



THE UNIVERSITY *of* EDINBURGH

“Everybody's different, everybody's got different needs”

Transition to adult healthcare services and the role of social support—the views of young adults living with HIV in Scotland.

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Abstract

This report explores the views and experiences of young adults living with perinatally acquired human immunodeficiency virus (YAPHIV) in relation to healthcare transitions in Scotland. With the benefits accompanying gains in antiretroviral therapy, new challenges have arisen. Individuals with perinatally acquired human immunodeficiency virus (HIV) are now living into adulthood, posing considerations not originally contemplated early in the epidemic. The transfer to adult healthcare has been linked with unsatisfactory outcomes in other chronic illnesses and HIV involves additional complexities. Without tailored healthcare transitions for YAPHIV, there is a threat to virologic suppression, limits to resistance to therapy and reduced onward sexual/vertical transmission. Individual semi-structured interviews were conducted with eight YAPHIV (median age = 19.5 years) and two healthcare practitioners. Regarding YAPHIV in isolation from their broader lives and the wider, still pervasive, discourse of stigma yields little benefit. Whilst it is difficult to establish concrete transition practice considering the heterogeneity of YAPHIV, it is argued that, fostering an understanding of one's illness and the responsibility that accompanies adult healthcare is beneficial. Though healthcare settings should ensure a non-judgemental, comfortable environment for YAPHIV care; it is suggested that the voluntary sector is not yet being fully utilised to ease transitions.

Acronyms

AIDS: Acquired Immunodeficiency Syndrome

BAME: Black, Asian and Minority Ethnic

HIV: Human Immunodeficiency Virus

YAPHIV: Young adults living with perinatally acquired HIV

CHIVA: Children's HIV Association

SPAIIIN: Scottish Paediatric and Adolescent Infection and Immunology Network

SES: Socio Economic Status

CHIPS: Collaborative HIV Paediatric Study

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1. Introduction

This report explores the lived experiences of young adults living with perinatally acquired human immunodeficiency virus (YAPHIV) and how their views and experiences can inform transitional practice from paediatric to adult healthcare. This study was undertaken as an eight week work-based placement with the voluntary sector organisation Waverley Care, who were seeking to provide social support to YAPHIV experiencing healthcare transitions in a more robust manner; going from a reactive to a proactive model of assistance (L Williamson, 2015, Pers. Comm., 14th July).

1.1 Background

The nature of human immunodeficiency virus (HIV) in Scotland is dynamic. Though many gains have accrued in terms of morbidity and mortality since the development and widespread use of highly active antiretroviral therapy in 1996 (Bartlett, 2006), the number of people living with HIV has increased. This can be attributed to new infections, enhanced testing and 'imported' infections from inward migration (Corson et al., 2015:A45). This study focuses on YAPHIV; a cohort who were not expected to survive into adulthood, but are now defying such expectations thanks to advances in antiretroviral therapy (Vijayan et al., 2009:1226).

The Scottish Paediatric and Adolescent Infection and Immunology Network (SPAIIIN) propose that there are 19 YAPHIV in Scotland, born between 1991 and 1999, who have gone through paediatric services (A Murray, 2014, Pers. Comm., 24th July). However, this may not comprehensively include all those who have transferred to adult healthcare. Additionally, though not the focus here, this statistic omits those not perinatally infected. Individuals recently infected or diagnosed may have gone directly into adult services. Figures also differ depending on how the question is posed and what data collection methods are utilised. Nonetheless, such small numbers could lead one to underestimate the associated issues. However, small numbers are not synonymous to small problems (Cree and Sidhva, 2009:27). Furthermore, healthcare transitions will continue to be important as the

Collaborative HIV Paediatric Study (CHIPS) reported that 1873 children living with HIV were made known to them by March 2014, in the UK. Eventually these children will have to progress to adult healthcare. Over half of these children were born abroad and a majority were perinatally infected. Of the 1037 individuals who engaged in follow up with CHIPS, 79% were from a Black¹ African background (CHIPS, 2014). This indicates that cultural understanding and appropriateness must be pertinent to the support provided and is a continuous theme in the current study. CHIPS (2014) indicate that 4% of the overall cohort have their healthcare needs met in Scotland.

The transfer from paediatric to adult services has been affiliated with adverse health outcomes in other chronic illnesses. Repercussions have included poorer clinical attendance and reduced medical adherence in asthma and diabetes patients (see Andiman, 2011; Sheehan, While and Coyne, 2015). Additionally, it has been illustrated that a patient's cultural background is significant to healthcare for childhood cancer survivors (see Casillas et al., 2010). Moreover, individuals with cystic fibrosis have faced hardship regarding attachment to the paediatric setting when transitioning to adult healthcare (Tiemey et al., 2012:744). All of these factors are also likely to be important to YAPHIV transitioning in healthcare, however, they have additional characteristics to contend with such as stigma, secrecy, disclosure and risk of transmission (Bundock et al., 2011:465). Without a planned process that meets the unique needs of YAPHIV that sustains their engagement in healthcare services and facilitates their independence in responsibility of care, there is a threat to gains achieved including: virologic suppression, limits to resistance to therapy and reduced onward sexual or vertical transmission (Bundock et al., 2011:466).

¹ Here 'Black' and subsequently 'White' is consciously capitalised to refer to 'race'/ethnicity as demonstrated by the Office for National Statistics (2015).

1.2 Aims and structure

This study will comprehensively explore the views and experiences of YAPHIV with the following interrelated research questions:

1. What are the experiences and views of YAPHIV in Scotland with respect to the transition process from child-centred to adult healthcare services?
2. How does accessing or linking into projects at Waverley Care affect YAPHIV today?
3. How can this cohort be better supported going forward?

General healthcare transition guidelines will be outlined in this introduction. A discussion follows regarding how the categories of childhood and adulthood are demarcated, as such classifications ultimately fuel where a person is seen for their healthcare needs and can inform transition practice. Chapter two presents the methodology specifying the research methods employed and the limitations to the study. Subsequently, three findings chapters are presented thematically: chapter three reflects upon the experiences and views of YAPHIV and repercussions for transition practice, chapter four focuses specifically on transitional services, whilst chapter five considers how a smoother transition process might be enacted and some associated challenges. A review of existing literature is important to place the current study within wider context (Blaikie, 2010:17). Rather than producing this separately, applicable literature is intertwined within the findings with critical analysis and discussion. When considering YAPHIV, there are many different yet interrelated facets to address and this structure was deemed best to unpack such complex situations. A concluding chapter then distinctly establishes the implications of the study.

1.3 Healthcare guidelines

The most apt definition of transition refers to:

“the purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems”
(Department of Health, 2006:14).

Though healthcare guidelines observe that there are no fixed templates to transition, some common principles are highlighted. Scottish healthcare institutions largely look to the Children’s HIV Association (CHIVA) and SPAIN for guidance on protocol. The following will examine what is typically advocated.

1.3.1 Timing

National Health Service (NHS) Scotland recently adjusted the upper limit for paediatric services from 13 to 16 years, allowing for flexibility up to 18 years (The Scottish Government, 2009:18). However, chronological age boundaries are less easily delineated when considering YAPHIV. For example, perinatally acquired HIV can affect neurodevelopment, potentially influencing illness management ability. Additionally, secrecy often seen within families can delay an understanding of one’s illness (Melvin et al., 2014:9). Thus, guidance advocates for transition to occur in a flexible, patient driven manner (SPAIN, 2014:6). Nonetheless, it has been illustrated that a guide age can be useful in allowing staff and patients to anticipate and prepare for changes (Viner, 1999:271). Most policy recommends that healthcare transitions occur simultaneously with the transition from primary to secondary school and that practice should address the wider context of individuals’ lives (Foster, 2010:6-10). SPAIN (2014:6) guidelines divide transition into stages; early (12-14 years), mid (14-16 years) and late (16+ years) and suggest that in late transition the patient should be introduced to the adult healthcare team within the paediatric setting.

1.3.2 Preparation

Ultimately transition should occur when an individual is developmentally ready, which can be assisted through appropriate preparation. CHIVA (2013:17) suggests that the professional support team should meet regularly to plan and review the development of individuals under their purview. Furthermore, preparation should actively engage patients, empowering them to lead their transition and consequently their illness management (SPAIIIN, 2014:6). This can be facilitated with a written plan developed with the young person which includes a review of their HIV history and likely timings of milestones in transition (Foster, 2010:7). Such plans should foster the ability to negotiate health systems, whilst remaining flexible and open to development even post-transfer (Department of Health, 2008:11). Additionally, once a patient is able to name their illness, discussion should promote an understanding of HIV and sexual health (CHIVA, 2013:24). Although understanding (and thus transition timings) can be obstructed by family secrecy or social isolation as aforementioned (Melvin et al., 2014:9), sensitive efforts to engage young people should be maintained (Howell and Hamblin, 2011:16).

1.3.3 Coordination

CHIVA (2013:28) puts forth that paediatric HIV services should actively collaborate with adult services to ensure a competent service for young people is in place. This can be initiated by engaging in joint consultations with the paediatric and adult doctors. As the patient becomes more comfortable, consultations can be entrusted to the adult team (Foster, 2010:8). Moreover, independence should be fostered by encouraging young people to slowly increase their consultation time without being accompanied by parents or carers. This may also facilitate conversation regarding relationships, sexual health and contraception (Foster, 2010:8). Coordination is likewise necessary between statutory and voluntary agencies (Howell and Hamblin, 2011:9). CHIVA (2013:37) advocates that close links between these sectors can help encourage discussion about difficult topics including naming or understanding HIV; facilitating successful transition. Furthermore, the voluntary sector can direct young people

towards peer support, promoting self-esteem and offsetting social alienation from which many living with HIV suffer (CHIVA, 2013:38).

Whilst general policies have been highlighted, practice varies around Scotland. Differences can accrue due to gaps between the availability of services between children's and adult healthcare and the nature of relationships between local authorities and NHS boards. Additionally, staffing pressure and information patients, parents and carers are party to can affect practice. Viner (2008:162) suggests that healthcare teams that meet the specific needs of young people are generally found to be exceptions to the norm in healthcare transitions.

1.4 Questioning the boundaries of childhood and adulthood

As aforementioned, policy tends to promote healthcare transitions in HIV services to occur simultaneously with progressions in schooling. Cree (2010:48) suggests that regulations regarding the minimum school leaving age serve as a marker of contemporary expectations concerning the distinction between childhood and adulthood. Despite this, recent analysis conveys that age is not best comprehended as a biological actuality; but an interplay of social, historical and cultural facets including relations of power (Cree, 2010:67).

1.4.1 From childhood to adulthood

The time bounded by what is commonly depicted as childhood and adulthood is typically referred to as 'youth'. The term employs an "intermediate social and cultural category" (Hall and Montgomery, 2000:13), consequently young people in the West lack the power associated with adult recognition whilst also leaving behind the innocence and protection that accompanies childhood. Bhat (2013:201) illustrates that much of this rhetoric stems from assertions derived from psychological and sociological discourse regarding youth as a progression through set stages, moving from one stable state; childhood, to another; adulthood (see Erikson, 1968). Whilst it is generally accepted that this time is characterised by negotiations of change in terms of physical capacities, intellectual abilities, emotional

and sexual development (Sharland, 2006:252; Cree, 2010:68); contemporary analysis contests sequential stages of development.

Traditionally, the path to adulthood was seemingly achieved through structurally defined, linear progressions including leaving the familial home, finding employment and getting married (Rogers, 2011:414). It is now recognised that these milestones are achieved with variability and do not necessarily ensure adult status (Barry, 2010:213). For example, Basit (2012:415) suggests that many Black, Asian and Minority Ethnic (BAME) young people develop coping mechanisms in light of experiencing discrimination. Resultantly they may refrain from moving out of parental homes as early as their majority counterparts. Alternative explanations include cultural norms regarding living with extended family or waiting until marriage to move out. Furthermore, young BAME individuals are generally able to negotiate between their ethnic, religious and national elements of identity (Basit, 2012:420). Thus, seemingly distinct identities mutually influence each other. It has also been shown that socioeconomic status (SES) has a positive correlation with educational and occupational expectation and outcomes in adulthood (Mello, 2009:502). BAME status and SES are interrelated variables, consequently, it can be difficult to ascertain which has the predominant effect in different circumstances (Haan et al., 2015:3). However, it is apparent that young people are able to ameliorate different aspects of their identity showing that the route to adulthood is highly individualised and dynamic.

Seemingly, traditional markers of adulthood are not necessarily congruent with adulthood per se. Andrew et al. (2004) found that emotional and psychological development was deemed more important to young people in achieving adult status than such life markers. Furthermore, though chronological age could trigger adult behaviour it did not necessarily define it (2004:23-24). Young people in their study associated adult status with responsibility that one actively seeks. A stable identity and self-reliance was also highlighted, though residential independence was not necessarily imperative (Andrew et al., 2004:11).

1.4.2 Legislation and terminology

Legislation in the United Kingdom (UK) presents disparate ideas of when adulthood commences. For instance, throughout the UK, at 16 years an individual can give consent to sexual intercourse (Family Planning Association, 2015). This same age delineates when an individual can get married without parental consent in Scotland, however in the rest of the UK this is not granted until 18 years (Citizens Advice, 2015). This illustrates the confusion in gaining consensus on the point at which adulthood begins.

Chapters 1.3 and 1.4 employ the terms 'youth' and 'young people' interchangeably. 'Youth' often refers to a broad range of ages, whilst 'young people' may cultivate an image of early teenage years. Sharland (2006:249) conveys that it is helpful to distinguish between the extremes of the spectrum. Consequently, hereinafter the term 'young adults' will be employed to describe the individuals informing this study who are aged 16-22. However, it is acknowledged that different authors delineate the upper and lower boundary of this category differently and that such boundaries are not necessarily best defined by chronological age.

2. Methodology

This chapter presents the methodological framework employed to answer the research questions posed in chapter one. It also provides reasoning behind the sampling, data collection and analysis processes chosen whilst highlighting ethical considerations of the study and possible limitations.

2.1 Data collection and analysis

Initially, an extensive literature review was completed to determine what was already known regarding YAPHIV and healthcare transitions. Using the University of Edinburgh's wide-ranging database, empirical findings were sought using the key words 'HIV' and various terms for what this study deems 'young adults'. This included 'youth', 'adolescents', 'young people' and 'children' allowing for the different conceptualisations of the category, with and without the term 'transition'. Literature that used samples with a similar age range to the current study were most apt. A web search to access 'grey' literature was also utilised to avoid bias (Hopewell et al., 2007:6). Findings published in the last ten years were exclusively considered due to the rapidly changing, dynamic nature of HIV (see Bartlett, 2006). Consequently, studies published before this may bear little resemblance to the present situation. Additionally, this review was restricted to the Global North as cases from the 'developing' world were deemed incomparable due to the discrepancies in routine access to healthcare (Cree and Sidhva, 2009:5).

Primary findings in this study ensue from qualitative, semi-structured interviews conducted with a sample of eight YAPHIV and two healthcare practitioners. Qualitative methods allow for a comprehensive understanding of complex realities, necessary in investigating multi-faceted experiences (Blerk, 2006:116). Semi-structured interviews permit informants to lead the conversation; whilst also ensuring reliable, comparable data as a general guide (see appendices 8.5), is followed (Bernard, 2006:210). Furthermore, this method is recognised as best when only one meeting with the informant is possible—a constraint that had to be addressed in the current study (Bernard, 2006:212).

However, in practice the discussions were not rigidly structured and were open enough to allow informants opportunities to move away from the schedule (Willis, 2006:145).

A purposive sampling technique was employed in which I actively sought out the most productive sample, through Waverley Care, to answer the research questions (Marshall, 1996:523). It has been acknowledged that this non-probability sampling technique is most effective when studying a domain where particular persons can provide invaluable information that cannot be acquired elsewhere (Maxwell, 1997:87). Thus, when considering YAPHIV, such individuals are crucial to the study. Furthermore, the inclusion of two practitioners, though not representative of all professionals in the field, enriched the dataset by providing insight from individuals who work closely with YAPHIV.

Data was analysed in this study thematically. Whilst general themes were derived from wider literature in order to inform the interview guides, scope was allowed for the discovery of emergent themes. Hence, the process was in-between inductive and deductive reasoning (Bernard, 2006:464). All interviews were transcribed by myself, facilitating a deep familiarisation with the data. Categorical codes were first attributed to the data that both corresponded to themes from wider literature and expanded upon them (Aronson, 1994:2). On further examination of transcripts, more specific sub-themes were deduced. Because thematic analyses rely on the judgement of the researcher and are often utilised for descriptive studies, their reliability can be questioned. However, Guest, MacQueen and Namey (2012:84) suggest that reliability is of less importance than validity in qualitative studies. Steps in this study were taken to ensure validity, including transcribing informants' accounts verbatim in a consistent manner. Themes and interpretations of the data have also been supported by verbatim quotes (Guest, MacQueen and Namey, 2012:85). Moreover, the appendices provided ensure transparency of data collection methods.

2.2 YAPHIV and BAME people: Statistical profile

It has been evidenced that “vulnerable” populations such as BAME groups, men who have sex with men and migrants are relatively overrepresented in terms of those living with HIV in the UK (Madden et al., 2011:542). For example, in 2012 Black communities made up just 3.4% of Britain’s population (Pears, 2012), but Black African people comprised of 34% of all HIV diagnoses in the UK (AVERT, 2014). Furthermore, stigma, referring to the exclusion of an individual from full social acceptance due to the possession of an attribute that is deemed discrediting (Goffman, 1990:9-11), can actualise distinctly amongst different groups. Thus, social identities have a significant bearing on experiences of YAPHIV.

The YAPHIV contributing to this study through individual interviews, were between the ages of 16-22. Every YAPHIV, with one exception who is of mixed White and Asian parentage, was born outside of the UK and self-identifies as African or Black African. However, the majority have lived in Scotland for most of their lives. A common characteristic of YAPHIV interviewed include a complex family background, as others have described (see Decle, 2011), such as losing parents and gaining step-parents and half-siblings. An equal amount of YAPHIV in the current study live with at least one parent or in an independent living situation including rented accommodation, residential child care and supported accommodation. Most are in education whilst working part-time jobs and one had completed university and is now employed full-time. The two professional healthcare practitioners interviewed were both from a paediatric background. A description of each young adult’s age, ethnic identity and gender (as self-ascribed) are shown in appendix 8.1; pseudonyms have been employed to protect the anonymity and confidentiality of informants (Ogden, 2008:695).

2.3 Ethical considerations

“Everything is a sensitive topic when you dig deep enough” (Bernard, 2006:186)

Though the above quote is certainly undeniable, it is especially relevant when considering this study. This piece of research centres on the experiences of living with a highly stigmatised condition, often enshrouded in secrecy within families (Cree, Kay and Tisdall, 2002:47). Moreover, the YAPHIV informing the study could be considered vulnerable in reference to both their positive status and their age. Thus, the University of Edinburgh’s ethical research requirements were incorporated into all aspects of this “sensitive” study (Lee, 1993:4).

Prior to the interview date, all informants were contacted via telephone by a Waverley Care staff member who the YAPHIV have pre-existing relationships with. They were also taken through a letter of invitation addressed to them and an information sheet instructing them on the nature of the project, the research objectives and logistical details prior to each interview before formal written consent was received (see appendices 8.2-8.4). At the end of all interviews a support sheet was distributed (see appendix 8.7) and there was an opportunity to talk with a Waverley Care staff member. All interviews with YAPHIV took place at the Waverley Care offices in Edinburgh or Glasgow; a place of familiarity and comfort. Interviews with practitioners occurred at their places of work for their convenience.

Though informed consent was sought and received from all individuals participating, Cree, Kay and Tisdall (2002:51) note that sponsorship, as seen here through Waverley Care, can make it difficult to truly ascertain whether young people have freely decided to participate. Consequently, consent was always open for review, even during interviews. Moreover, at the outset of each interview it was made clear that I had no affiliation with Waverley Care and no information prior to the interview had been divulged. This allowed YAPHIV the chance to narrate their own life stories. It was felt that this distinction was understood successfully. Informants were also regularly reminded that we could break or switch the recorder off, which many utilised. All interviews lasted between 30 and 90 minutes, with

practitioner interviews clustering at the shorter end of the spectrum. Interviews were recorded and then transcribed alongside the interview process enabling modification of the interview guide accordingly, thus, data collection and analysis was connected and fluid (Bernard, 2006:501).

The use of a semi-structured interview format allowed a comfortable rapport to develop between the informant and myself when discussing personal and sensitive matters. I wanted my informants to feel at ease and confident that I would be non-judgemental. Responses as below suggest I was successful in gaining such trust:

“I think it kinda felt good talking about it... I’ve never ever talked about it with anyone... You’re the first” (Travis)

This also supports Walls et al. (2010:30) assertion that informants can find qualitative interviews therapeutic or cathartic. It could be argued that my position as a young adult aided this. Additionally, many YAPHIV projected their own age onto me, perhaps facilitating an atmosphere of balanced power. Furthermore, all of the YAPHIV interviewed identified as BAME. As an individual of this status myself, it is possible this may have helped informants feel at ease. Hodkinson (2006:146) suggests that researchers who hold a position of initial proximity to informants may experience benefits of access and rapport as shown above. At the end of each interview informants were asked to fill in a socio-demographic questionnaire, (see appendix 8.6), which sometimes caused confusion. In answering informants’ questions I answered honestly whilst emphasising there was no ‘correct’ answer and that their answer should reflect how they felt.

2.4 Limitations

As with any study there are certain limitations that must be considered. One such limitation included an inability to engage with YAPHIV who were not already accessing social support. Arguably these individuals would be of utmost interest as they lack the desire or ability for various reasons to come to support services and this would be useful to explore. However, it is logical that if they are not

already pursuing avenues of support, they are unlikely to wish to inform them, as evidenced in the lack of their involvement in this study. Feasibly, those that are accessing social support are likely to be dealing with the tribulations that come with living with HIV better than those who are not and this must be noted in the current study. It was also difficult to engage more practitioners in the study, though many were approached. This is perhaps indicative of the barriers in collaboration between the healthcare and voluntary sector as contact was initially made through Waverley Care. This may include structural barriers of, for example, different regulations and also distinct professional cultures (see Axelsson and Axelsson, 2006). However, it must be acknowledged that this study had a very short timeframe and schedules simply may not have coincided. Moreover, because only two locations—Glasgow and Edinburgh—were studied, there may be problems of generalisability. Especially considering that these cities are likely to have a higher concentration of available and accessible support services.

An additional worry included the potential “research fatigue” (Clark, 2008:954) that this cohort of YAPHIV might have suffered from because of the small numbers of people living with HIV in Scotland. Research fatigue can emanate from the high coverage of research projects that may or may not result in tangible results (Cree, Kay and Tisdall, 2002:49). Consequently, at the outset of interviews, YAPHIV were asked if they had previously been involved in any studies. Only one answered yes, however, she had an altruistic attitude towards research regarding her involvement as a way to help others. Research fatigue could also apply to practitioners in the field and may have contributed to some practitioners’ lack of participation.

Nonetheless, the data analysis does highlight important recurrent issues with regards to transition in healthcare for YAPHIV. Though only eight YAPHIV were interviewed, it has been highlighted that there are only approximately 19 YAPHIV in Scotland. Thus, this possibly accounts for almost half of all YAPHIV in Scotland currently.

3. “Sometimes I live in denial... I just wanna be normal”: Living with HIV

As outlined in chapter one, this study aims to explore the views and experiences of YAPHIV and how this may be able to inform practice regarding transition from paediatric to adult healthcare. This chapter considers young adults’ accounts of living with HIV, providing a valuable insight into the environment in which transition occurs. Debbie, a healthcare practitioner, reiterated a need to “get a feel for what their lives are actually like” in order to understand YAPHIV transition needs. An analysis of the context in which YAPHIV were told of their status, how YAPHIV attempt to present themselves, difficulties YAPHIV wrestle with in understanding HIV and lastly the responsibility affiliated to their HIV-positive status, will follow.

3.1 Finding out you have HIV

Though healthcare guidelines advocate that a child should be told of their HIV status by school-age (Hogwood, Campbell and Butler 2012:45), ‘school-age’ in fact incorporates a wide range of ages. As guidelines also stipulate that healthcare transitions should occur simultaneously with the transition from primary to secondary school it is likely that this ambiguity refers to when children begin school. In Scotland this occurs at five years old (National Foundation for Educational Research, 2013). Hogwood, Campbell and Butler (2012:48) found that individuals were generally not told of their status until between 8-16 years, normally in the presence of doctors. This was typical of the current study. Often the YAPHIV acknowledged that their initial reactions were somewhat subdued. Ostensibly, the shock of being told can immobilise action. Moreover, simply to be told of one’s diagnosis does not necessitate an acceptance or understanding of the illness. This is aptly illustrated by the case of an informant who was told of her diagnosis in the last two years:

“I’d been getting sick all the time since I was a child, it would just go... Now to tell me that you have HIV that will stay in you for a long time, it's just like eh? I didn't really know how to take that in, so I was like... I'll just say OK, yeah I have HIV, but, it's, I don't know... Yeah I haven't really fully taken it in” (Sarah).

Caregivers that disclose late to their children tend to be HIV-positive. Delayed disclosure is often associated with caregivers’ concern regarding family secrets. There is an aversion to adding a perceived burden to the child that could lead to negative repercussions within the wider community or guilt arising from vertical transmission (Wiener et al., 2007:157).

Finding out one’s status as HIV-positive is often the first concrete experience YAPHIV recall with respect to living with HIV. Within this study, YAPHIV experiences illustrated that this regularly coincided with nearing the end of their time in children’s healthcare. The time following finding out about one’s status is frequently marked with denial (as seen above), anger and or hopelessness. Medication can serve as an unwanted reminder and can consequently lead to non-adherence (Wiener et al., 2007:162). HIV disclosure followed by a change in the way healthcare is delivered could exacerbate such repercussions as an understanding of HIV has not necessarily developed. This will be taken up again in 3.4.

3.2 Everything is “normal”

The majority of YAPHIV interviewed endeavoured to project a veneer of ‘normalcy’ congruent with comparable studies. In discussing the re-framing of HIV as a ‘normal’ and manageable disease by the medical profession, Mazanderani and Papparini (2015:66) explore how those living with HIV tend to present a narrative of normality, which is generally beset with contradictions. In the current study informants often began by presenting themselves in what they perceived as a ‘normal’ way, underplaying how living with HIV affects them. However, most struggled to keep this up consistently. The breakdown of these façades presented by some of the informants may have been due to trust developing between myself and the young adults as discussion became more focused on particular

events or experiences. For example, approximately half way through our conversation, an outwardly confident informant acknowledged that:

“Sometimes I live in denial... I just wanna be normal” (Annie).

Annie moved to the UK at six years old after losing both her parents; she does not know whether they died from HIV-related illnesses. Following a turbulent experience of living with relatives, Annie moved out at the age of 17 or 18 “couch surfing” with acquaintances and eventually acquiring her own flat. Throughout this process, she juggled living with HIV, school, university and employment. Seemingly, it is difficult to reconcile her experiences with what is generally conceived to be ‘normal’. Though Cree and Sidhva (2009:49) recognise that the desire to be seen as normal is indicative of the presence of stigma, it has also been repeatedly shown that young people place high value on being analogous to their peers (Almquist, Modin and Augustine, 2013:690). The same could be said for young adults, as it has previously been suggested that the borders of such categories are somewhat arbitrary and fluid. Additionally, Baumeister and Leary (1999:522) conclude that most motivations of human beings are derived from a need to belong.

One informant detailed his struggle in leading a double life:

“...The hardest part [is] like trying to live two lives... Like the person that’s well the real Daniel and the other Daniel that nobody knows. Trying to split yourself in two... Nobody’s normal you know... I try to be as normal as possible...” (Daniel).

Though Daniel conveys that there perhaps is no “normal” he still refers to the persona he constructs that is free from HIV as “real”. Many of the YAPHIV depicted an ability to overlook their difference with respect to living with HIV up to a point. For Daniel, developments among his peers engaging in intimate relationships contributed to confronting his illness at around the age of 17. He felt unable to behave similarly or communicate to his peers why he did not do so, resulting in a need to address his illness. This pivotal turning point was recognised by many of the YAPHIV interviewed and it could be

suggested that this is in part galvanised by the changes associated with this time in life as aforementioned in chapter one.

This time of re-evaluation and heightened sense of self tends to occur around the same time that YAPHIV are likely to experience changes in healthcare provision. The majority of the YAPHIV voiced discontent with regards to the adult healthcare setting; many felt that they were invasively faced with their illness, exemplified below:

“The [adult clinic] itself could stop like putting up so many posters about HIV and stuff like that cos it just scares people. It's like in your face kinda thing” (Amber).

Others cited that their difference was further accentuated from the naming of the ward as “infectious diseases”. Consequently, informants worried about forced disclosure, comparing it to the lack of specificity in the children’s setting. This sentiment led one informant to avoid consultations, preferring to rely on repeat prescriptions for her medication until she realised she could be seen at a sexual health and reproductive clinic that lacked such specificity. Hamblin (2011:44) likewise found dissatisfaction amongst a wider age group of 13-28 year olds in the naming of the adult healthcare setting, owing to the potential to endanger anonymity of patients. Furthermore, she found allowing a choice to be made regarding where healthcare needs are met and when transfer occurs encourages YAPHIV to take control of their healthcare (2011:48).

Though choice is an important aspect of YAPHIV taking control of their illness, the dissatisfaction seen with the name “infectious diseases” poses a significant challenge. It could be put forth that if steps were made to ‘neutralise’ the name of the adult setting, this may reinforce HIV-related stigma and contribute to HIV being seen as ‘exceptional’. Particularly as other chronic illnesses such as diabetes have designated self-titled wards. This demonstrates the precarious nature of the field of HIV, where care must be taken to ensure that individual needs are respected, whilst ensuring a wider discourse of stigma is not perpetuated.

3.3 Making sense of HIV

Though all YAPHIV could name their illness, a pre-requisite for transition, most informants demonstrated confusion in their understanding of HIV. An overwhelming majority of informants exhibited bewilderment in how they acquired HIV, which subsequently has affected other aspects of their lives. Travis' narrative was typical in that the stories told by his parents were inconsistent and he had an acute desire to find out the truth. Other YAPHIV expressed similar environments of secrecy:

“My dad is a secretive person... like I'm not even too sure if I got passed it on from my mum, cos my mum passed away when I was one, my dad doesn't talk about it at all. Like sometimes I feel like my situation, nobody knows about it in my house, so it's just completely quiet. My little sister doesn't know... I'm not too sure if my big brother knows... maybe my mum's—my step mum's—told him but I dunno. Because like my dad's kinda brought me up just to keep everything quiet” (Daniel).

Such confusion was seen distinctly amongst those who self-identify as African or Black African. It has been widely illustrated that African diaspora communities exhibit characteristics of secrecy and generally a higher degree of in-community HIV-related stigma (Stutterheim et al., 2011:396). It could be posited that this is because such groups tend to suffer from social marginalisation that can stem from racism, anti-asylum or immigration rhetoric and barriers to employment, healthcare and social services (Stutterheim et al., 2011:397). Thus, in a group that generally holds diminished power relative to the majority population, stigma may be operationalised as a means of leveraging power within the community (Dodds, 2006:473). Using social identity theory, Tajfel and Turner (1979) convey that a person's sense of self is delineated with the desirable features of the in-group. Consequently, out-group members are constructed in a negative manner and boundaries are demarcated between the two so the in-group's membership is not tarnished. Taylor (2001:794) suggests that this discourse arises due to the way in which HIV is often associated with deviant behaviour which is widely documented elsewhere (see Parker and Aggleton, 2002). Though it has been acknowledged that there

are some who are perceived to be “innocent victims” (Taylor, 2001:794), such as YAPHIV, families may still be unlikely to be open about this as it signals to a wider circle not only the young adult’s status, but potentially other members of the family.

These arguments put forth a rationale as to why secrecy is perhaps commonplace within this group. Garddezi et al. (2008:721) term this environment of secrecy as “cultural silence” suggesting that in such communities sexuality and physical or psychological health issues are seldom discussed and community members are socialised to endure certain problems independently. In Stutterheim et al.’s (2011) study concentrating on African and Afro-Caribbean communities in the Netherlands, informants expressed that even when they wanted to discuss HIV with their family, they were often ignored or their families reacted with discomfort (2011:401), reflecting the experiences of the YAPHIV in the present study. Though it is important not to pigeonhole the many cultural groups that are categorised under ‘African’ such discussion does shed light on some important issues.

Secrecy serves to emotionally isolate these YAPHIV as they lack opportunities to discuss their confusion regarding their status honestly and openly within their families. This atmosphere can foster internalised stigma, causing individuals to endorse the negative feelings around their status and apply them to themselves (Earnshaw et al., 2013:1786). This was shown in the way in which many of the informants had decided to stop broaching the subject with their parents because of the adverse feedback that had previously ensued. Additionally, Madden et al. (2011:546) highlight that HIV rates tend to be higher in areas of high deprivation. This is seen in the current study through the working patterns of YAPHIV parents. Consequently, many YAPHIV also complained of physical isolation because of how much time single-parents had to spend at work.

Lacking an understanding of how HIV was acquired had important repercussions on the YAPHIV interviewed. This was most notable with regards to telling loved ones about their status. Being so accustomed to secrecy makes ‘opening up’ to others difficult for YAPHIV. Furthermore, not fully

understanding one's own illness can leave young adults feeling ill-equipped to disclose to others as shown below:

“Deep down I know that my questions are not answered and then how do I explain it to somebody else?” (Annie).

Perhaps even more concerning was the effect a lack of comprehension was seen to have on some informants' medical adherence. For example, one young adult has yet to accept her illness and when the topic of medication arose she openly explained she was not taking her medication because:

“I don't believe that I have it so I'm just floating right now. I think that's maybe cos I don't have the full story of how I got it” (Sarah).

Thus, through the experience of the informants of the present study it is apparent that having little understanding of HIV and how transmission occurred can have dire ramifications, particularly when combined with a process of transition. This lack of comprehension is highly connected to when YAPHIV find out about their diagnosis. Because this is so often delayed, it can work to jeopardise an understanding of HIV developing and being facilitated by the paediatric healthcare team. This is an issue that is difficult to circumvent because of the potential consequences of disclosing against parental wishes. There has been much debate on the merits of early disclosure of a HIV diagnosis, as seen in Sweden, and whether Scottish protocol should consider this (SPAIIIN, 2011:1). However, it has previously been acknowledged that HIV tends to affect the already vulnerable. Consequently, such families have many other competing priorities, for instance, asylum or housing worries. Making this facet of their lives more difficult may result in disengagement with healthcare, with perhaps worse repercussions. Although these considerations are important, it could be suggested that this is one way in which young adults or children are not afforded the same rights and responsibilities that accompany adulthood as discussed in chapter one (Durham, 2000:116).

3.4 Responsibility

Chapter one outlined the debate on conceptualising adulthood. It has been posited that young adulthood is characterised by a negotiation of responsibility (Park, Adams and Brindis, 2006:305). Such negotiations become more complex when HIV is incorporated into the debate. Informants in the current study talked about responsibility with respect to keeping themselves and others healthy.

Often, an initial burden was felt in managing their illness, especially when pill dosage was high. For Amber, the medication represented a reliance on something to “stay alive” and consequently made her confront her own mortality. Facing one’s mortality has been likened to a grieving process, in which the foundations of self-understanding and place in the world are disturbed (Attig, 1989:361-2). It is thought that during adolescence this is commonplace (Hogwood, Campbell and Butler, 2012:54), however living with HIV can perhaps make this a difficult sentiment from which to move on. Consequently, YAPHIV who cannot cope with such feelings may be inconsistent in their adherence to medication due to an associated despondency. If this is not managed before a transfer to adult healthcare, medication adherence may deteriorate further.

Many of the YAPHIV expressed that as they got older different priorities influenced their perceived responsibilities. For example, one informant expressed a more serious need to adhere to medication due to the altruism she felt towards her partner:

“Right now my motivation is because when you get to a certain level you can go undetectable. Which means there is less chance of you like passing on to somebody else... I was like, OK fine, I have a boyfriend now, so I should be taking them” (Annie).

Similarly, Tevendale and Lightfoot (2006:169) find that sexual behaviour practice among young adults living with HIV is contingent upon the individual’s concern for others. Other informants of the current study worried about how living with HIV would affect marriage and having children, consistent with the surrounding literature describing uncertain futures (Hogwood, Campbell and Butler, 2012:44).

Discussion at times turned towards how the law and media shape YAPHIV perceived obligations. One informant expressed anger at how such institutions fail to frame responsibility as a reciprocal relationship. Legislation in England and Wales states that individuals can be prosecuted if they wilfully set out to transmit HIV, however in Scotland people can be prosecuted for recklessly exposing another individual to HIV; regardless of transmission occurring or not (Terrence Higgins Trust, 2013). It is widely perceived that the responsibility to protect others against infection lies predominantly with those who are infected. This stance could perhaps correspond to the widely-held belief that they 'chose' their condition through immoral behaviour (Smith, 2007:237). Dixon-Mueller (2007:285) highlights this as a clash between the equal rights of two individuals in intimate interactions. The criminalisation of HIV transmission can cause distress to those who are infected and this is seen in the current study in which one informant expressed how he actively tries to stay away from sexual relationships due to the cloud of confusion that surrounds them:

“[It] stops me from speaking to other girls. I'm scared of the police so I'm just like I'm not doing anything bad and I'm just staying away” (Daniel).

Criminalisation of HIV transmission consists of many ambiguously defined areas. For instance, what constitutes reckless? Is having HIV and engaging in sexual behaviour always a risk or does condom use or an undetectable viral load negate this? Burriss and Weait (2011:11) problematise the criminalisation of HIV transmission from a moral standing. They suggest that such principles fail to demarcate the responsibility of the whole community to keep safe, suggesting that no one's obligation should be more imperative than any other's. Nonetheless, the law is as it stands and an area in which YAPHIV could have more support with is knowing exactly what they can and cannot do with regards to work, the law and relationships.

Evidently, the lived experiences of YAPHIV are pertinent to transition practice. Social identities are an important facet that permeate all aspects of such experiences and will continue to do so. As Madden et al. (2011:542) convey, the most “vulnerable” groups are now more likely to access support,

although only once their situation has become quite severe. Most of the YAPHIV in this study found out about their status much later than recommended by guidelines which has seemingly affected their acceptance and understanding. Such findings are deeply intertwined with the stigma seen distinctly in African diasporic communities and the wider stigma seen towards such communities, which will be explored further in chapter five. Moreover, most YAPHIV work hard at trying to cultivate an exterior that is 'normal', disassociated with HIV. This can be disturbed by a physical transfer to an adult setting where their illness is brought to the fore, which can be particularly upsetting if YAPHIV have yet to accept their status.

4. “I thought that’s where I was gonna go for the rest of my life”: Transitional services

After considering the lived experiences of YAPHIV in chapter three, this chapter will focus on the reflections that were made by YAPHIV on their experiences or thoughts about transition in relation to both healthcare and social support. Relevant literature will also be utilised to elucidate whether such experiences are common in the wider sphere and the associated implications will be contemplated.

4.1 Transition and healthcare

The transition process in Edinburgh and Glasgow was outlined by the practitioners interviewed in the current study. Prior to the process beginning, YAPHIV are seen in a dedicated children’s hospital. Once the process commences, both localities move patients into a transition or young person’s clinic. In Glasgow this occurs within the paediatric setting, in Edinburgh however, though the process begins in the paediatric setting the actual clinic is based in the adult hospital. Such practice is not to be confused with having an entire setting dedicated to adolescents and young adults as seen with the 900 clinic in London (Bundock et al., 2011:466). This practice may be more commonplace in London because historically the highest number of patients was concentrated there (Bamford and Lyall, 2014:185). Though this process was clearly delineated by both practitioners, informants were generally unaware of whether they were in a transition clinic or not. Furthermore, none of the informants had ever considered adult healthcare prior to their transfer. More than one informant expressed the following:

“I didn't know there was another hospital that dealt with that kind of situation... I thought that's where I was gonna go for the rest of my life” (Daniel).

Though such findings are upheld in comparable studies (see Fair et al., 2012), it is important to unpack the potential reasoning behind this sentiment, especially considering that healthcare guidelines advocate for transition to be patient-led. Whilst Hamblin (2011:42) suggests that this is not necessarily attributable to healthcare services and may correspond to forgotten discussions or preoccupations

with other issues, one of the practitioners in the current study addressed the problem with mixed feelings. When asked when changes in healthcare provision are broached with patients for the first time she answered:

“We probably don't mention it enough... I don't know that we actually say the things like this is the early transition, this is middle, this is late, we probably just do it... we probably need to explain the stages to the young people a bit more than we do” (Debbie).

If those being transitioned are not aware of the process, whether that be due to communication barriers or simply not being told, once they are physically transferred the shock of the change and related repercussions can be difficult to avoid.

In their study on expectations regarding transition in the United States (US), Fair et al. (2012:427) found disparities between patients and practitioners views on healthcare transition, suggesting a need for improved communication. Communication can be enhanced by actively listening to YAPHIV, providing written and verbal explanations as put forth by healthcare guidelines and providing a comfortable environment in which consultations occur (Boudreau and Fisher, 2012:323). Findings from the current study suggest this is not routinely happening in Edinburgh and Glasgow.

Most of the YAPHIV in the present study expressed displeasure regarding their experiences concerning healthcare transitions. An inconsistency can be seen in what an adult setting expects of YAPHIV and what their experiences prior to this have taught them about illness management. YAPHIV are often raised with a degree of secrecy regarding HIV as explored in chapter three. Hardon and Posel (2012:S4) illustrate that everyday life is a delicate balance between openness and concealment and this can be perceived as a way to control and manage aspects of one's illness. Thus, it can be difficult for YAPHIV to be open and honest with new doctors that are not seen as within their safe, strictly defined circles. Cree and Sidhva (2009:50) found this in their study on children infected and affected by HIV in Scotland and seemingly little changes once individuals reach young adulthood.

Perhaps contributing to the barriers to a successful transition to adult healthcare is the good, longstanding relationships YAPHIV often have with paediatric providers. Most YAPHIV have seen these providers from an early age. Consequently, leaving this environment can seem like quite a loss (Fair et al., 2012:426). Additionally, adult providers often do not have the resources required or the flexibility to be amenable to the complex needs of YAPHIV comparably (Wiener et al., 2008:6). Emily, a practitioner in Edinburgh, suggests that this is more of a problem in Scotland because of the cohort size. A small team looks after individuals in the children's setting and relationships are consequently relatively informal and friendly. It could be suggested that this is why an incongruence is seen between this study and Bundock et al.'s (2011) study in London. There it was found that YAPHIV preferred a more adult setting and the responsibility that went with it (2011:468). Conceivably those patients may have had less familiar relationships with paediatric team members because of their larger numbers.

Nonetheless, many of the older informants in the current study, who had transferred to the adult setting, reflected that at some point they noticed or would have noticed that they were too old or physically too big for the children's hospital. This implies that even those who are disinclined to move to an adult setting will wish to eventually, in their own time. This perception supports a patient-motivated transition. Though the majority of informants felt their transition had occurred too quickly with little preparation, some good practice was highlighted by YAPHIV who were happy with their experiences:

“A good thing that happened is that the doctor I was seeing in the [children's setting], she kinda came... and it wasn't an overwhelming move that like I didn't know anybody... she introduced me to another doctor, who I'm seeing now. But I think that transition from her coming along with me and seeing her for the first few appointments and then her passing me on to somebody else... Personally that helped a lot” (Daniel).

This is one way in which coordination between the paediatric and adult healthcare teams, described in chapter one, can be realised. Hamblin (2011:43) illustrates that a slow-paced transition and an

introduction to the new team or doctor can help curtail associated anxiety. Furthermore, contributing to this positive experience for this particular YAPHIV was that the location of the adult setting was much more convenient for him. Certainly location cannot be perfectly situated for all, however it is worth noting all considerations that come into play for a young adult to deem something a good experience. Other informants, in contemplating how their transition could have been improved, cited the following: knowing where the new location was, being told when they were to leave their current setting with advanced warning and knowing the doctors who would take on their care. Healthcare guidelines also stipulate for such factors to be included in individualised transition plans. Many scholars depict the usefulness of transition plans not only to prepare patients but also families and healthcare teams (see Vijayan et al., 2009; Cervia, 2013). This information may negate associated anxiety of the unknown and allow time to consider the practicality issues in getting to an appointment in a setting with which the individual may be unfamiliar. Kennedy and Sawyer (2008:404) particularly highlight the benefits associated with having an agreed date for transfer in reducing confusion among all parties in their review of recent studies and position statements on transitions in healthcare. It has been suggested that early, innovative and continuous education for young people is needed to ensure successful transition and that this should include learning how to navigate adult healthcare systems independently (Maturo, Major-Wilson and De Santis, 2011:22). If transfer occurs without such negotiation skills, follow up appointment rates are likely to plummet which risks the ability of YAPHIV to self-manage, therefore threatening medical adherence and health outcomes (Kennedy and Sawyer, 2008:404).

4.2 Transition and social support

All of the YAPHIV interviewed in this study were accessing social support with Waverley Care and this was often regarded as an integral part of their lives during transition. Voluntary organisations, such as Waverley Care, can be central to providing psychosocial support for YAPHIV (Hamblin, 2011:23). Services provided by voluntary organisations are multi-faceted and can include anything from building the confidence of YAPHIV and providing information about living with HIV, to support regarding associated issues like immigration or the law. Gillard and Roark (2012:103) advocate that social support can act as a buffer for the negative psychological consequences of stigmatisation that so often pervade the lives of those living with HIV, including social isolation or loneliness.

Every informant highlighted that a key benefit to attending Waverley Care support groups are the resultant friendships and peer support. Marino, Simoni and Silverstein (2007:67) detail the associated benefits of peer support in relation to social acceptance, personal growth and empowerment and reciprocal support. The importance of social acceptance is perhaps unsurprising given the value that young adults tend to place upon fitting in with their peers. YAPHIV tend to put themselves under constant self-surveillance to integrate amongst their HIV-negative friends, both in explaining away difference and perhaps more exasperatingly, in everyday life to avoid the materialisation of such moments (Philbin, 2014:296). Many informants in the current study commented on the feeling of relaxation they have around a group of people in which they do not have to worry about withholding a secret and filtering their conversation, even if they are not speaking about anything HIV specific. Personal growth and empowerment can also be recognised in the current study through the means of peer support. Harris and Larsen (2007:854) depict how peer support counsellors can show other individuals what is obtainable in the future. In the current study one YAPHIV expressed how she gains hope from her peers at Waverley Care:

“I see how they are living so, it gives me hope... When she tells me about her life—her love life and how she found a man and it's like oh OK, maybe I will get one too” (Sarah).

Hope allows individuals to look forward to a life that is not characterised by isolation and bleakness. Consequently, positive health-related behaviour is encouraged, like being more empowered to lead consultations with doctors (Marino Simoni and Silverstein, 2007:73). A process of transition seeks to actualise YAPHIV taking ownership of their healthcare needs and peer support can help facilitate this. One YAPHIV in the current study illustrated that through peer support he was able to take responsibility for his medical adherence:

“I used to look up to them if you know what I mean, so they just helped me get over it, I'd just watch them take their meds, like no pressure, no nothing, then that gave me confidence to take them” (Josh).

Harris and Larsen (2007:855) suggest that peer counsellors can find meaning and purpose in being a support for someone and in this sense there is reciprocity. Though the peer support that ensues from Waverley Care is not identical, such an ethos is apparent. The informant Josh exemplifies this; he is embarking upon formal mentor training as he feels a need to help others the way he has previously been assisted. In addition to this, all informants spoke positively about how freely they could speak to the staff-members' at Waverley Care about anything of concern to them, not necessarily HIV-related. Many talked about seeking help with education, discussing arguments in the family or support in looking for jobs. In talking about one particular staff-member all informants echoed the sense of general, wide-ranging support:

“My main support is her. She has helped me, not only with the diagnosis part, but everything in general” (Annie).

Ostensibly, what young adults most appreciate about such support is that they are seen as whole people. They are not defined by their HIV status, though naturally this tends to be a topic of discussion. However, the young adults can also explore other issues they may be having. This corresponds to the needs of YAPHIV to be seen as 'normal' and not solely defined by their illness as discussed in chapter three. Furthermore it highlights that YAPHIV tend to have other priorities that may not be directly

associated with HIV. This is reflected elsewhere in the literature where concerns also centre on making friends, claiming independence and navigating developing sexuality (Hogwood, Campbell and Butler, 2012:54). Healthcare services generally do not have enough time or space to support YAPHIV in this way, thus, this is a major avenue in which social support can assist in healthcare transitions as the context in which transition occurs is extremely important to consider. Perhaps what needs to be addressed is how YAPHIV not yet accessing any social support can be encouraged to come forward. This is especially important for Black African YAPHIV as it has been put forth that this community is often particularly accustomed to social isolation and they do not generally access health or social support until their situation becomes too problematic to deal with alone (Madden et al., 2011:542).

Seemingly, although there are transition healthcare protocols, discrepancies occur in the practitioners' understanding and knowledge of transition and what YAPHIV understand and experience in such a process. Subsequently, there is perhaps a need for improved communication between healthcare practitioners and YAPHIV. Furthermore in Scotland, as this study has conveyed, challenges arise for the small cohort of YAPHIV in leaving behind long-established relationships in paediatric healthcare. As suggested in chapter one, key to a successful healthcare transition is preparation and coordination. An important facet that helps foster a smooth transition is access to social support, particularly peer support which seems to promote empowerment of YAPHIV to take control of their healthcare and look towards a positive future.

5. “Everybody’s different, everybody’s got different needs”: Future aspirations and challenges

This chapter aims to explore what might facilitate a smoother transition process for YAPHIV in the future, drawing on both informants’ considerations and pertinent literature.

5.1 Education and information

Healthcare guidelines advocate patient-centred preparation which is conceivably facilitated through imparting expertise to YAPHIV, empowering them to take ownership of themselves and their illness management. The practitioners interviewed put forth that this was unlikely to occur without an understanding of one’s diagnosis. Most of the informants cited education and information as a key pathway to illness acceptance and understanding, consequently fostering empowerment.

One informant expressed how understanding what is needed in terms of illness management alleviates a massive amount of stress:

“As soon as you know what you have you don't worry about anything cos you know like what to do and what not to do and what happens” (Josh).

If such understanding is promoted before individuals physically transfer to an adult setting, negative repercussions such as inconsistency in medical adherence, loss of healthcare engagement and thus related consequences such as viral loads increasing, resistance to therapy increasing and greater chances of onward sexual or vertical transmission are less likely to occur.

In addition to education and information centred on healthcare, transition practice needs to consider the backdrop in which the process occurs. As aforementioned, other changes are usually occurring simultaneously during this time. For example many informants expressed a desire to have more information on trying to plan for their futures—whether this be with regards to jobs, the law or queries concerning reproducing. Most informants advised that information that they would find useful should

begin by being disseminated by their consultants, as they are the people that the YAPHIV have the most likelihood of seeing in the first instance.

5.2 Wider public awareness

As previously suggested, stigma is something that infiltrates all informants' lives on a daily basis. This can include the worry of perceived stigma in addition to concrete stigma. Thus, it is unsurprising that in their aspirations for the future the YAPHIV hoped for wider public awareness. Many of the informants compared living with HIV as the same as cancer and wished that society at large saw HIV is a similar light and distinct from acquired immune deficiency syndrome (AIDS). For example one young adult thought the government should do more to make this happen:

“It’s awareness... There’s all these adverts like let's fight cancer, but never once have I ever seen [campaigns] about HIV—or AIDS. Although they are two different things” (Annie).

It has been acknowledged that the discourse surrounding HIV is one of fear. This can be exacerbated by the common myths still circulating in society and images dispersed by the media. Negative images are often associated with public health campaigns that seek to use such discourse to influence safe behaviours around HIV transmission (Hogwood, Campbell and Butler, 2012:54). Smith (2007:245) highlights that media depictions regarding health either take the format of challenge or stigma. Challenge corresponds to non-infectious illnesses that show positive imagery and hope, whereas stigma corresponds to illnesses like HIV in which the health concern is illustrated by a particular character personifying the illness, separated from the rest of the community through terms like “they” and “them”. Media campaigns that foster HIV-related stigma can deter people from accessing health and social care and inhibit disclosure, further contributing to their social isolation. Moreover, the way the media positions HIV as a problem owned by an ‘other’, a position taken up by gay men during the emergence of HIV/AIDS, and now arguably is taken up by Black African immigrants, works to locate this health concern as distant from the general public and thus may do little to enact safe sexual practice as HIV is only associated with certain individuals (Grove and Zwi, 2006:1938). Therefore,

altering media portrayals of HIV would not feasibly curtail safe sex and may significantly challenge HIV-associated stigma (Smith, 2007:246).

A finding that was perhaps less anticipated from the current study was that many YAPHIV felt they had experienced judgement from adult healthcare staff. For instance, Annie highlighted that a nurse had once seemed much more preoccupied with her own safety, which she had misconstrued to be in danger, rather than keeping up a professional relationship. This YAPHIV went on to suggest that medical staff should receive more training in their bedside manner. In this instance it is feasibly important to outline that Annie self-identifies as Black African. In Dodds' (2006) study that followed the experiences of gay men and heterosexual African migrants in the UK living with HIV many discrepancies were found between the experiences of the two groups. Within a focus group including both communities, British gay men were surprised by the discrimination African individuals faced having thought that such negative attitudes had been eliminated long ago. The African informants of Dodd's (2006) study were made to feel as if all of the preconceived prejudices healthcare providers' may have had towards African migrants had been validated once their HIV status was clarified (2006:475).

The majority of the informants of the current study self-identify as Black African. Though stigma within the African community has already been explored, it has been posited that HIV-related stigma may be intensified amongst the wider community in cases where individuals are members of already stigmatised and marginalised groups (Aggleton et al., 2005:6). Flowers et al. (2006:109), in their study, found that people's experiences of living with HIV was located within the context of being Black Africans living in the UK. If such wider-stigma is felt whilst YAPHIV are transitioning in healthcare, a loss of engagement is likely to ensue.

Further to this, a shift from paediatric to adult healthcare can lead to YAPHIV having to navigate different views of HIV, which may come as a shock. Often in a paediatric setting, patients are viewed sympathetically (Taylor, 2001:794), infected due to someone else's 'immoral' behaviour. However,

once YAPHIV transfer to an adult healthcare setting an individuals' route of transmission is not clear to all staff, and a culture of blame can be seen.

Thus, regardless of what kind of stigma is considered, of utmost importance is listening to and respecting YAPHIV views as well as engaging in a non-stigmatising environment (Bundock et al., 2011:467).

5.3 Challenges

Though all of the young adults in the current study were keen to try to reflect on what they would find helpful with regards to transition, some anticipated a few challenges. For example, one informant explained that social support organisations like Waverley care are often limited by the fact that they do not know the exact process of healthcare transitions and consequently cannot inform the YAPHIV on what will happen. Such organisations are often not privy to the exact healthcare protocols, and though there has been much focus on a multidisciplinary effort in guidelines to transition, it is clear that more work is required in building harmonious relationships between the healthcare and voluntary sectors.

Moreover, one YAPHIV highlighted the heterogeneous nature of the group of young adults living with HIV in Scotland:

“Everybody's different, everybody's got different needs... there'll be some people that find it so hard, emotionally, to live with HIV... then there's other people living with HIV... there's other things that they need help with... like finding somewhere to go when things get tough at home” (Daniel).

Daniel conveys the issue in trying to find a template that will suit all young adults living with HIV indicating at why it is difficult to legislate for support and transition in healthcare. This ethos was echoed by Debbie, one of the practitioners interviews who advocated that “there's no set template to transitions” and that each case has to be guided by each individual. The heterogeneous nature of

the cohort living with HIV in the UK is outlined in other studies also. Madden et al. (2011:542), in assessing the access of marginalised groups of community services, put forth that in countries in which antiretrovirals are widely disseminated concern needs to turn to issues that might assume a high priority for people living with HIV such as immigration, poverty or psychological issues. For YAPHIV these concerns are likely to also echo the issues that most young adults are grappling with, previously outlined and as suggested by Daniel above.

This chapter has reiterated the need to consider YAPHIV with respect to their broader experiences. Furthermore it problematises the way in which HIV is conveyed in media depictions and how some non-specialised staff deal with YAPHIV. Perhaps most pertinent to this study, this chapter has shown that, what YAPHIV need from transition is heterogeneous. It is vital that transition practice reflects this in order to better support YAPHIV and secure continued engagement in furthering their self-management of HIV.

6. Conclusions and implications

The discussion that ensues from the questions posed at the outset of this study are difficult to untangle from a wider discourse of HIV-related stigma. Embedded within this is the discrimination associated with already marginalised groups, because of the overrepresentation of HIV-infection amongst certain communities. Healthcare transitions occur against this backdrop of stigma, thus permeating all of the challenges this study has highlighted. It has been suggested that a change in the way public health campaigns are framed could challenge such stigmatising outlooks. Furthermore, a HIV-centred education campaign may help to dispel related myths that are still propagated. However, challenging the status quo in terms of socio-cultural, economic or political-legal norms happens gradually. Factors that are so entrenched in society or tradition take time to modify (Evans, Jana and Lambert, 2010:451). Nonetheless, such ambitions are certainly worthwhile and should not be undermined.

Seemingly, healthcare guidelines delineate what a good transition process constitutes, albeit in an ambiguous manner. Though the equivocal nature of these guidelines yield frustration, perhaps this is because every individuals' transition process should be self-lead. Though many informants of the current study expressed dissatisfaction with their transition processes, they may have gone through this before certain protocols were enacted. For example, Amber, the youngest informant, depicted that she was allowed to delay her transfer because she did not yet feel ready. This signals that the process of transition is perhaps slowly modifying. Nonetheless, the older informants' views still highlight important issues and have repercussions for future generations going through healthcare transitions.

Despite the individualised needs regarding healthcare transitions and the wider realm of stigma seen, this study has illustrated some more readily actionable recourse to avoid negative outcomes associated with transition. For instance, there is a need amongst the healthcare sector for non-specialised staff to alter their sometimes stigmatising attitudes towards YAPHIV. Conner, Wilson and Lyon (2006:186) found that in an HIV/AIDS speciality clinic in Columbia, US, staff and the reception

team made the whole experience more favourable by simple being friendly and polite. This attitude change could be fostered by a few straightforward training sessions. It is of absolute importance that the adult healthcare setting is a place of non-judgement and comfort for YAPHIV. Hostile environments can contribute to a loss of engagement in healthcare (Hamblin, 2011:44). Furthermore, there is a need to recognise that practical matters are often as important as medical matters to YAPHIV. This includes where the healthcare setting is located and when appointment times occur. Not appropriately accounting for how important such factors are to YAPHIV can work against a successful transition. Skills such as navigating adult healthcare systems need to be instilled before all safety-nets are removed. Simply transferring to adult healthcare does not guarantee such developments and this must not be assumed.

Additionally, it has been illustrated that the context in which transition occurs is pertinent to consider. Thus, the healthcare sector cannot sufficiently deal with all transition related elements alone. Social and voluntary support organisations like Waverley Care can help YAPHIV enormously, but are not yet being fully utilised to facilitate positive transition experiences. This could be altered through greater transparency in the way healthcare transitions are facilitated. Though this process should be made clearer to the YAPHIV going through transition, it is recognised that at times young adults may not give such discussion high priority due to other life events occurring simultaneously (Hamblin, 2011:42). Thus, if the voluntary sector was able to work more closely with the healthcare sector, they could be more informed on healthcare practice and assist in fostering YAPHIV understanding of the process. Within this is the challenge of ensuring YAPHIV have come to terms with their condition. This study shows that many issues are interrelated with this. Informants' inability to come to terms with their HIV status in the current study is associated with being told about their diagnosis at a late age. This is often particularly found in African communities. In meeting the needs of YAPHIV, because HIV disproportionately affects Black Africans in Scotland, it is impossible not to address issues that are interrelated with ethnicity. However, when facing such challenges, it is important not to attribute all issues regarding transition to this 'other' culture which risks pathologising Black African culture as a

whole, endorsing dangerous stereotypes which may contribute to the wider ethos of discrimination or racism already touched upon. Whilst reflections are made on this issue within this study, it is clear that this dimension is not easily addressed and warrants further research.

Finally, there are some ways in which this study was possibly restrained. For example the limited time frame in which it was carried out meant that only one interview was possible with each informant. An opportunity to follow up with YAPHIV would have been beneficial as often those who had not yet transferred to adult healthcare suggested they had not given the process much thought. An initial meeting could have introduced the topic, whereas a follow up interview may have allowed for deeper insight. It is also important to recall the methodological limitations highlighted in chapter two. Nevertheless, important issues have been conveyed which could inform healthcare transitions to reduce negative outcomes. Furthermore, such findings prove valuable as the wider cohort of YAPHIV look very similar to the group that inform this study.

This research has illustrated the complexities that are associated with healthcare transitions for YAPHIV and that there are no quick fixes. Nonetheless, whilst the process of transition has been shown to be multi-faceted and diverse, informants' experiences and views have illuminated some ways in which the process may be better facilitated. Ultimately considerations need to centre on YAPHIV coming to terms with their diagnosis, which then allows for responsibility of their illness management to ensue more easily. Voluntary organisations that provide social support are extremely valuable in this respect and need to be permitted to do more, facilitated through a stronger sense of cooperation and transparency between them and the healthcare sector.

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8. Appendices

8.1 Description of informants

The below details reflect the status of each informant at the time of interview.

Essie is 21 years old and self-identifies as African and female.

Helen is 19 years old and self-identifies as Tanzanian, African and female.

Daniel is 22 years old and self-identifies as Black African and male.

Amber is 16 years old and self-identifies as mixed-race and female, she was born in Scotland.

Sarah is 21 years old and self-identifies as Black African and female.

Annie is 21 one years old and self-identifies as Black African and female.

Josh is 19 years old and self-identifies as Black African and male.

Travis is 17 years old and self-identifies as Black African.

Emily is a professional practitioner in paediatric healthcare in Edinburgh.

Debbie is a professional practitioner in paediatric healthcare in Glasgow.

8.2 Letters of invitation

8.2.1 Letter of invitation for young adults

29th April 2015

Dear.....,

Transition to adult healthcare services and the role of social support: the views of young adults living with HIV in Scotland²

Waverley Care would like to carry out a study of the views of positive young adults about social support. They have given me your details as someone who might be willing to help with this study.

If this is something you would like to talk to me about, I would like to interview you. The interview will take place at Waverley Care offices. Each interview will last no more than an hour and a half and we would like to tape record these or take notes, as long as this is OK with you. Anything that you choose to say as part of the study will be kept confidential to the project, as long as you do not tell us you are being hurt in any way.

If you are interested in participating in this study please have a look at the information sheet and contact me if you have any questions (details below) and sign the consent form.

Thank you

With best wishes,

Raeesah Haque, Student Researcher,

School of Social and Political Science, The University of Edinburgh

Contact: s1442184@sms.ed.ac.uk

² The title of the study adjusted slightly after data had been collected in order to include a pertinent quote from an interview with a YAPHIV.

8.2.2 Letter of invitation for practitioners

27th May 2015

Dear.....,

Transition to adult healthcare services and the role of social support: the views of young adults living with HIV in Scotland

Waverley Care would like to carry out a study on how support can be better tailored to positive young adults transitioning from child-centred to adult healthcare. Though the main focus is on the young adults themselves, it would be helpful to understand the views of practitioners that work closely with this group. Waverley Care have given me your details as someone who might be willing to help with this study.

If this is something you would like to talk to me about I would like to interview you. The interview will take place at a mutually agreed upon location that is convenient for you. Each interview will last no more than an hour and we would like to tape record these or take notes, as long as this is OK with you. Anything that you choose to say as part of the study will be kept confidential to the project.

If you are interested in participating in this study please have a look at the information sheet and contact me if you have any questions (details below) and sign the consent form.

Thank you

With best wishes,

Raeesah Haque, Student Researcher,

School of Social and Political Science, The University of Edinburgh

Contact: s1442184@sms.ed.ac.uk

8.3 Information sheets

8.3.1 Information sheet for young adults

Transition to adult healthcare services and the role of social support: the views of young adults living with HIV in Scotland

Hi, my name is Raeesah Haque and I would really appreciate your help with some research I am doing with Waverley Care. This sheet will give you some more information about the study.

Q. Who is Raeesah Haque?

A. I am a student at the University of Edinburgh, doing this research for both Waverley Care and my final project at the university.

Q. What is the project about?

A. Social support services need your help in understanding how best to support you. The project wants to know your views, and how organisations like Waverley Care can better help you in all areas of your life, especially as you move to adult healthcare services.

Q. What do I have to do?

A. If you would like to take part in the study you will be asked to participate in an interview with me, discussing your views on what you feel you need from social support to make your life happier; what you may have experienced that has already done this; and any issues that are important to you.

If at any time, you do not want to continue or discuss something, you are always free to refuse or stop the interview.

Q. How much time will it take up?

A. Not more than an hour and a half at a time that is good for you.

Q. Where will the interview take place?

A. In Edinburgh: Waverley Care, 3 Mansfield Place, EH3 6NB

In Glasgow: Waverley Care, 12 Queens Crescent, G4 9AS

Q. How will I get there?

A. Travel expenses will be reimbursed by Waverley Care and transport can be provided to and from the interviews if needed.

Q. Will the information be kept confidential?

A. Yes, as long as you do not tell us you are being hurt in any way. Interviews will be recorded and notes will be made if you do not mind, but only for the use of this project. All names will be changed in the report.

Q. What happens next?

A. If you decide you would like to be involved in this study please sign the consent form and Lynne from Waverley Care will confirm the meeting details.

Q. Is there anything else I need to know?

A. To show our appreciation of giving up some of your time you will receive a high street voucher to the value of £10.

Thank you,

Raeesah Haque, Student Researcher,

School of Social and Political Science, The University of Edinburgh, Contact: s1442184@sms.ed.ac.uk

8.3.2 Information sheet for practitioners

Transition to adult healthcare services and the role of social support: the views of young adults living with HIV in Scotland

Hi, my name is Raeesah Haque and I would really appreciate your help with some research I am doing with Waverley Care. This sheet will give you some more information about the study.

Q. Who is Raeesah Haque?

A. I am a student at the University of Edinburgh, doing this research for both Waverley Care and my final project at the university.

Q. What is the project about?

A. Social support services need your help in understanding how best to support young adults. The project wants to know your views, and how organisations like Waverley Care can better help young adults in all areas of their lives, especially as they move to adult healthcare services.

Q. What do I have to do?

A. If you would like to take part in the study you will be asked to participate in an interview with me, discussing the process of transition and how young adults can be best supported from your own point of view and what you think young adults' would want during this time of transition.

If at any time, you do not want to continue or discuss something, you are always free to refuse or stop the interview.

Q. How much time will it take up?

A. Not more than an hour at a time that is good for you.

Q. Where will the interview take place?

A. A mutually agreed upon location that is convenient for you.

Q. Will the information be kept confidential?

A. Yes. Interviews will be recorded and notes will be made if you do not mind, but only for the use of this project. All names will be changed in the report. The study will be conducted in accordance with ethical guidelines from the university (<http://goo.gl/k22Rbv>).

Q. What happens next?

A. If you decide you would like to be involved in this study please sign the consent form and Lynne from Waverley Care or I will confirm the meeting details. If you have any questions please do not hesitate to contact me.

Thank you,
Raeesah Haque, Student Researcher,
School of Social and Political Science, The University of Edinburgh, Contact: s1442184@sms.ed.ac.uk

8.4 Consent form

Consent Form

Transition to adult healthcare services and the role of social support: the views of young adults living with HIV in Scotland

Please sign below if you agree with the below statements:

1. I understand what the study is about.
2. I understand that my participation is completely up to me and I can withdraw at any time.
3. I understand that the interview will be taped and notes will be made if I do not mind.
4. I understand that all personal information, including identity, will be kept confidential and anonymous to the project.
5. I agree to take part in the study.

Name of Informant:	Name of Student Researcher: Raeesah Haque
Date:	Date:
Signature:	Signature:

For any further information about the study, please contact:
Raeesah Haque
Email address: s1442184@sms.ed.ac.uk

8.5 Interview guides

8.5.1 Interview guide for use with young adults

As I mentioned before, this is a part of a project for my degree... Though WC/ [REDACTED] helped set this up I haven't been told much from them so I'm really interested to find out a little bit more about you...

1. Have you ever taken part in any research before? (Background)

(Prompts: How was it?; Did you enjoy it? – What aspects did you like/dislike?; How can it be made better from your point of view?)

2. Could you tell me a little bit about yourself? (Background)

(Prompts: What would you usually do on a day like today? – School/work/college?; Tell me about a normal week in your life; Who do you live with?; – How is that?; what do they do?; How do you spend your free time? – Who do you do that with?; How about where we are today – have you always lived nearby?; If no – why/when did you move?; yes – how is it?)

3. As you know this study is about young adults living with HIV. How does living with HIV affect your life? (Managing Illness)

(Prompts: What healthcare services are you using?; What happens if you are unwell?; How often do you have to see a doctor/clinician?; Do you have a regular doctor/clinician that you might see?; What about your medication? – How could this be made easier? – How does this affect your social life/relationships?)

BREAK?

4. Where are your healthcare needs met at the moment? (Transition)

(Prompts: When you go to see a doctor/clinician where do you go?; Has it always been like this? – where your healthcare needs met differently when you were younger?; If yes - what happened?; How do you feel about this?; Can you give me an example?; What do you like/dislike?; What did you expect from these changes?; If no – is there anything you wish would change about your healthcare now?; What do you expect from adult healthcare?)

5. What social supports do you draw on? (Support/Coping)

(Prompts: As you know we're interested in the kind of support you use... What support do you have in your life? (Family member / friends / social workers / support groups - WC / health care professionals / spirituality or religion / social media); What do you come to WC for? – What groups do you take part in?; When did you first come?; Have you developed any friendships within WC?; Does anything special make you feel better?; Is there anything you would avoid?; If I were to draw a picture of you here.... – where would you place these different supports in relation to you?)

BREAK?

6. What else do you think could be done to support you that isn't happening now? (Support 2)

(Prompts: Anything you'd like to see being set up in the future?; in what areas of your life do you think you could have more help?)

Wind down

7. This has been a really interesting conversation. Is there anything finally you would like to talk about? (Closing)

Would you mind finally filling out this small questionnaire just so that I have a little bit of background to your answers? Again it will remain confidential and anonymous and if you have any questions I am here.

Share information or material about possible avenues of support.

8.5.2 Interview guide for use with young adults

1. Could you tell me a little bit about what you do? (Background)

(Prompts: What would you usually do on a day like today?; Tell me about a normal work week of yours?; How is that?)

2. Could you tell me about the procedure for supporting children/young people with HIV and the procedure for supporting adults? (Before go on to transition process) *Whichever is applicable*

(Prompts: What happens when a child/young person/adult comes in for an appointment at the hospital?; Is there any other support available in this setting?; Is this process quite set in stone or can it change from patient to patient?)

3. Could you tell me what 'transition' means to you in terms of healthcare? (Transition process)

[Transition can be defined as a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult oriented health care systems. (Transition: getting it right for young people, Department of Health, 2006)]

4. Can you take me through the step by step process of transition in Edinburgh/Glasgow for young adults living with HIV? (Transition process)

(Prompts: What deems a young adult ready for transition?; What, if any, preparation do they go through?; Has this changed over time?; Will it change?; What is the time frame like?; Is this process quite set in stone or can it change from patient to patient?); How do you respond to a young person that would like to stay in paediatric care? – When does it get pressing for them to move up?)

5. What, if any, benefits have you found with how transition occurs now? (Transition views)

6. Do you have any suggestions for how the transition process could be improved to make it more successful from a young adults' point of view? (Transition views)

(Prompts: What would you see changed to improve the lives of young adults' living with HIV?)

7. Have you noticed any differences in young people from before the process of transition begins to after? (Transition views)

If applicable

8. How much support do you think young adults get in relation to transition? (Support)

(Prompts: Anything you'd like to see being set up in the future?; in what areas of do you think they could have more help?; do you think there's anything more the voluntary sector or health care sector could be doing?)

Wind down

9. This has been a really interesting conversation. Is there anything finally you would like to talk about? (Closing)

Thank you so much for talking with me today, once my report has been finalised I will send out a summary to all of the people that informed the study.

8.6 Socio-demographic background questionnaire

Socio-demographic background questionnaire

Thank you so much for taking some time to talk with me! Finally, it would be really helpful if you could provide a little bit more information about yourself so that what we have spoken about today has some context. All of your answers will remain anonymous and confidential just like our earlier discussion. Feel free to ask me any questions if anything isn't clear.

How old are you?

_____ (Please fill in the blank)

How would you describe your gender?

_____ (Please fill in the blank)

How would you describe your ethnic identity?

_____ (Please fill in the blank)

8.7 Support sheet for young adults

Further Support:

General Support

Samaritans – Providing support for people experiencing distress or a general low mood	Call: 08457 90 90 90 http://www.samaritans.org/
Young Scot Infoline – Information on any topic, from money to health	Call: 0808 801 0338 http://www.youngscot.org/

Sexuality and Relationships

The Spark – Relationship support for families, couples and individuals	Call: 0808 802 2088 http://www.thespark.org.uk/about-us/
LGBT Youth Scotland - A community-based organisation to support young lesbian, gay, bisexual and transgender people in Scotland	Call: 0131 555 3940 / Text: 07786 202 370 https://www.lgbtyouth.org.uk/

Drugs and Alcohol

FRANK – Friendly, confidential drugs advice	Call: 0300 123 6600 / Text: 8211 http://www.talktofrank.com/
Scottish families affected by alcohol and drugs – Support groups and helpline	Call: 08080 10 10 11 http://www.sfad.org.uk/

Learning Disabilities and Ethnic Minority specific Support

Roshni - Support and advice for the safety and wellbeing of children, young people and vulnerable adults within the ethnic minority communities.	Call: 0141 218 4010 http://www.roshni.org.uk/esf/
ENABLE - Information and services for people with learning disabilities and their families in Scotland	Call: 0131 516 4195 http://www.siaa.org.uk/

HIV and Health Support

NHS 24 – Health advice and information	Call: 111 http://www.nhs24.com/
Waverley Care – Supports people in Scotland with HIV and Hepatitis C	Call: 0131 558 1425 http://www.waverleycare.org/
Terrence Higgins Trust - Provide of HIV and sexual health services in the UK	http://www.tht.org.uk/
Positively UK – Support, advocacy and information	Call: 020 7713 0444 http://positivelyuk.org/

If you are looking for something that isn't on this list don't hesitate to ask, or if you'd rather, contact me later. Thank you.

Raeesah Haque, Email address: s1442184@sms.ed.ac.uk