to covid patients with a high proportion of areas repurposed into intensive care facilities. One participant summarised the process in their large teaching hospital:

*We are a 12 floor building and we started off with the 1st floor, the cases came in and they went to the high dependency unit, so the 1st case and then the 2nd case, then there was a whole ward, then there were 2 wards, then 1 ITU, then 2 ITU's then 3 ITU's, then ITU took up the whole floor, then of the 12 floors, it slowly moved down floor by floor by floor, and pretty much all of the hospital, at it's peak, was COVID, there were just a couple of floors and the ground floor that were other things. (35)*

A proportion of those who were redeployed were working on the covid wards and exposed to the stress and the trauma of the situation. Their accounts illustrate the enormity of the challenge; the unknown quantity of what they were dealing with, particularly in the early days, the unprecedented levels of death they had to deal with and the rapid and unexpected nature of those deaths;

*I think the unknown, what was to come, was it going to get worse, how were we going to treat this virus that we didn't know very much about, and people getting so sick so quickly, like within hours, it got easier over time as we started to recognise the symptoms. (24)*

*People were dying left, right and centre, and we were also one of those areas where bodies of people who had passed away couldn't be moved because the mortuary was full. Sometimes bodies would stay on the wards for up to 6-8 hours... at one point we were all feeling that we*

*were at war, that we were fighting the enemy that we didn't know, it was just there, unseen and people were dropping dead. (16)*

*I did look after some very sick people and there was quite a lot of death ... I can't think of any other condition where you can sit and have a normal conversation and in 45 minutes, you're dead. It was very difficult, it was very fraught for staff, there was this unknown quantity. (53)*

Also, the difficult ethical life and death decisions about allocation of those resources which were having to be made, and the culture of suspicion and distrust around those decisions that rapidly emerged among distressed relatives and had to be sensitively negotiated:

*It was quite difficult for a lot of people to see and also people were dying and that whole decision is being made about care and saying no they can't go to ICU, ICU's full and they had to make harsh decisions about who's going. (7)*

*So there was this rumour going around that hospitals were giving patients too much oxygen and that it was killing them, so we had relatives calling us say "we know you are giving our, our family member too much oxygen, you need to turn it down". And it was just really exhausting having loads of these conversations over and over again. And we'd have patients who were made palliative, whose family maybe didn't agree with them being made palliative, and obviously that was really difficult and traumatic for them. We had quite a lot of people shout at us, on the ward, because they weren't allowed to come onto the ward (9)*

Caring for HIV patients

The cost of caring for their HIV cohort increased for many of the participants, particularly during the first wave which was characterised by uncertainty, separation and social isolation. Those who were redeployed to the covid frontline were concerned about how well their HIV patients were coping and '*there was a worry that they might need things and they might get missed, or people might be needing help*' (23). Most of them responded to this by continuing to be available to their patients during redeployment and effectively doing two jobs at once. This had a personal cost as one explained:

*So wellbeing, it was tough... A bit exhausting really, that sort of whole ward experience, you know, trying to keep your links with your base ... when you do get back, trying to change and restructure the model of working with HIV positive people, you know, doing the best that you can. Managing patient's anxiety along the way. (13)*

For those who remained in the HIV service, the balance of care shifted. Closing clinics and cancelling routine consultations shifted the care balance more towards psychological care work and that work

often became more difficult. A high proportion of the HIV patients experienced difficulties. For many patients, *'their mental health was going through the roof' (12)* and services *'never stopped receiving calls about their mental health, about how they were worried about COVID and their anxieties about that' (44)*.

Some concerns for patients' wellbeing were unexpectedly unfounded as one participant explained:

*I think I worried a lot, I worried a lot about my caseload of patients and how they were coping with lockdown, particularly people with mental health issues. I thought it was quite interesting ... but some of my patients who I would normally have been really concerned that they wouldn't cope were fantastic and ... then they were 'how are you, are you alright, how are you coping with all of this ' to the point where I was thinking who's supporting who here I'm phoning you cos I'm worried that you're going to lose the plot and do I sound really that stressed over the phone? (14)*

Overall however, participants were coping with an increased demand for psychological support and responding to that demand whilst being less able to access support themselves because they were part of a depleted workforce. One explained that *'I felt quite overwhelmed, sometimes I was carrying a lot of anxiety, carrying it around with me. I would take a call from someone, and I would worry about them all day.'* (35) Alongside the increased need for psychological care, the scaling back of other services increased patients' dependency on the HIV services:

*The patients we had were very much more isolated during covid because lots of other services weren't doing face to face home visits. So we found that the cohort that we had were very much more dependent and isolated and in need of support because everyone else had backed off basically, everything was telephone consultation ... our patients didn't respond well and couldn't cope well with remote services so they were very much more isolated. (36)*

*What I was spending a lot of time doing was helping people to manage anxiety.... There are a couple of people I was phoning daily at one point and that was quite stressful really because I don't work at weekends, and I do leave them to rely upon the generic services [which had been scaled back]. (20)*

As time went on, the devastating effects that the pandemic had had on the lives of some of their patients started to emerge:

*It was more traumatic during the second wave because a lot of our patients had lost relatives and there had been quite a lot of devastation and people losing their jobs and things like*

*that, children who just didn't want to leave the house and that sort of thing, more domestic violence, you just became aware of more issues and I think that's why people liked coming in cos they could come in and maybe share a little bit of what they hadn't been sharing before particularly, like domestic violence and stuff, people in really bad situations and wanting the chance to get away. (21)*

*And then a small cohort of our really complicated patients got sick and some got admitted to other hospitals and one of them died and I found that really really hard. As they were the really tough resilient patients who had had transplants and been on dialysis, the really tough and you know, you're always thinking about how well we can manage HIV, about how clever we are, we've got this and actually you are alright, and then this thing comes along which just sweeps them away. There were times when I felt really overwhelmed. (35)*

#### Preparing for the storm

At the beginning of the pandemic, there was an overwhelming sense that everyone was working in the dark and walking into the unknown in terms of the scale and nature of the challenge. As one participant summarised *'people didn't know what the risks were, we didn't know what we were getting into, we didn't know how at risk we were, and it was quite a scary time in many respects.'* (53)

Health services were focused on mobilising all possible resources from within the workforce, not only from within the existing workforce but also from everyone else who could contribute.

Notwithstanding what the personal risks might be, participants were anxious to play their part and felt a strong sense of moral obligation to be on the front line and to contribute to the collective effort. One explained that *'I knew it was something I had to do'* (44), another that *'It was, you know the right thing to do at that time'* (45) and another that *'I just felt a responsibility that I really had to go and help'* (13). Similarly, one explained that *'I needed to show that I was doing my bit'* (22) and another how *'We [the nursing team] all volunteered because we felt it was the right thing to do'* (1).

Several had relatively recent clinical experience of working in acute care and redeployment for them was unproblematic. One explained that *'I was totally up for it, quite excited about it'* (28) and another that *'I found that a very easy decision, I'm an acute medical nurse, there was a problem, these were acutely unwell patients'* (53). The majority however had been working in HIV for at least ten years and in several cases considerably longer. Most of them had major reservations about what redeployment might involve and what would be expected of them. They were extremely apprehensive about the prospect of being redeployed and working shifts in an acute clinical area

with which they were entirely unfamiliar. They were worried about what would be expected of them in that setting and how useful they would be.

*I've worked in HIV for so long I was thinking will I be any good, will I know what I'm doing, will I be just an albatross round somebody's neck or will I be helpful? (14)*

*I hadn't been doing any ward nursing for a long time so that was stressful thinking am I going to know what to do because everything is computerised and done differently. (23)*

The transitions to and from redeployment were characterised by uncertainty and frustration. There was an overall lack of agency with participants feeling that they were not in the place where they were most needed and in many cases that they were ill-prepared for what was required of them. At the beginning of the pandemic, some found themselves working in an HIV service that had largely shut down and were frustrated by delays in being redeployed when wards were working under increasing pressure. A more common experience was of being redeployed too early, either because they arrived on wards where staffing levels were high and they had little to do whilst colleagues in the HIV service were working under intense pressure, or because they had received insufficient preparation and essential updating:

*We would be like hanging around ... and so it just felt like we were there on the ward as an extra pair of hands that weren't particularly needed, when our workload [in the HIV service] was building up and up and up and the people that were there doing it were just working flat out (1).*

*We were getting a lot from the hospital as well about how short staffed they were and things, and I thought actually, my job has changed already completely because I stopped doing home visits, so I felt like I was just waiting to go, so by the time the decision was made that I was going to go, I was just like "can we please just, like get it over with." (9)*

The end of redeployment was also characterised by difficulties and the competing concerns of services trying to restore some normality and simultaneously prepare for the inevitable next wave. There was a consensus of opinion that people were redeployed for too long. As pressure of the wards eased, redeployed staff were used to cover sickness and annual leave and there was considerable resistance to releasing redeployed staff. Those in management positions had to forcibly negotiate for staff to return to the HIV services:

*The challenge of it was getting the staff back... It wasn't a case of "you can go back now", you had to appeal for staff, so you had to go to the top leads of nursing and appeal for staff*



*to come back and one staff member got rejected 3 times and all she was doing was covering absences on the wards. (12)*

Those in redeployment had the *'frustration of wanting to get back to our work really, we knew there was stuff that needed doing and as things started to get back to normal, patients were starting to come out of the woodwork and come back into the clinic'* (23). There was a lack of certainty about when they would return and a lack of advance warning which caused substantial stress and anxiety:

*There wasn't really clear communication as to "well ok, we are going to keep you until this time, and then we'll let you go"..... then got a message on the Friday to say that I was going back to my normal job on the Monday... So I didn't really even get any closure from working on the ward ... and then the same thing happened [after a 2<sup>nd</sup> period of redeployment]. I think I got told Saturday that I was going to go back to work on the Monday. (9)*

*There wasn't any idea of any agency as to when I was going to go back to my normal job. So, it got to the point where actually there weren't many COVID cases ...I kept saying "when am I going back, I need a plan, when am I going back?" That was the point that I started to really struggle... there weren't any answers, I couldn't pace myself... there was just nothing, there was just silence... I ended up going off sick at the end of that 1st wave, because I just sort of snapped. (45)*

When the 2<sup>nd</sup> and 3<sup>rd</sup> waves arrived, the pressure on services rose rapidly again and staff were once more anticipating redeployment. Far fewer participants were redeployed, primarily those with recent clinical experience. By the second wave, those who had been scarred by their experience during the first wave were extremely anxious about and resistant to the possibility of redeployment which hung over them like a black cloud.

*There was still that anxiety going into work thinking, are you going to get redeployed again and for some people they were more anxious because they knew what it was like and people were just saying "I'm not going, I'm just not going again, if you're saying I've got to go, I just won't go." (13)*

Some services managed to ride the storm and retain their nurses, but others did not. Three participants reported that the nursing workforce in their service had been decimated during the 2<sup>nd</sup> wave because people could not contemplate the possibility that they would be redeployed and felt compelled to resign and find another job where that could not happen.

## Physical and emotional exhaustion

The increased work demands and pressures frequently required changes to working patterns and increased working hours which added to the emotional and physical burden. In the first wave, the physical demands were most pronounced in those who were redeployed. Working on the wards required them to work twelve-hour ward shift pattern to which they were unaccustomed, and in some cases to work much longer hours because of the ward demands. The physical nature of ward work was extremely challenging for participants. They were working in unfamiliar and high stress environments, and on an extremely steep learning curve which was mentally draining. In addition to these demands, some were working overtime, doing HIV work or shifts on the covid testing service. The whole experience was physically and mentally exhausting and took a substantial toll with some going off sick and others struggling to recover.

*I think a lot of us struggled, I had a lot of staff who struggled, and me as well ... I used to finish when I was doing my oncall for the site, I would leave work at midnight after being at work at 8 o'clock in the morning and so it has taken so much out of me. (16)*

*I think we're all exhausted, like when I finished on the ward after the first wave and came back, I had 2 weeks off and I came back to work and I was back a month and I thought I would love 3 months off, I was walking around like a zombie, I think I was mentally drained from it, and even now nearly a year later ....I feel like I'm running on empty now. (24)*

By the second wave, the feelings of enthusiasm and determination that had characterised the first wave had evaporated and had been replaced by an overwhelming feeling of physical and emotional exhaustion. As one participant explained; *'when the first wave came everyone was very gung-ho and we're all nurses, this is what we do ... second wave and then third wave really I think people's resilience was going so it felt like, not more of this'* (21). Whereas in the first wave the warm weather had had a beneficial on people's sense of wellbeing, in the second wave, the cold dark winter nights made things very much harder, adding to the emotional and physical exhaustion people were experiencing.

*I found it harder to get up and go to work, there was just an element of fatigue with it all. (52)*

*It was was very, very hard. A number of people I know fell off the tree a bit, it was very hard, it was long, it was dark, it was miserable. (53)*

*The second time ... I think people were just done in and tired of people at the top with all their pressure. So in a way mentally the first wave was easier, mentally the second wave was harder because I just think people were exhausted, emotionally people are exhausted. (56)*

## Help and support

Four sub themes contribute to this theme. *Daily routines* describes how practical aspects of working during the pandemic helped whilst the emotional aspects of support are explored in *Informal networks*. *Trust wide initiatives* considers the range of approaches used to support staff and the extent to which they were helpful. The final subtheme *supporting recovery* focuses on those measures introduced by the Trusts to support the workforce as they returned to base and services were resumed, and the degree to which they seemed to be helpful.

### Daily Routines

Participants valued the opportunity to continue working during the pandemic when large sectors of the national workforce were furloughed. Several commented on the highly beneficial effect it had had on their emotional wellbeing:

*I consider it a privilege that I was able to get up every day and go out to work and contribute in my small way to keep things ticking over – so I think that definitely helped with my mental health and I would have been much worse if I had had to stay at home. (10)*

The majority travelled to their place of work although a minority had to work from home, for personal or family health reasons. Those who did have to work from home found it intensely difficult. One described it as *'very isolating and insular'* (34) and another explained that *'I hated being at home and doing the work ..... I felt remote from the team and lonely actually'* (20).

Travelling to work enabled people to maintain boundaries between home and work and commuter journeys were less stressful and more enjoyable. Those who drove to work benefitted from the lack of traffic and substantially shorter travel times. Those who normally used public transport largely abandoned it, either through choice or necessity. Walking or cycling to and from work increased commuter times for some participants but the journey itself provided a valuable opportunity to *'process things and clear my head'* (35), helping them to achieve work-life separation so that *'by the time I get home, work is already parked in my head'* (16).

### Support networks

Informal support came from a variety of sources, primarily family, friends and colleagues. In many cases those support networks were themselves under pressure because the pandemic was affecting everyone. Many participants were in family units where family members were furloughed or home

working. Those with young children were commonly home schooling and several were also caring for elderly or vulnerable family members. Home lives were often '*stressful and took its toll*' (10) or '*choppy and disrupted*' (54) but they provided a place of sanctuary and support for the majority, reducing isolation and offering an important source of practical and emotional support.

*So bless them they were feeding me and my daughter was ordering all sorts of things for the bath. (14)*

Friendship groups, played a vital role for some, a respite from work and home, and a welcome outlet for ongoing frustrations:

*My friends were in contact quite regularly ... all I would have to do is say can I have a chat and we'd arrange a time and that was quite an avenue for me 'cos it was nice to talk to people who didn't really know what was happening and you could just curse the dog or curse my partner or curse work or whatever, but that was my avenue probably. (54)*

Many also spoke of the benefits of peer support. Most who were redeployed had benefitted from the support of those they were working with. One worked on a ward where they were '*very approachable and a really really lovely team to work with*' (13) and another in a team who were '*brilliant, really really helpful*' (23). The primary source of workplace support came from long term colleagues within the HIV team. They were regularly '*checking in with each other*' (14), particularly during periods of redeployment, and in most cases '*supported each other incredibly well*' (56), something which was recognised as playing a vital role in the recovery process:

*It was a tough time and I think it was just everybody trying to be understanding that everybody was coping with things very differently. A lot of people had things go on in their personal life, they might have lost family members and things like that, so a lot going on really. I think there was a lot of compassion at the time. I think people wanted to look after each other and wanted to understand that people had had these tough times and to help support them back into the job. (52)*

Trust level initiatives and support

Communications within the Trusts and the practical measures and initiatives that were introduced at trust level played a major role in supporting staff during the pandemic.

Regular senior management communications kept people up to date about the national picture and the local trust wide response. In some Trusts, '*communication from high up was awful ...we didn't know day to day what really was going on*' (56) but in others it was much better. One participant explained that their Trust had provided '*daily updates and a weekly update with the chief executive*

*by Zoom or Teams' (20) and others that they 'wrote us lots of emails and communication about the numbers [of covid cases]' (53) and 'there were often newsletters informing us of how things are going, how many patients we have, how many are ventilated, how do we see things going forward' (2). Some had benefitted from a clear expectation in their trust that staff took the time to listen and keep up to date with developments:*

*Our chief executive of the trust would do a chat, so we would all down tools and sit and listen to her .... we were told that we needed to stop and listen to what was going on in the trust, what were the numbers, what was the introduction of this ... when vaccines were introduced also how that was being rolled out and supported within the trust. So that was quite helpful, hearing her. (54)*

Practical support and initiatives took different forms and served a number of different purposes. For those who continued to work in the HIV services, easing of some work restrictions, budgets for couriering medications, providing local outreach services and rapid improvements in IT and remote communication teams were critical in enabling them to function.

*The trust were amazing, they really facilitated a lot of stuff ... the permissions and allowances they were giving to work slightly differently were really good. The budget that they just freed up for couriering medicines anywhere and everywhere, I mean it was just amazing, it was unspoken, it just happened. (35)*

*I think the trust did a fantastic job and managed to have some negotiations with local authorities ... [to] provide some local centres where people could walk into to access some services, and get samples sent into the local hospitals ... that was helpful. (16)*

*What was helpful was the amazing scale up of IT, I got a new mobile phone, a smart phone, I'd never had a smart phone at work before, a new laptop, we got video calls like this and the opportunity to speak to patients by video on the Attend Anywhere platform, the NHS's video consultation platform, and the take up for that was reasonably good. (20)*

For those working in the acute covid areas, a range of support facilities were provided. In one trust there was *'an emergency Gynae clinic, and stuff for people with kids' (46)* and in another there was *'a drop in place, where you could get cornflakes and towels and washing powder for people who were really struggling and couldn't get to the shops' (35)*. Several participants mentioned that their trust had created *'wellbeing spaces, spaces for staff to go to' (16)* although in some places, *'nobody went in it, because nobody had any blooming time to go in, you know, can you imagine, "I'm just going to go and chill out in there for 30 minutes", it just wasn't used'. (13)*

At the beginning of the pandemic, there was an enormous outpouring of community support for healthcare workers. Facilitated at trust level, this translated into food, gifts and other tokens of appreciation. These gestures were highly appreciated as a symbol of how much those working on the frontline were valued and appreciated by the community:

*People couldn't give enough stuff, particularly in Intensive Care. We were getting bags of like, it was minor stuff, but you know, nice hand cream and cakes. We were given so much food, we were given like 3 meals a day, ... from people who fundraised and got nice restaurants to give us food. It felt ok, I am doing this, but the acknowledgment of how big a thing it was that I was doing was there ... I felt that I did feel cared for, not necessarily by work itself, or the trust itself, but I felt very sort of cared for by my community. (45)*

However, these gestures generated more mixed emotions in some of those who remained in the HIV services because they served to reinforce the differences between and by implication the value of the two roles:

*All I heard was about these freebies and we had nothing, nothing. ... So if you were lucky enough to be on the ward when the freebies came, then you might have got something, but the rest of us, sat in the outpatients department, ploughing through all the lists and lists of people to phone and try and reassure. There was no b\*\*\*\* Kath Kitsen there. Nothing. So, it was just like, I dunno. It just felt rubbish. (01)*

*At that time there were a lot of food companies sending in lunches to feed the heroes - having a free lunch with a side of guilt, so I felt a bit guilty about my role [in the HIV service]. (10)*

Many of the participants had had opportunity to access specialist psychologist support. In some Trusts mental health nurses, psychiatrists and psychologists had visited the wards and offered drop-in sessions although the ability to access these were inevitably limited by ward pressures and shift patterns. Access to psychological support was actively promoted to staff 'with 10,000 emails coming in saying you could contact the well-being service' (54). Demand was high with 'Help services [that] were just inundated.' (18). The level of demand and the process of accessing the service could potentially serve as a deterrent to those that would have benefitted. As one explained, 'you had to self-refer and call these people and make an appointment and whatever. I had this idea that I'm holding on, I'm coping, there are other people who are not coping, you cannot just call the line just because, you must call if you have a reason, they will be busy' (2). Others had benefitted from easier

processes for self-referral to talking therapies and use of outside agencies to increase capacity which had helped to make the service more accessible and had been taken up by several respondents:

*We were always getting emails about well-being, so I did take up 2 of those offers, for like extra talking therapies. (46)*

*Got some support from the trust, so had some talking therapy ... that was helpful (45)*

### Supporting recovery

Those who had been deployed returned to the HIV service emotionally and physically exhausted. Some had been given one or two extra days off to help them recover although this was difficult in small teams where staffing levels were affected by sickness and by people having to isolate, and in areas where workload demands were high:

*When I came back, I think it was recognised that we needed time, we got an extra day off .... I was literally, the first day I just lay down all day and that's not like me at all, that's just pure exhaustion really, but emotional exhaustion rather than just physical exhaustion. (53)*

*It was difficult for people to have time off because other people were in isolation, all that impacted on getting people to have time off and have a rest .... Even though we tried .... it didn't work very well for us. (16)*

*A lot of stuff comes from the trust just generally, we're so grateful to you, take your holidays, be kind to yourself but the reality of it all is you still don't get your half an hour break because you've got people to see and things to do. (21).*

Emotional support to aid recovery came primarily from the teams they worked in. Some teams had remained strong and cohesive and *'there was a lot of talking about what people's experiences had been as we all came back together (14)*, providing *'unofficial supervision if you like in the office' (21)*. Other teams had fared less well and so that support was not available. One explained that in their team *'Staff morale was just so low' (56)* and another how the experience of redeployment had resulted in their team being *'ripped apart [so] people have had to deal with their own emotions and what they've seen and what they have had to deal with' (44)*. Working alone meant there was no opportunity to share the workload and no ready source of informal support as one participant who had recently acquired a colleague explained: *'I had a new nurse working with me so that was a lot easier ... also support from her and being able to debrief more with somebody was really nice, as a solo nurse it's quite difficult. (52)*

Debriefing opportunities had been provided in some services, but they had not been well timed:

*it's a bit too late cos actually everyone's leaving, it's too little too late to start this investment in staff well-being (56)*

*I think staff when they came back it was awful ... there were people who were very traumatised by what they had seen, felt that they had just been told that they were going to that ward with no experience, coming back and now in this role. The trust did a debrief for us ... about 3 months after we had come back ... by that time... some people had had breakdowns and we supported each other really, rather than having this formal powerpoint debrief, 3 months later. It was too little too late for the debrief. (13)*

One service had introduced ongoing access to support which was much more valuable. A participant from that service explained that *'we get clinical supervision now ... every 3 or 4 months we are having group psychology session, to be able to talk about if things have been difficult in the clinic and stuff, so it's not necessarily COVID related, but we are getting more psychology support in our everyday clinic work, which has been really good' (9)*. Another participant from the same service explained that they had started *'a weekly session where you talk about some of the challenges [because] PTSD doesn't always happen immediately so it's so important that we have some sustainability in those processes to check in with people and provide that psychological support consistently (16)*.

## Future directions

### Changing career

The experience of working through the covid pandemic caused many people to reconsider their employment options and career decisions, with almost half of the study participants describing decisions that they or their colleagues had made. For some, the experience had re-affirmed their decision to work in HIV. In some cases, that they *'still want to be an HIV nurse specialist despite everything' (21)*. The overall picture however suggested difficulties with recruitment and retention in many services across the countries. Some staff had decided to bring forward retirement decisions and others to re-locate to be closer to family. Some had altered their career path within the NHS and others had left the NHS entirely.

The experience of being re-deployed was a key factor in the process, with both positive and negative experiences serving as a trigger for major career decisions. Some people had had a largely positive re-deployment experience which had provided them with the opportunity to *'see another side of a career or a path they might go down that they hadn't thought of before' (10)*. The critical and high



intensity activity they had been involved in had resulted in some re-assessing the value of what they were doing in HIV. As one explained:

*What is the point of this job if I'm not saving people's lives or .... the high pressure interventions ... I definitely had quite a long crisis like, is this what I want to do? (45)*

This re-assessment had resulted in one person leaving the HIV service because she 'decided she wanted to go back [to ICU]' (24) and others were considering whether to do so:

*There is a lot that COVID has brought up about .... I do sometimes feel like I'm not stimulated as I should be at work, but now is not the time to be making decisions about that. (45)*

*People really don't put that much value into HIV care anymore, and that's quite depressing and it does make you start to question what you're doing, and it makes you start to question if you should be working in this field and maybe you should be looking to work in another area. (56)*

Several people had had an extremely negative experience of working through the pandemic and of being re-deployed which had triggered major career decisions. Two participants from one HIV service explained in detail what had happened in their service where the re-deployment process had been very badly managed and there was a total lack of managerial support throughout the pandemic. They and their nursing colleagues had all been traumatised by the experience and as a result had all resigned from the service and taken up jobs elsewhere, some within and some outside the NHS.

Others who needed to ensure they were never exposed to the possibility of re-deployment again, saw a career move out of nursing as the only option. One participant was questioning their decision to stay in nursing; because 'there is always a sense, that's hanging over you, will I have to go back [to the wards]' (23). Another explained how they and their colleague had both left the NHS because 'you'll never have to work in intensive care ever again, you will not be redeployed [if you are] working outside of the NHS' (47).

Changes to HIV services

Many of the HIV services had re-assessed their working practices in the wake of the acute crisis as participants explained:

*It's made us really look at a lot of things that we were just doing because it's historical to do and it's maybe in the guidelines to do but do we actually really need to be reviewing people so often. (25)*

*An opportunity to review how we work in the broadest way, and make some adjustments .... a real opportunity for allowing a much more flexible model of how we manage patients and a much more flexible way of how we manage our workforce. (35)*

Several described changes which had been introduced during the pandemic and were now embedded resulting in service improvements. One service had introduced an electronic prescribing system and another a home delivery service for medication. Others had made changes to reduce footfall through the clinic and waiting times by introducing processes that ‘*simply speed up the various waiting points along the patient journey*’ (10).

Several participants explained how their services had capitalised on the improved technology and their improved confidence in using that technology to fast-track changes that had already been planned, with an overall shift towards a greater proportion of remote consultations and an overall streamlining of care:

*We simply moved to implementing what the future vision was for the service, we’d have face to face annual review and a virtual review at 12 months. (12)*

*Because telephones had been successful it gave us the impetus to move to more virtual medias for some patients .... to minimise the number of times they were coming in. But it also pushed us to a one stop model, so we’d been thinking about doing it for a long time and we’d started to move about a quarter of the patients to one stops, but it pushed us to move about 80% of our patients to one stops. (52)*

However, some concerns were expressed about the practical considerations that could impact on the quality of clinical consultations with someone when they are at home:

*There’s a lot of people who don’t actually have their own privacy at home so when you phone them you get monosyllabic answers and they’re trying not to say anything and they’re not asking too many questions and it’s hard. It did feel that when you were phoning patients that you knew well it was a very easy consultation on the phone because they knew who you were and they trusted you, but when you’re starting with someone new it’s quite hard to get much information out of them, people were quite guarded I found. (21)*

Part of the general shift towards improved efficiencies was a greater use of the nursing workforce. In services where they were under-used they had stepped up to the mark and demonstrated their capability so that, as one suggested ‘*it will be difficult to backtrack on that now*’ (10). Long standing practices had been challenged such that Drs who had previously been seeing stable patients for every consultation were ‘*encouraged to let go, and get them to go to the nurses’ stable clinic or even*

*the virtual clinic where we use text and email' (16). A greater use of the nursing workforce had improved efficiencies because 'they [the patients] don't wait around in the waiting room' (18) and improved patient satisfaction. One participant explained that 'the patients say it's great, we don't have to wait for doctors running over, we just come and get our bloods done and get our meds and we're out in 10 minutes, it's fantastic, so they love it' (7).*

However, there were indications that some services were resisting change, not ready to embrace the move towards increased nurse delivered services:

*I thought part way through that it was going to cause management to look more significantly at who they had and how many doctors and senior doctors they had in the team, if they could easily leave everything to the nurses, but I'm not quite sure that that has happened. (34)*

*I feel for the first time that we're running a nurse-led service and we're getting to control what's happening ..... now the face to face is opening up ... because they're an overarching consultant in charge of the care they all seem to be panicking slightly.... so I think it'll be challenging times ahead because I think trying to convince them ... that do not need to see a consultant ... I feel we've done really well up to this point and we've got to keep this momentum going. (7)*

*I think people have got very short memories when it comes to this. A year ago it was all about the learning ... what have we learnt from Covid ... and I heard that one consultant had said about how fantastic community HIV nurses were and where would we be without them and six months on I think old habits are slipping back. (14)*

Additionally, whilst the move towards less frequent monitoring and reduced face to face consultations were largely considered improvements, there were some concerns about what these changes might mean for some patients in times of possible vulnerability:

*During COVID it appeared that patients didn't need 6 monthly appointments, so they didn't get them... I think people will be pushed out much further, I think people won't have their bloods done as often ... but I think what is going to happen is we are losing individualised care of patients who do need extra hand holding ..... so I think we will lose the ability to tailor make our care for the person, it will just be like, this is the way we can do it now. (44)*

## Discussion

The overall aim of the study was to establish how caring during the covid-19 pandemic had impacted on the professional quality of life of HIV nurses in the UK. In this discussion we will achieve that aim by initially bringing together the findings from both the survey and the qualitative interviews and exploring key aspects in relation to the wider body of relevant literature. Focussing on the future, the discussion will consider the long-term implications of the study findings for HIV services and their nursing workforce which will in turn inform a series of evidence-based recommendations.

The study participants were highly experienced. In the survey, 86 % (n= 85) of respondents had been qualified for more than ten years and just over half of them (53% n = 54) had worked in HIV services for more than ten years. This profile was reflected in the subsample who contributed to phase two of the study, with 23 of the 28 in senior roles including clinical nurse specialist, advanced nurse practitioner or service manager roles.

Two in five survey respondents reported a greatly increased workload in the first wave, which was still reported by 1 in 4 in subsequent waves. 1 in 8 reported an unchanged workload in the first wave period increasing to 1 in 4 in the subsequent waves. Just over 1 in 3 of survey respondents reported that they were redeployed in the first pandemic wave dropping to 1 in 6 in subsequent waves. Phase two interviews highlighted the limitations of the binary categories of redeployed/not redeployed and captured the full complexity of localised redeployment arrangements. Just over half (15/28) of the interview participants had experience of being redeployed which happened primarily during the first wave and lasted variable lengths of time, from a few weeks to several months. Whilst some were fully redeployed, a larger proportion combined it with their HIV role.

### *The impact of working through the pandemic*

The mean ProQOL scores were 37.6, 26.2 and 22.6 for the three domains of compassion satisfaction, burnout, and secondary traumatic stress (STS) respectively. The proportions recording moderate and high levels of compassion satisfaction were 73.7% (n=73) and 26.3% (n=26) respectively. In terms of compassion fatigue, just over two-thirds (67.7%, n=67) of respondents recorded moderate levels of burnout with the remaining scores being in the low category. Just over half (51.5%, n=51) recorded moderate levels of STS and one person recorded a high level of STS. Levels of burnout were significantly greater in those who were redeployed during both waves of the pandemic.

These survey findings contribute to a growing body of international evidence indicating the heavy toll that the covid pandemic has had on psychological wellbeing on the healthcare workforce whatever role they were in. Surveys conducted in Iran, Spain and Italy at various points during the pandemic and involving both frontline healthcare workers and those working in other services have all reported high proportions of staff with moderate or high levels of compassion fatigue (Azizkhani, Heydari et al. 2021). In the UK, researchers used social media to survey the national nursing and midwifery workforce at three timepoints (T1-3) from April to August to assess the impact of COVID-19 on their wellbeing during the first pandemic wave (Couper, Murrells et al. 2022). The workplace profile of survey respondents was broadly comparable at the three timepoints with approximately one quarter working in acute services, one quarter in primary and community services and one-sixth in critical care services. Their survey used the events-revised scale to identify potential factors associated with signs of post-traumatic stress disorder and reported scores of  $\geq 33$  (probable PTSD diagnosis) in 44.6%, 37.1%, and 29.3% of participants at T1, T2, and T3 respectively.

In phase two of our study, the first two themes of 'working through during the pandemic' and 'emotional and physical demands' detailed the unprecedented challenges that confronted HIV nurses and the demands placed on them as they worked through the pandemic, collectively responding to the two-fold challenges of maintaining an HIV service and contributing to the covid-19 effort. The ever-present threat of infection permeated everything. It shaped and determined every behaviour and interaction and was a major source of anxiety. Everyone was navigating uncharted territory and managing the uncertainties of the situations they frequently found themselves in. Whilst some did adjust to working elsewhere, redeployment experiences were largely negative for many and in some cases, they were highly traumatic. Other studies have reported similar findings with the redeployed workforce experiencing stress and anxiety associated with higher exposure risk and expanded responsibilities, a lack of preparedness, clinical skills misaligned to the clinical setting, the need for essential training and for ongoing psychosocial support (Tang, Charmaine Jinxiu, Lin et al. 2021, Spiers, Buszewicz et al. 2021, Lion, McClenaghan et al. 2021, Veerapen, Mckeown 2021).

Our findings established that nurses were primarily responsible for maintaining the essential aspects of an HIV service during the pandemic and detailed the challenges of doing so in the strange reality of social isolation and remote communication. Those challenges were also explored in relation to mental healthcare workers working to maintain an essential community provision and generated broadly comparable findings indicating that the quality of those professionals' working life was impaired by increasing levels of daily challenge associated with trying to provide care in trying and constrained circumstances, the problems of forging new ways of working remotely, and constraints on the ability to access informal support (Liberati, Richards et al. 2021).

Those who remained reported a substantial shift in the balance of care which carried a heavy emotional toll. Routine monitoring and care were temporarily suspended and large amounts of the nurses' time and energies were taken up with responding to calls from worried and anxious patients, and supporting those with deteriorating mental health. One study quantified the increase in mental health problems in a survey undertaken to examine the impact of Covid-19 restrictions on the wellbeing and access to care among people living with HIV (PLWH) (Pantelic, Martin et al. 2021). The survey took place in May - June 2020, two months into the first national lockdown and was circulated to people with HIV who attended care at three HIV services in Sussex. A little over three quarters of the respondents (77.6%, n = 501) reported feeling more anxious, 71.8% (n = 464) reported feeling more depressed than usual; and nearly one in five (19.8%, n = 128) reported having suicidal thoughts since the start of the pandemic. Respondents worried about running out of HIV medicine (n = 264, 40.7%); accessing HIV services (n = 246, 38.0%) as well as other health services (n = 408, 63.0%). Questions arise as to whether the findings of the Pantelic survey reflect a temporary response that resolved over the subsequent months or whether the covid pandemic has had a long-term impact on the mental health of a population who are recognised as having increased mental health needs (Tang, Chulei, Goldsamt et al. 2020, Ayano, Duko et al. 2020, Chaponda, Aldhouse et al. 2018).

#### *Supporting recovery*

Our findings demonstrated the substantial psychological impact on the physical and emotional wellbeing of all HIV nurses of working during the covid pandemic. The levels of compassion fatigue we identified has potentially adverse implications for individual wellbeing and for the HIV services. A substantial body of research evidences the physical, psychological and occupational consequences of job burnout (Salvagioni, Melanda et al. 2017) and secondary traumatic stress is similarly considered to have long-term implications. That impact may have been ameliorated to some degree by the high levels of compassion satisfaction that we found. Compassion satisfaction is considered to serve a protective function (Cocker, Joss 2016) and regression analysis of our survey findings demonstrated that the levels of compassion satisfaction were associated with a reduction in burnout scores supporting the idea that compassion satisfaction has a moderating or protective effect.

Informal peer support was commonly identified as the most important source of support with access to more formalised psychological support limited by accessibility issues. Several other studies involving healthcare professionals during the covid pandemic have reported similar findings (Ménard, Soucie et al. 2022, San Juan, Aceituno et al. 2021, Billings, Abou Seif et al. 2021, Billings, Greene et al. 2020) and there is evidence to suggest that when a worker has the informal support of

their peers following traumatic exposure, they are less likely to need formal intervention (Billings, Greene et al. 2020).

Notwithstanding the contribution of these protective factors and supportive measures, it is essential that HIV nurses are able to access the support they require to recover from the impact of the pandemic and to ensure that this support is available on a long-term basis given the emotional demands of the role. Whilst it was encouraging to note that this was happening in one of the larger services represented in our study, and others may have well established already have structures in place, several of the participants in our study were either the sole HIV nurse in their service or one member of a small team. As well as not having access to the support of colleagues that others had found so helpful, questions arise as to whether they will have the support they require going forward.

The recovery plans for the NHS in England, Wales and Scotland all include a commitment to staff recovery and staff wellbeing. In Scotland a new Workforce Specialist Service has been launched to provide tailored, confidential mental health support to regulated staff across the NHS and social care workforces. In England, the NHS RESET document released in March 2021 laid out a vision for shaping what the health and care system should look like in the aftermath of the pandemic and highlighted the importance of supporting and nurturing the healthcare workforce with a people-focused approach and continued national investment to enable NHS organisations and integrated care systems to supplement their local support to staff (NHS Reset 2021). The national roll-out of the Professional Nurse Advocate (PNA) training programme that will enable nurses to have access to restorative clinical supervision is a core component of the staff support package. The PNA scheme is a new professional clinical leadership and advocacy role introduced to deploy the A-EQUIP model which uses a restorative approach to clinical supervision. Restorative supervision which promotes reflection of personal emotions and practice and has a positive impact on emotional wellbeing has been demonstrated to be effective in producing improvements in the mental health and wellbeing of staff with reductions in burnout and stress (Wallbank, Woods 2012). HIV nurses may wish to train as PNA's if such opportunities are available to them and others may benefit from restorative supervision provided through PNA's offering this within their organisation.

#### *Moving forward in HIV services*

The nurses played a key role in keeping essential services the service running. They expanded their scope of clinical practice, making better use of their clinical decision-making skills and demonstrated their ability to have a greater role in managing routine care. Capitalising on the investment in IT facilities and the skills and confidence that HIV nurses acquired in remote care management will enable HIV services to deliver on the 2019 long term plan for the NHS (Alderwick, Dixon 2019) which

called for a redesign of outpatient services and a substantial reduction in the number of face-to-face appointments. Our findings suggest a mixed picture with some participants reporting a substantial shift in their service towards greater remote care management and a greater role for the nurses as part of those developments. Others indicated some resistance to change and pressure to return to previous working practice within which nursing roles were under-developed. Where this was happening, it was clearly a source of frustration. If realised it can be expected to have a negative effect on job satisfaction and is likely to result in staff resignations, further contributing to the HIV nursing workforce crisis which was highlighted several years ago (Piercy, Hilary, Bell et al. 2018) and has been further exacerbated by the pandemic as the findings of this study demonstrate. Previous research demonstrating the contribution of HIV (Piercy, Hilary 2021, Piercy, H., Bell et al. 2016) will be helpful for those nurses needing to resist that pressure but there is a clear need for all HIV nurses to generate outcomes-based evidence in their own service and to have access to that generated elsewhere. Local and national networks have a key role in facilitating information sharing whilst the work which has recently begun to articulate an HIV nursing model provides opportunity to collect and collate evidence generated at local level to build a substantial and robust body of evidence.

Remote consultations offer substantial time and cost savings for patients, particularly those in rural locations who have to spend an entire day travelling to attend a clinic appointment that might only last ten minutes. The resistance participants had encountered when clinics re-opened, and patients were expected to attend suggests that many of them would welcome moves to greater remote care management. However, as the findings indicate, there are a number of factors, including lack of privacy and lack of access to adequate technologies which may adversely impact the quality of those consultations, highlighting the importance of service-level monitoring and evaluation to establish the acceptability and effectiveness of remote management and sharing of good practice between services.

## Strengths and Limitations

The mixed methods approach, and the scale and scope of the project, particularly the sample size for phase two which enabled us to interview participants from highly diverse contexts and situations which contributed to the richness of the data are strengths. The wide range of services represented in phase two increases confidence in the applicability of findings to those HIV services which were not represented. However it is important to acknowledge that the study populations were skewed towards those in the senior roles because grades 5 and 6 were less well represented in the survey and few of those agreed to be interviewed which limits the generalisability of the findings to the entire HIV workforce. We also failed to interview anyone from Wales in phase two. One of the



interviewers knew several study participants in a professional capacity. That familiarity may have influenced the interview although we used a topic guide and agreed ground rules at the start of the interview which will have helped to mitigate that effect.

## Conclusion

HIV nurses had a key role to play during the covid-19 pandemic which involved both contributing to the redeployed workforce and maintaining essential HIV services. The substantial challenges associated with working through the pandemic and the emotional and physical demands of both being redeployed and maintaining the HIV service were reflected in the PROQOL scores. Ensuring all HIV nurses have access to workplace support and supervision will be important for emotional recovery and ongoing mental wellbeing. The temporary ways of working introduced during the pandemic has created conditions for long term service improvements within which nurses should have a major role.

## Recommendations

- The national initiatives identified in our report that are intended to support recovery have the potential to benefit many healthcare professionals. Individual HIV nurses will benefit from taking a proactive approach to identify the recovery support initiatives operating within their organisation and negotiate access to those most applicable to them.
- The landscape of HIV care has changed in the wake of the covid pandemic. Our report identified several important areas of enquiry related to that changed landscape that are highly relevant to HIV nursing. Overarching questions concern the long-term impact of covid on people with HIV, the shift towards greater remote delivery of routine care, and health outcomes of nurse delivered HIV care. A nurse research collaboration would provide a powerful vehicle through which to take forward this research agenda, enabling a substantial body of high-quality evidence to be generated which would be highly applicable to a wide range of settings and contexts. NHIVNA are well placed to play a key role in establishing and supporting such a collaboration.

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