Riccardo Zito BSc Hons BFA MSc

ILLNESS RELATED UNCERTAINTY IN THE LIVES OF PEOPLE LIVING WITH
HIV

Section A: Illness uncertainty in the lives of people living with HIV: A review.

Word Count: 7942

Section B: The social environment, illness related uncertainty and quality of life of
people living with HIV

Word Count:7324

Overall Word Count: 15266

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

December 2020

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I would like to express my gratitude to the many people that have participated in this study.

I would also like to thank my supervisors, Prof Margie Callahan, and Dr Stuart Gibson for their support in preparing this thesis.

I am indebted to my friends who through the years have supported me both emotionally and materially, especially: Elsa, Ezgi, Veronika, Ralph, and Tito & Rosalba.

Finally, I would like to thank my mum and dad, Margaret and Mario, for once again housing and feeding me while writing this thesis during the COVID pandemic.

Summary of the major research project

Section A

This systematic literature review analysed twenty-three qualitative and quantitative studies investigating the experiences of illness uncertainty in the lives of people living with HIV. Specifically, the review aimed to identify sources of illness uncertainty for this population and the ways in which people living with HIV manage these uncertainties. These results were discussed within the frame of current theory and further areas of research were identified.

Section B

This is a cross-sectional online survey investigating the relationships between self-report measures of social environment (i.e. social support and experiences of discrimination), illness uncertainty and quality of life in an opportunity sample of people living with HIV. In line with theory, discrimination and social support were found to be differentially related to illness uncertainty. Furthermore, illness uncertainty was found to be related to quality of life. Clinical and theoretical implications as well as limitations to the study and future research were discussed.

Section C

This section contains appendices to sections A and B.

Table of Contents

Sections A: Illness uncertainty in the lives of people living with HIV: A review

Section B: The social environment, illness related uncertainty and quality

of life of people living with HIV

Section C: Appendices

List of Tables

Section A: Literature Review

Section B: Empirical Study

List of Figures

Section A: Literature Review

Riccardo Zito BSc Hons BFA MSc

Section A: Literature review

Illness uncertainty in the lives of people living with HIV: A review.

Word Count: 7942

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background and objectives: People living with HIV face a broad range of complex decisions related to the illness, and as a consequence experience uncertainty. Evidence and theory suggest that uncertainty related to illness can have a significant impact on the experiences and outcomes of people living with a variety of chronic conditions. The aim of this review was to provide a synthesis of the empirical evidence illustrating the way in which illness uncertainty impacts the lives of people living with HIV.

Methodology: A systematic literature review was conducted to identify qualitative and quantitative literature. A sequential exploratory synthesis was employed in analysing the studies.

Results: Eighteen qualitative studies and five quantitative studies were identified. The major sources of uncertainty identified were: medical aspects of the condition, the consequences of the illness on the person's professional, financial and relational contexts, and living with a highly stigmatised condition. PLWHIV reported managing these uncertainties through the interplay of seeking information and avoidance strategies while also relying on different structures of social support. Some participants in the studies also described a process of adaptation to uncertainty which in some cases allowed them to stay hopeful for the future.

Conclusions: People living with HIV experience a broad range of uncertainties related to living with the condition. Qualitative analysis identified themes reflecting theory as well as aspects of uncertainty specific to living with HIV. Quantitative literature replicated findings in populations of individuals with different chronic conditions and converged with qualitative findings as well as theory. Limitations of the studies reviewed and areas of further research are discussed.

Keywords: HIV, illness uncertainty, chronic conditions

Introduction

People Living with HIV

The Human Immunodeficiency Virus (HIV) was first isolated in 1983. The virus attacks the body's immune system and it can lead to life threatening opportunistic infections and specific types of cancers if diagnosed late and/or not treated with medications. At the end of 2019 there were an estimated 38 million people worldwide living with HIV (World Health Organization, 2020) of which over one-hundred-thousand lived in the United Kingdom (National AIDS Trust UK, 2020). At the beginning of the HIV pandemic the majority of people becoming infected with the virus developed fatal illnesses with a shortened lifespan. A decade later the introduction of highly active antiretroviral therapies (HAART) had a major impact on the prognosis for people diagnosed with the condition in higher-income countries (Palella et al., 1998) and later for people in lower-income countries (Ford et al., 2011). Over the years these changes in treatment led to radical improvements in life expectancy and quality of life (May, Ingle, et al., 2014). The life-threatening implications of the condition were greatly reduced and the term 'People Living With HIV' (PLWHIV) came into use to reflect the management of the disease as a chronic condition. However, in spite of these improvements, the condition remains difficult to manage for many PLWHIV. PLWHIV face complex illness-related challenges such as having to manage health conditions that pre-existed HIV infection or developed as a consequence of it (United States Department of Health and Human Services, 2019). Managing the condition can be complex and can entail: taking decisions about treatment while considering medication side-effects (Kremer et al., 2006); managing HIV-diagnosis disclosure in order to protect oneself and loved ones from stigma (Greeff, 2013); managing intimacy while negotiating protective sexual practices (Leblanc et al., 2017); and

planning a family while considering the risks of vertical transmission (Bravo et al., 2010). These are but some of the many challenges with which PLWHIV must contend.

It is unsurprising then, that reports of uncertainty related to managing the illness are prevalent in the experience of PLWHIV (Brashers et al., 2009), as exemplified in the many challenges and decisional dilemmas they have to confront. Systematic reviews of the literature have gathered ample evidence indicating that uncertainty in illness is linked to the mental health and physical wellbeing of individuals with chronic conditions (Neville, 2003; Zhang, 2017). This is particularly important for PLWHIV, as compared to the general population they are more likely to experience mental health problems (National AIDS Trust UK, 2018). Minoritiesed[1] groups identified by ethnicity, gender, sexuality and social status experience higher risks of developing mental health issues, while also experiencing higher risks of contracting the virus (Public Health England, 2018). This is because both HIV-infection and mental health share many of the same risk factors including socioeconomic deprivation, stigma and isolation (Brezing et al., 2015).

In summary, while the last few decades have seen considerable improvement in the treatment and prognosis of HIV, people living with the condition still face many illness-related challenges which can lead to experiences of uncertainty (Bravo et al., 2010). Evidence has surfaced showing that uncertainty in illness is related to both mental health and physical outcomes of people living with chronic conditions. The following sections will be outlining the development of the conceptualisations of 'illness uncertainty' (IU) in the context of health and will discuss the rationale of this review as well as its aims.

---

[1] The term 'minoritised' was drawn from Selvarajah et al. (2020)

Uncertainty in Health Care

As a theoretical construct, uncertainty extends across a wide range of theoretical domains and professions. To date, there is no readily identifiable body of literature that unifies the concept of uncertainty (Kasperson, 2008). Different authors have presented reviews of the concept of uncertainty within medical and illness contexts (Han et al., 2011). One of the most influential and referenced theories of uncertainty in illness was proposed by Mishel (1988, 1990).

Uncertainty in Illness Theory. Uncertainty in Illness Theory (UIT) was first proposed by Mishel (1988) to explain the processes involved in adaptation to acute illness. It proposes that when individuals are unable to form cognitive schemas of their illness experiences, this leads to "the inability to determine the meaning of illness-related events [that] occur in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1988, p.225).

According to this model individuals structure a cognitive schema of their illness experience through the 'stimuli frame'(see Figure 1). The stimuli frame is the degree to which the course of the illness follows a pattern and is familiar and congruent with an individual's expectations. In this model two variables can support the stimuli frame: the cognitive capacity of the individual and structure providers.

Figure 1

Model of perceived uncertainty in illness (adapted from Mishel, (1988)
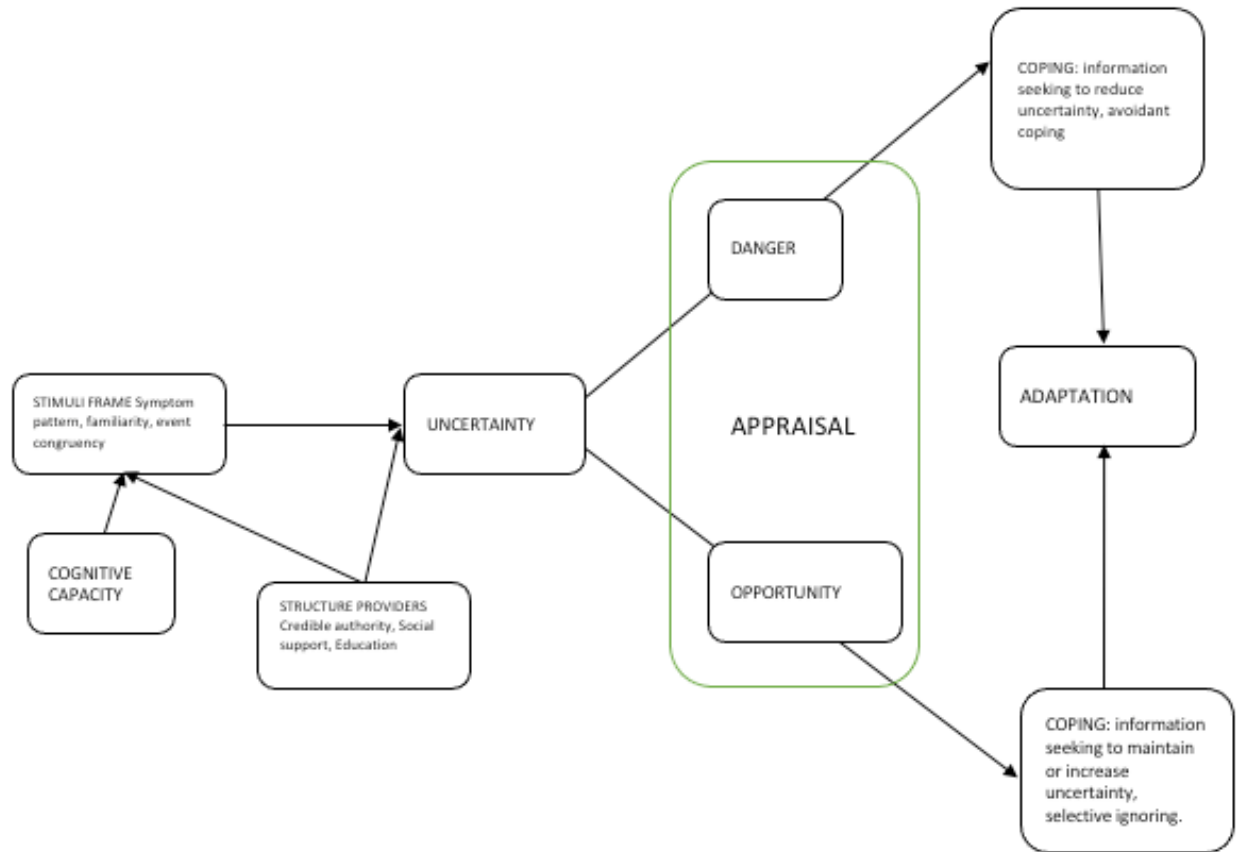
Cognitive capacity is understood as the information processing ability of an individual. Reduced capacity to process information due to medication, for instance, is postulated to have a deleterious effect on the ability to process the stimuli frame. Structure providers are constituted by the social resources the individual has at their disposal. Health care providers for instance, can function as credible authority and providers of expertise and education. Friends and family can also assist in the interpretation of the stimuli frame. Structure providers can help form a cognitive schema of illness events and also provide resources that directly reduce illness related uncertainty.

Based on these premises, the theory proposes that barriers to the development of a cognitive schema are constituted by illness stimuli that have poor patterns, are unfamiliar and incongruent. Ineffective support from structure providers and poor cognition will also lead to uncertainty.

Drawing from Lazarus and Folkman (1984), Mishel proposed that uncertainty is neither inherently good nor bad, and can be appraised by individuals as danger or opportunity. For example, PLWHIV may perceive uncertainty about the efficacy of medication as a threat, while perceiving uncertainty about long-term prognosis as opportunity because it can help promote change with optimism (Brashers et al., 2000). Mishel (1990) later expanded her model of UIT in order for it to also explain experiences of uncertainty in chronic conditions. In this later version of the model the final stage of 'adaptation' was conceptualised as a new sense of order where uncertainty becomes an accepted and integral part of a person's life. In this version of UIT individuals experience a shift towards probabilistic thinking, in which the expectation of certainty and predictability is abandoned. This is in contrast to a previous understanding of adaptation that saw the individual return to pre-illness psychological, behavioural and social functioning.

Managing Illness Uncertainty. Illness Uncertainty Theory distinguishes itself from other conceptualisations of uncertainty which see individuals as inherently motivated to reduce uncertainty through a variety of information seeking strategies (Berger and Calabrese, 1975; Selder, 1989). Over the years empirical evidence has grown in support of an understanding of uncertainty as not inherently threatening but rather, potentially related to a variety management strategies that are aimed at both uncertainty reduction and promotion (Kuang and Wilson, 2017).

A meta-analysis by Kuang and Wilson (2017) has evidenced three main strategies in the management of IU. These are: 1) seeking information, 2) avoiding information and 3) cognitive reappraisal of illness related uncertainty.

Seeking additional information can have the effect of both increasing or decreasing uncertainty. If uncertainty is appraised as opportunity because the individual has negative beliefs concerning illness prognosis, searching for additional contradictory evidence can increase uncertainty by introducing an alternative perspective (Frey et al., 1996). Alternatively, an individual may search additional information regarding symptoms they have experienced, in order to ascertain the cause of the symptoms and reduce uncertainty (Mishel, 1990).

If uncertainty is appraised as threat this may lead the individual to avoidant coping (Lazarus and Folkman, 1984). Avoidance can protect people from confusing and distressing knowledge and provide relief from a distressing certainty. Avoidant coping can include: distracting oneself from illness related stimuli, avoiding thinking about the illness, denying that the situation is problematic, disengaging from treatment and other illness related contexts, and avoiding any media or social situation that reminds the person of the illness (Brashers et al., 2000; Ratneshwar et al., 1997) Finally, individuals also manage uncertainty by engaging in the cognitive reappraisal of IU where the individual is able to develop a new sense of order about their illness experience. According to Mishel (1990) this is achieved through a dynamic process where the experience of chronic IU is integrated in the cognitive representation of the self and the world.

Illness Related Uncertainty in Chronic Illnesses

Empirically, IU has been investigated within a wide range of chronic conditions and has been shown to be related to a broad variety of outcomes. Wright, Afari, and Zautra (2009) conducted a review of quantitative and qualitative studies investigating the effects of IU in several chronic conditions. They concluded that IU influences adaptation to illness and can alter the experience of perceived acute pain in a variety of conditions. Of note is a longitudinal study by Reich, Johnson, Zautra, and Davis (2006) who carried out a study with patients living with fibromyalgia. They

were able to show that IU was positively associated with anxiety, negative affect and avoidant and passive coping. There is much cross-sectional evidence across types of chronic conditions suggesting negative associations between IU and coping and quality of life (Lynch et al., 2001; Schneider, 2000; Wonghongkul et al., 2006a). Pertinent to PLWHIV is also evidence in paediatric transplant patients suggesting there may be a link between IU and treatment adherence (Maikranz, Steele, Dreyer, Stratman, and Bovaird, 2006). A longitudinal study by Hoth et al. (2013) with 400 participants suffering Chronic Obstructive Pulmonary Disease (COPD), was able to demonstrate that uncertainty around experienced physical symptoms predicted clinical outcomes over a two year period. Furthermore, a series of interventions targeting IU have shown their effectiveness in improving clinical symptoms, self-efficacy and life satisfaction, in addition to lowering pain (Bailey et al., 2004; Gil et al., 2006; Jiang and He, 2012; LeFort, 2000; Mishel et al., 2002).

Summary and Rationale

Because PLWHIV face a broad variety of complex decisions related to the illness, they often have to manage the uncertainties inherent in their condition. There is considerable evidence in line with Illness Uncertainty Theory that suggests that uncertainty related to illness can have a significant impact on the experiences and outcomes of people living with a variety of chronic conditions. Both qualitative and quantitative studies have brought forward evidence of the impact uncertainty can have on quality of life, coping abilities and illness progression. Despite the documented impact of IU on a variety of chronic conditions, to date there is no study that has reviewed the role of IU in the lives of PLWHIV and how it may be related to specific aspects of living with the condition.

Aims

The aim of this paper was to review studies that have investigated the role of IU in the lives of PLWHIV and to provide a synthesis of the empirical evidence illustrating the ways in which it impacts their lives. The research questions that guided this review were: 1) what are the experiences of IU reported by PLWHIV? 2) how do PLWHIV manage these uncertainties? Both quantitative and qualitative studies were included in this review in order to provide a breadth of empirical evidence representative of the areas of research covered since the advent of the HIV epidemic from its beginning in the 1980s. This evidence will be considered in the light of current theories of IU with the objective of discussing implications for future research.

Method

Literature Search

The literature search was carried out in compliance with PRISMA guidelines (Moher et al., 2009). An electronic title search was conducted in December 2019 with the aid of the following database systems: Medline, PsychINFO, ASSIA, and CINAHL. A combination of search terms was adopted using the 'AND' function (e.g. 'HIV' AND 'Uncertainty). Synonyms were included in searches using the 'OR' function (e.g. 'Uncertainty' OR 'Ambiguity'). The asterisk function was also used to ensure that variations of the same search-term would be included in search results (e.g. Uncert*). A complete list of combination search-terms used in the literature search is available in appendix A. No time limit was applied to the search as the results reflected the historical advent of HIV/AIDS in academic research.

Inclusion Criteria

Studies were included in the review if:

- Participant population samples consisted of PLWHIV of any age;

- 'Uncertainty' or 'Ambiguity' in illness were themes that emerged during qualitative study;

- 'Uncertainty' or 'Ambiguity' in illness were constructs integrated in the design of a quantitative study;

- The 'Uncertainty' or 'Ambiguity' in illness under study was that experienced by PLWHIV;

- They were published in a peer reviewed journal;

- They were published in English;

Study Selection

Initial search results were checked for duplicates. A title screen and abstract screen were carried out based on the inclusion criteria. A selection of papers meeting the selection criteria was made after reading the full texts. The bibliographies of the articles selected were hand searched to identify further articles that met the review criteria. This process yielded twenty-three studies. An illustration of the search process can be viewed in Figure 2.

Figure 2

Flowchart illustrating systematic search process

Identification

Records identified through database searching
(ASSIA n = 78; CINAHL n = 170; MEDLINE = 165; PsychINFO n = 118)

Duplicates removed
(n =102)

Screening

Records title screened
(n = 429)

Records excluded
(n =378)

Records abstract screened
(n = 51)

Records excluded
(n =17)
Uncertainty: not illness related; not
of PLWHIV. Not empirical paper;

Eligibility

Full-text articles assessed
for eligibility
(n = 34)

Full-text articles excluded, with
reasons
a) Uncertainty not of PLWHIV (n = 2)
b) Paper not empirical (n = 2)
c) Conference summary (n = 1)
d) Not peer reviewed (n = 4)
e) Uncertainty not of illness (n = 3)

Included

Studies included in the
review
(n = 23)

Records included from
manual bibliographical
search
(n =1)

Quality Assessment

A quality assessment tool from Kmet et al. (2004) was adopted to aid the critical appraisal

of the selected studies because it allows for the concurrent evaluation of both qualitative and

quantitative studies. A summary of the evaluation with corresponding quality scores can be viewed

in appendices B and C. All studies selected through the search scored above the 75% cut-off and were included in the review.

Literature Synthesis

Pluye and Hong (2014) propose taking a sequential exploratory synthesis in mixed methods reviews in order to facilitate the emergence of gaps in the literature. This type of synthesis consists of an initial stage where qualitative studies are analysed with a qualitative method (e.g. thematic analysis) and a subsequent stage where quantitative studies are synthesised through quantitative methodology (e.g. meta-analysis). This allows for emergent themes in qualitative literature to be compared with areas explored quantitatively, thereby allowing for the identification of gaps in the literature and the creation of new hypotheses.

After more than 20 years of theory development in illness related uncertainty for chronic conditions, a hybrid deductive-inductive thematic analysis was adopted to synthesise qualitative data (Fereday and Muir-Cochrane, 2006). A meta-analysis of the quantitative data was not possible due to the small number of quantitative studies returned from the search.

Review

A comprehensive table summarizing the studies included in the review can be found in appendix D.

Sampling

The majority of the studies took place in North America (USA n=11; Canada n=3) and the UK (n=6). One study took place in Tanzania, one across Serbia and Montenegro and one in Iran. This means that, with the exception of these three studies, experiences of uncertainty related to living with HIV in other than British and north-American cultural contexts were largely unaccounted for.

The majority of participants were recruited in HIV specialist clinics, and various HIV advocacy and peer support groups. Only one study used online recruiting (Frain et al., 2008). The large majority of sampling was purposive with participant self-selection. This is possibly creates sampling bias, especially when considering the evidence for avoidant coping being related to experiences of IU (Mishel, 1990).

The participant population from the selected studies tended to be predominantly gay, male, of white ethnicity and living in urbanised areas. Nevertheless, women, ethnic and other sexual orientations were present in the samples and are likely to have brought differing accounts to the qualitative studies reported here. However, no trans PLWHIV appear to have participated in the selected studies, a population that is often neglected or not reached.

The majority of PLWHIV that participated to the selected studies were of adult age and four studies sampled participants over the age of fifty. Only one study reported the experiences of children living with the condition.

Of the studies, only one was based on interviews that had taken place prior to the introduction of HAART in the late 1990s. This is important to consider as the introduction of HAART impacted on the level of threat that the condition posed to PLWHIV across the four decades of the pandemic, thereby creating at least two cohorts of PLWHIV i.e. those diagnosed prior to the introduction of HAART and those diagnosed after.

The studies selected yielded a mix of participants at advanced stages of the condition and participants who were asymptomatic with variance in the time since diagnosis.

Design Characteristics

The majority of the studies selected were qualitative (n=18), followed by five quantitative. Of these studies only three were prospective (Brashers et al., 2017; Shannon and Lee, 2008; Rose

Weitz, 1991), with the majority being cross-sectional designs. While qualitative cross-sectional accounts can allow for participants to express retrospective accounts of their experiences of change, generally these designs are unlikely to capture the extent of the processes involved in change. This means that it was difficult to gather information on how IU for study participants changed across time and what factors may have impacted that change. Furthermore, quantitative cross-sectional designs do not allow for inferences of the direction of any relationship and are often susceptible to third variable effects i.e. the effect of a confounding variable that has not been accounted for.

Two quantitative studies were prospective and allowed some inference of the direction of the relationships being investigated (Brashers et al., 2017; Shannon and Lee, 2008).

Of the five quantitative designs selected, four adopted the Mishel (1981) Illness Uncertainty Scale which has been widely used and is a well validated measure. One study used the Parent Perception of Uncertainty Scale which measures a parent's uncertainty of the child's HIV illness (Shannon and Lee, 2008). In all cases acceptable Cronbach's Alpha scores were reported.

Of the quantitative studies selected, grounded theory was the most common methodology employed in analysing the data (n=9) followed by thematic analysis (n=7).

Thematic Account of Qualitative Research

This section of the review is structured according to the core themes and sub-themes that emerged through the thematic analysis. Table 1 summarizes themes and sub-themes identified. A thematic table with a selection of participant's quotes can be viewed in appendix E.

Table 1

Core themes and sub-themes

Global themes	Organizing themes	Basic theme
Sources of Uncertainty	Medical sources of uncertainty	• Making sense of symptoms • Disease progression • Health care systems and competing sources of knowledge
	Personal sources of uncertainty	• Professional identity • Interpersonal roles and identity • Future financial security
	Stigma and disclosure	
Managing Uncertainty	Seeking information	
	Avoiding information	
	Accepting uncertainty	
	Accessing social support	

Sources of Uncertainty

Similarly to a review carried out by Brashers et al. (2003), three main sources of uncertainty were identified in the reports of PLWHIV: 1) medical sources of uncertainty, 2) personal sources of uncertainty and 3) social sources of uncertainty related to HIV-disclosure and stigma.

Medical Sources of Uncertainty.

Making Sense of Symptoms. Participants in different studies reported at times experiencing uncertainty in discerning the causes of the physical ailments they experienced, especially if these were unfamiliar (Yarbrough et al., 2001).

In general, many PLWHIV reported feeling unsettled by the unpredictability of the fluctuation in their symptoms and found it difficult to discern whether the symptoms they were experiencing were due to their HIV, to adverse effects of the medications they were taking (Bernays and Rhodes, 2009; Brashers et al., 1999; Furlotte and Schwartz, 2017; Siegel et al., 1999), or sometimes to their mental health and cognitive capacity (Furlotte and Schwartz, 2017). The lack of knowledge around cause was reported to trigger anxiety because this could signify disease progression.

Uncertainties related to symptoms also seemed to be linked to the aging process of PLWHIV. For instance, older adults living with HIV appeared to question the cause of the symptoms and were unsure if these were part of growing older or of HIV progression itself (Furlotte and Schwartz, 2017; Rosenfeld et al., 2014; Solomon et al., 2014). As a participant remarked: "You've never been 50 before you have got HIV. So you never know whether it's HIV" (Rosenfeld et al., 2014, p. 23).

Disease Progression. There were several reports of participants experiencing difficulties with the unpredictable nature of the disease and its progression. Many described the episodic

nature of the condition and how it caused a sense of uncertainty for the future (Cochrane, 2003; Solomon et al., 2014). One older participant exemplified this stating: "I do have these troughs and peaks – and I'm thinking – well, will I get one more peak?"(Rosenfeld et al., 2014, p. 26). Another participant questioned the meaning of their AIDS diagnosis because their CD4 count often fluctuated above and below the diagnosis criterion (Crossley, 1998). Participants in different studies also expressed their concern for the impact that the condition would have on their longevity (Davis et al., 2006; Perrett et al., 2013; Rosenfeld et al., 2014)

There were several reports of the effects of unexpected improvements with the condition which appeared to result in increased uncertainty for the future (Brashers et al., 1999; Cochrane, 2003). Many older adults who contracted the virus prior to the introduction of HAART, described having experienced perplexity at their own survival and the uncertainties related to having to re-engage with life and re-entering old social roles again after having accepted the inevitability of their death (Furlotte and Schwartz, 2017).

__Health Care Systems and Competing Sources of Knowledge.__ The selected studies spanned across different health care systems. This allowed for some of the similarities and differences in the provision of HIV treatment to surface. While uncertainty related to access to treatment was not reported in any of the more recent studies published in the UK and USA, a study based on interviews in Serbia and Montenegro reported chronic unreliability around the delivery of HAART (Bernays and Rhodes, 2009). In this study, participants reported that their uncertainty around accessing treatment was influenced by a perceived lack of authority and trust towards health care professionals.

In the USA, where treatment delivery is comparatively more consistent, health care provider's credibility and authority also surfaced as a theme in the reports of PLWHIV (Brashers

et al., 2000). This seems to be particularly important in a context where medications are believed to be in constant development and new information, whether of medical or lay origin, is in constant supply. PLWHIV reported often being confronted with the uncertainties that arose through disparities between official medical narratives of HAART and the narratives based on lived experience of its use (Davis et al., 2006). Furthermore, participants in some studies also reported their difficulty in sometimes receiving discordant information from different health care professionals and experiencing scenarios where doctors disagreed on appropriate courses of treatment or where alternative information available might be discordant with medical opinion (Brashers et al., 2000; Furlotte and Schwartz, 2017). In Zambia, incongruencies between lay knowledge and medical knowledge were posing PLWHIV the dilemma of which source of knowledge to trust and which treatment course to follow (Wringe et al., 2009).

These studies seem to indicate that conflicting discourses and systems of knowledge can be major sources of IU for PLWHIV and often form the backdrop through which they have to navigate other medical uncertainties such as uncertainty in treatment provision, the long term effects of treatment, the choice of treatment regimen, and the interpretation of medical information (Brashers et al., 2003; Cochrane, 2003; Davis et al., 2006).

Personal Sources of Uncertainty Related to HIV. PLWHIV described how the unpredictable nature of the condition impacted their ability to make middle and long-term life plans (Cochrane, 2003; Davis et al., 2006; Weitz, 1989).

 In the US some interviewees reported the dilemma of taking risks in career progression. They were concerned about the possibility of losing health coverage if they became ill when they started their new job (Brashers et al., 1999, 2003). In the UK, participants recounted their dilemmas of deciding to remain in employment and managing the unpredictable nature of their condition or to

stop working and apply for disability allowance (Crossley, 1998). Participants reflected on the impact these decisions had on their professional and personal identities in addition to the potential loss of valued roles. However, they also discussed the potential gains of ending employment and being able to focus on their health (Crossley, 1998; Perrett et al., 2013). In the US, financial consequences of these decisions were also frequently mentioned in relation to the consequences of long-term medication costs and the implication of not being able to save money for older age (Brashers et al., 1999; Solomon et al., 2014). Family planning was also reported to be a source of uncertainty due to difficulties in accessing family planning support and risks associated with onward transmission during pregnancy and/or birth (Crossley, 1998; Davis et al., 2006).

Finally, older PLWHIV in the UK who identified as sexual and gender minorities expressed concerns for their future housing and for the inability of current older adult residential services to provide for their specific health needs, especially considering the lack of residential housing designated for LGBT communities (Furlotte and Schwartz, 2017).

HIV-stigma and Uncertainty Related to Disclosure. In the selected studies, HIV related stigma was often reported as a substantial hurdle for PLWHIV. Interviewees frequently reported experiencing uncertainty around who to disclose their HIV status to and what the outcome of disclosure might be (Brashers et al., 2003). Disclosure in effect meant the loss of control of sensitive information to third parties that could result in loss of social support, housing, prestige or employment (Wringe et al., 2009).

In Wringe et al. (2009), PLWHIV described avoiding HIV treatment clinics due to the risk of being seen by others from their communities and being identified as being HIV positive. Participants to this and other studies described the risks of their medication being found by others, and potentially disclosing their HIV status (Campbell et al., 2010). Further perceived risk of

unintentional disclosure of HIV-status were also related to fears of potential changes in facial appearance that are often associated with specific medications (Davis et al., 2006). This was reported to impact treatment choice and medication adherence.

While most studies reported experiences of stigma related exclusively to HIV, participants in the study by Furlotte and Schwartz (2017) spoke of the multi-layered nature of stigma related to their HIV status. A participant, for instance, spoke of their uncertainty at disclosing their mental health diagnosis within an HIV peer-support group and having to manage this in order to protect themselves from feared negative responses and possible loss of support.

In summary, PLWHIV reported experiencing uncertainty around disclosure of their HIV status due to the potentially negative response of friends, family and community members. Participants in these studies reported concerns related to the potential loss of access to support and social networks.

Managing HIV-related Uncertainty

Seeking Information. Some participants in studies by Yarbrough et al. (2001) and Weitz (1989) explained that they tended to seek information (e.g. temperature monitoring or seeking advice from health care professionals) when symptom patterns felt unusual. Being active in researching information pertinent to a specific condition was reported as helping interviewees understand their condition better to reduce uncertainty (Brashers et al., 2000; Davis et al., 2006; Furlotte and Schwartz, 2017; Weitz, 1989). Participants also explained that educating themselves about their conditions allowed them to feel like they could respond appropriately to illness events (Davis et al., 2006; Weitz, 1989) and helped them to communicate with health care professionals and take collaborative decisions about their health care (Davis et al., 2006).

In two studies PLWHIV reported investing time and energy in accessing HIV-clinics, groups and events because they could increase the probability of learning new useful information about their condition (Brashers et al., 2004; Bernays and Rhodes, 2009). Peer-support groups were also reported to be particularly helpful as participants were less likely to experience stigma or judgmental behaviour from others (Brashers et al., 2004). They also found that peers were sometimes more able than professionals to provide accurate or meaningful descriptions of illness events, such as medication side effects (Brashers et al., 2004).

Somewhat less frequently, participants reported seeking information with the aim of increasing uncertainty. Participants recounted seeking information on alternative therapies and/or experimental medical trials which might increase their chances of improved health and wellbeing. While this may help to increase hope for some participants, it also involves uncertainty with regards to the effectiveness of these alternative therapies and treatments (Davis et al., 2006).

Avoiding Information. There are several accounts by participants of the role of avoidance of information in managing IU. Information avoidance reduces exposure to potentially distressing knowledge and preserves hope.

Participants in a study by Brashers et al. (2000) reported avoidance behaviour following a period of information seeking. Seeking information was reported as being overwhelming at times, due to the quantity and sometimes upsetting content of new information. This could lead to engaging in a form of intermittent information avoidance. A similar process was described within the context of uncertain treatment delivery. Participants explained "rationing" contact with other PLWHIV was a way of controlling information flow and reducing exposure to potentially alarming information (Bernays and Rhodes, 2009).

Though there are many accounts of the usefulness of peer support groups for PLWHIV, participants in some studies explained how these groups were sometimes more stressful than helpful due to the distress generated by others sharing their illness related experiences (Brashers et al., 2000; Weitz, 1989). Participants reported this information would sometimes lead them to form frightening forecasts for their own futures. Avoiding peer support groups was therefore important for some participants as a way to avoid the apparent certainty of a future involving pain, disability and even death. In avoiding such groups, PLWHIV could sustain their own hope for a different future.

With regard to illness symptoms, some participants reported preferring to maintain a degree of ambiguity around their symptoms, especially if learning the cause of the symptoms was signifying deterioration. They reported that maintaining ambiguity facilitated the hope that symptoms were merely transitory and not significant (Siegel et al., 1999).

Similarly, in Yarbrough et al. (2001), PLWHIV spoke about not acknowledging or validating physical sensations such as chills or night sweats as symptoms of fever. These participants explained they would avoid taking their temperature and "ride out" their fever until it broke.

Accepting Uncertainty and Becoming Hopeful. Some participants recounted gaining new perspectives through the process of accepting their HIV-diagnosis and learning to live in the present (Katz, 1998). Participants in Cochrane (2003) and Weitz, (1989) explained how accepting HIV-related uncertainty in their lives meant they could not make long term plans. They did not want to make far reaching plans because they did not want to experience the frustration or disappointment that would come should their health interfere with the achievement of their goals. This meant adapting to living their life "one day at a time" (Cochrane, 2003, p. 385; Weitz, 1989, p.276).

In more recent studies, participants described a tendency to make longer term plans for their future as they became accustomed to living with HIV with increased optimism (Perrett et al., 2013). These participants were able to think about past times of extreme uncertainty and hardship and reflect on their being able to get through them. These reflections gave participants hope for the future in spite of feeling vulnerable. Similarly, participants in Davis et al., (2006) observed the exceptional and unexpected technological advances that had been made over the decades and considered the substantial improvements these advances meant for their illness trajectories. Davis et al., (2006) argued that this allowed participants to reframe their IU around hope of continued technological development and medical advancements.

Social Support. Participants reported the importance of discussing new HIV-relevant information with friends, family and professionals in helping them manage uncertainty. As one participant explained, this process helped "by validating knowledge, plans, and feelings" (Brashers et al., 2004; p. 314). At times, supportive others helped deciding when to seek new information or when not to. Some participants reported finding it useful at times when friends and family fostered avoidance by refusing to talk about HIV-related topics (Brashers et al., 2004). Family and friends were also reported acting as advocates. This kind of instrumental support was reported as helpful in enhancing the perception of support availability – which in itself helped individuals to feel less threatened by the unknown (Brashers et al., 2009).

As already discussed, some participants reported the usefulness of fostering social networks with other PLWHIV as a way of increasing exposure to up-to-date information. Social networks were also argued by (Brashers et al., 2009) to help PLWHIV develop decision-making and self-advocacy skills.

Peer-support groups were reported by both adults and children as being particularly helpful in the normalising of experiences in a context with less risk of judgement (Brashers et al., 2004; Campbell et al., 2010).

In summary, supportive others were reported to assist PLWHIV by regulating information seeking and avoidance, providing instrumental support, encouraging the development of new coping skills and conveying acceptance and validation.

Synthesis of Quantitative Research

In line with evidence from other studies on the impact of IU with other chronic health conditions, HIV-related IU appeared to have a strong predictive relationship to self-reports of quality of life in a cross-sectional survey of 125 PLWHIV (Frain et al., 2008). In contrast to other research, this study also explored the predictive power of medical markers of illness progression (i.e. CD4 counts) on quality of life. The researchers found that quality of life was not predicted by illness progression, as measured by CD4 cell counts. However, it should be considered that CD4 counts were relatively high for most of the participants and the majority of them were reportedly asymptomatic. It is therefore possible that should the sample have included a larger proportion of symptomatic participants with lower CD4 counts, these might have reported significantly lower levels of quality of life. This is important to consider because disease progression and the experience of ambiguous symptoms could be postulated to moderate the relationship between IU and other health outcomes such as quality of life.

All four quantitative surveys reviewed in this paper reported moderate to strong relationships between various forms of social support (i.e. health care professionals, family, friends) and IU, where higher levels of reported social support were related to lower levels of IU (Frain et al., 2008; Sajjadi et al., 2015; Shannon and Lee, 2008; Santacroce, 2000) . While three of the four studies

were carried out in the USA, one study (Sajjadi et al., 2015) was based on an Iranian sample, thereby providing some evidence of the cross-cultural validity of these results. A small longitudinal survey carried out by Shannon and Lee (2008) also reported a moderate inverse relationship between IU and social support. However, this relationship was only significant when participants reported intense sources of uncertainty (i.e. when participating mothers living with HIV were waiting for their new-born baby's HIV test results). These results differ from previous literature in that they would seem to suggest that the presence and intensity of sources of uncertainty, can potentially moderate relationships between IU and social support.

Finally, a randomised waiting-list control design reported by Brashers et al (2017) tested an intervention aimed at improving participant's skills in managing IU. The intervention aimed at improving participant's communication and increasing access to social support in their community. This study provided evidence for a moderate size effect of the intervention on participant's IU. However, it is important to note that the waiting-list control group had fewer participants likely due to attrition. It is possible that some participants with higher levels of IU (or very symptomatic participants) might have discontinued their participation in the study, thereby impacting the intervention's effect size. Unfortunately, neither effect size nor attrition were discussed by Brashers et al (2017). Overall, evidence from Brashers et al (2017) suggests that improving the ability of individuals to access helpful social support can reduce IU for PLWHIV and improve quality of life.

In summary, these results bring substantial quantitative evidence of the importance of the social environment in the management of IU of PLWHIV. However, in one study, the presence and intensity of sources of uncertainty was found to moderate the strength of the relationship of IU to

social support. Furthermore, IU was found to be a better predictor of quality of life than markers of disease progression.

Discussion

The aim of this review was to explore the experiences of IU of PLWHIV and to gain an understanding of how these uncertainties are managed.

Twenty-three studies were selected for review and analysis, of which eighteen were qualitative and five quantitative studies. Themes identified in the qualitative studies reflected past research in other chronic conditions but also brought to surface some aspects of uncertainty specific to living with HIV. Quantitative studies also reflected theory and previous findings in populations with other chronic conditions. These findings will now be discussed with the aim of identifying limitations to the research and areas of further study.

Mishel's model (Mishel et al., 1991) proposes that cognitive schemata of illness are dynamically influenced by the ability of an individual to process information derived by the 'stimuli frame' (e.g. disease pattern, predictability of symptoms) and by 'structural providers' (e.g. social support network, health care system, welfare system etc.). The appraisal of IU is then postulated to moderate the coping mechanisms individuals engage in.

Structural Providers

Several reports provided evidence of aspects of structural providers which were specific to the experiences of 'PLWHIV'. Ample quantitative and qualitative research has identified the importance of social support in managing IU. However, in contrast to people diagnosed with many other chronic conditions, PLWHIV have to contend with stigma related to the illness and the potential impact this has on their ability to access social support (Brashers et al., 2003; Campbell et al., 2010; Davis et al., 2006; Solomon et al., 2014; Wringe et al., 2009). Especially for PLWHIV,

social contact can be both a resource for managing uncertainty while also being a source of uncertainty itself. Within the reports of HIV-stigma, what also surfaced through qualitative analysis was that, because many PLWHIV identify with minoritised communities, their experiences of accessing social support are also susceptible to other forms of stigma as exemplified by participants in Furlotte and Schwartz (2017). This, potentially further restricting their access to social resources in the management of uncertainty.

The review evidenced further dilemmas specific to the structural providers of older PLWHIV. Four of the nineteen qualitative studies specifically consulted samples of older adults (Furlotte and Schwartz, 2017; Rosenfeld et al., 2014; Siegel et al., 1999; Solomon et al., 2014). The reports in these studies described the experiences of the first cohort to age with the condition. In spite of progress in treatment, older PLWHIV expressed their awareness of the limitations of current medical knowledge with regards to long-term treatment and aging with the condition. Furthermore, participants in this cohort expressed concerns for the ability of current support systems to cater for their future needs (Furlotte and Schwartz, 2017; Solomon et al., 2014).

Similarly to individuals suffering from other chronic conditions, the uncertainty of whether to leave work or stay in work was also reported (Brashers et al., 1999, 2003; Crossley, 1998). This structural obstacle is what appears to be the manifestation of an inflexibility of welfare and employment systems across national contexts in addressing the needs of individuals with chronic conditions, such as PLWHIV.

Another important aspect of structural providers reported in one of the studies included in this review was that of unreliability of treatment provision (Bernays and Rhodes, 2009). While this aspect was only encountered in one study, it reflected the reality of the 12.6 million individuals globally who are still not accessing treatment (UNAIDS, 2020).

Stimuli Frame

Participants in the qualitative studies included in this review confirmed that making sense of symptoms and disease progression caused great uncertainty around the meaning of illness events (Bernays and Rhodes, 2009; Brashers et al., 1999; Furlotte and Schwartz, 2017; Rosenfeld et al., 2014; Siegel et al., 1999; Yarbrough et al., 2001). These descriptions fall in line with previous findings and with Mishel's model of uncertainty in illness while also highlighting the particular ambiguity of HIV clinical presentation and treatment. Of note were older PLWHIV who in multiple studies reported their difficulties at discerning illness and treatment related symptoms from normal aging – and the uncertainty this caused (Furlotte and Schwartz, 2017; Rosenfeld et al., 2014; Siegel et al., 1999; Solomon et al., 2014). Furthermore, review of quantitative studies posed the question of whether symptom severity might interact with other factors influencing uncertainty, such as social support (Shannon and Lee, 2008). It is feasible that social support gains particular valance in reducing IU during a particularly distressing and painful time. In interpreting these results however, it should be noted that Shannon and Lee (2008) did not adopt the Mishel Uncertainty in Illness Scale adopted in most quantitative literature in the field, thus posing the question of whether this result may also be related to the measure used.

Cognitive Capacity

Cognitive impairment was at times described as a source of IU in older PLWHIV (Furlotte and Schwartz, 2017). However, a lack of research investigating the effects of cognition on the experiences of IU of PLWHIV was evident. This is an area of particular importance for PLWHIV, especially with regards to the first aging cohort of individuals living with the condition and the frequency of HIV-associated cognitive impairment (Alford and Vera, 2018).

Appraisal of Illness Uncertainty and Coping

There were different reports of IU being appraised as threat and the link of this appraisal to avoidance and information seeking. Examples of when IU was appraised as opportunity were scant and reported only when certainty of a negative outcome was imminent (Davis et al., 2006; Weitz, 1989). This is a phenomenon present in the wider literature on IU (McCormick, 2002). Lack of research renders it difficult to discern differences specific to PLWHIV in the appraisal of uncertainty as opportunity.

Participants also described accepting uncertainty in their lives – though it appears that a cohort difference may be emerging: while in several of the studies participants told of the impossibility of planning for the future and having to live 'day by day'(Cochrane, 2003; Weitz, 1989), others in a more recent study described a process of adjustment to uncertainty that lead to the realisation that there was little to adjust to in the short term while holding the awareness that challenges lay ahead in years to come (Perrett et al., 2013). These latter accounts are only found in one study of eight men in the UK. However, its striking difference could arguably be attributed to advances in treatment and fewer experiences of illness in the lives of newer cohorts of PLWHIV.

Limitations of the Studies

Most of the studies reported here were cross sectional and were not able to explore the way different factors influence IU over time. For example, this potentially limits our understanding of the mechanisms involved in the dynamic process of IU appraisal.

A further limitation of the research reviewed here was that it showed a large focus on the relationship between IU as threat and negative psychological outcomes. This is particularly true for quantitative research and it limits our understandings of the appraisal process of IU as opportunity in PLWHIV. It is possible that the self-report measure of IU used in four of the five

quantitative studies (and indeed in most quantitative research on IU) is not sensitive to experiences of uncertainty as opportunity. If this were the case it would be cause of concern for a method effect across the majority of the quantitative literature which has used the Mishel Uncertainty in Illness Scale (Mishel, 1997). Social desirability and self-selection are also likely to have influenced the results in these studies, especially considering the relationship between illness uncertainty and avoidance and its potential impact on motivation to participate to research studies on HIV.

The studies identified in this review showed there to be an under-representation of women, trans people and children. This reflects a phenomenon present in other HIV fields of research and is likely to result in the omission of important experiences specific to these populations (Loutfy et al., 2013).

Furthermore, in reviewing the quality of the studies, it is noteworthy that many of the qualitative studies had little or no reference to bias with the exception of Weitz (1989) and Cochrane (2003). An example of lack of reflectiveness in the research process can also result in a lack of transparency. An example of this was the fact that three of the studies from Brashers and their colleagues (Brashers et al., 2000, 2003, 2004) appeared to be sourced from the same sample though no reference of this was made. This is important to consider because it can lead to biased findings being repeated in publications.

Lastly, the majority of research sprung from European and north American contexts. It is important to consider the possible bias that similar cultural understandings of uncertainty may contribute to the results of this review. Indeed, Babrow et al. (1998) cite Levine when considering that while in some cultures the essence of understanding may be seen as a complete lack of ambiguity, in other cultural contexts, indeterminacy may be conceived as the very nature of knowledge (Levine, 1985).

Research Implications

The following recommendations stem from the considerations discussed previously in this section.

- Further research into the processes involved in appraising uncertainty as opportunity and the specific behavioural and cognitive strategies related to it are warranted;

- Longitudinal study of IU is warranted to gain better understanding of the dynamic nature of the appraisal of IU. Specifically, how appraisal and particular forms of avoidance of PLWHIV change over time may be of interest: an example of this would be to explore the relationship between IU appraisal and treatment adherence.

- There was a small number of quantitative research exploring IU in PLWHIV, thus warranting further quantitative research in this population. The use and, potentially, the development of other measures of IU would further validate the extant quantitative literature.

- There were no quantitative accounts of how experiences of discrimination and HIV-stigma may affect IU. It could be postulated that individuals identifying with multiple minoritised communities who have been subjected to high levels of discrimination may struggle accessing social support and mistrust health care systems, and as a consequence experience higher levels IU and that this may be linked to worse outcomes.

- Several populations of PLWHIV were underrepresented in the literature reviewed here. Indeed, different portions of the population, such as women, trans persons, children, individuals with minoritised ethnic backgrounds etc. may experience different forms of IU and manage it differently. Further research focusing on underrepresented groups is needed.

- Literature reviews of empirical research from non-European and north-American countries published in other languages than English would allow to further explore the cultural differences in discourse around IU as well as identifying gaps in the literature.

- Finally, the lack of research investigating the impact of cognition on the experiences of IU in PLWHIV warrants further exploration of this relationship.

Conclusions

In summary, PLWHIV experience a broad range of uncertainties related to living with the condition. The major sources of uncertainty identified by a hybrid inductive/deductive thematic analysis were: the medical aspects of the condition, the consequences of the illness on the person's professional, financial and relational contexts, and the social intricacies of living with a highly stigmatised condition. PLWHIV reported managing these uncertainties through the interplay of seeking information and avoidance strategies while also relying on different structures of social support. Some participants to the studies also described a process of adaptation to uncertainty which in some cases allowed them to stay hopeful for the future. Quantitative literature replicated findings in populations of individuals with different chronic conditions and converged with qualitative findings as well as theory reviewed here.

References

Alford, K., and Vera, J. H. (2018). Cognitive Impairment in people living with HIV in the ART era: A Review. In *British Medical Bulletin*. 127(1), 55-68. https://doi.org/10.1093/bmb/ldy019

Babrow, A. S., Kasch, C. R., and Ford, L. A. (1998). The Many Meanings of Uncertainty in Illness: Toward a Systematic Accounting. *Health Communication*, *10*(1), 1–23. https://doi.org/10.1207/s15327027hc1001_1

Bailey, D. E., Mishel, M. H., Belyea, M., Stewart, J. L., and Mohler, J. (2004). Uncertainty intervention for watchful waiting in prostate cancer. *Cancer Nursing*, *27*(5), 339–346. https://doi.org/10.1097/00002820-200409000-00001

Berger, C. R., and Calabrese, R. J. (1975). Some Explorations in Initial Interaction and Beyond: Toward a Developmental Theory of Interpersonal Communication. *Human Communication Research*, *1*(2), 99–112. https://doi.org/10.1111/j.1468-2958.1975.tb00258.x

Bernays, S., and Rhodes, T. (2009). Experiencing uncertain HIV treatment delivery in a transitional setting: qualitative study. *AIDS Care*, *21*(3), 315–321. https://doi.org/10.1080/09540120802183495

Brashers, D. E., Basinger, E. D., Rintamaki, L. S., Caughlin, J. P., and Para, M. (2017). Taking Control: The Efficacy and Durability of a Peer-Led Uncertainty Management Intervention for People Recently Diagnosed With HIV. *Health Communication*, *32*(1), 11–21. https://doi.org/10.1080/10410236.2015.1089469

Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., and Haas, S. M., (1999). "In an important way, I did die": uncertainty and revival in persons living with HIV or AIDS. *AIDS Care*, *11*(2), 201–219. https://doi.org/http://dx.doi.org/10.1080/09540129948090

Brashers, D. E., Neidig, J. L., and Daena, J. (2009). Social Support and the Management of Uncertainty for People Living With HIV or AIDS. *Health Communication*, *16*(3), 305–331. https://doi.org/10.1207/S15327027HC1603_3

Brashers, D. E., Neidig, J. L., and Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication*, *16*(3), 305–331.

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., and Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs*, *67*(1), 63–84. https://doi.org/http://dx.doi.org/10.1080/03637750009376495

Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., Garland, M., McCartney, B., and Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing*, *24*(5), 497–522. https://doi.org/10.1080/01612840305292

Bravo, P., Edwards, A., Rollnick, S., and Elwyn, G. (2010). Tough decisions faced by people living with HIV: a literature review of psychosocial problems. *AIDS Reviews*, *12*(2), 76–88.

Brezing, C., Ferrara, M., and Freudenreich, O. (2015). The Syndemic Illness of HIV and Trauma: Implications for a Trauma-Informed Model of Care. In *Psychosomatics*, 56(2), 107-118. https://doi.org/10.1016/j.psym.2014.10.006

Campbell, T., Beer, H., Wilkins, R., Sherlock, E., Merrett, A., and Griffiths, J. (2010). "I look forward. I feel insecure but I am ok with it". The experience of young HIV+ people attending transition preparation events: a qualitative investigation. *AIDS Care*, *22*(2), 263. https://doi.org/10.1080/09540120903111460

Cochrane, J. (2003). The experience of uncertainty for individuals with HIV/AIDS and the

palliative care paradigm. *International Journal of Palliative Nursing*, *9*(9), 382–388.

Crossley, M. (1998). "Sick role" or "empowerment"? The ambiguities of life with an HIV positive diagnosis. *Sociology of Health and Illness*, *20*(4), 507–531.

Davis, M., Frankis, J., Paul;, F., Flowers, P., Paul;, F., and Flowers, P. (2006). Uncertainty and "technological horizon" in qualitative interviews about HIV treatment. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *10*(3), 323–344. https://doi.org/http://dx.doi.org/10.1177/1363459306064489

Fereday, J., and Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International journal of qualitative methods*, 5(1), 80-92.

Ford, N., Calmy, A., and Mills, E. J. (2011). The first decade of antiretroviral therapy in Africa. In *Globalization and Health*. https://doi.org/10.1186/1744-8603-7-33

Frain, M. P., Berven, N. L., Chan, F., and Tschopp, M. K. (2008). Family resiliency, uncertainty, optimism, and the quality of life of individuals with HIV/AIDS. *Rehabilitation Counseling Bulletin*, *52*(1), 16–27. https://doi.org/http://dx.doi.org/10.1177/0034355208316344

Frey, D., Schulz-Hardt, S., and Stahlberg, D. (1996). Information seeking among individuals and groups and possible consequences for decision making in business and politics. In E. H. Davis and J. H. Witte (Eds.), *Understanding group behavior* (pp. 211–225). Lawrence Erlbaum Associates Inc.

Furlotte, C., and Schwartz, K. (2017). Mental Health Experiences of Older Adults Living with HIV: Uncertainty, Stigma, and Approaches to Resilience. *Canadian Journal on Aging*, *36*(2), 125–140. https://doi.org/10.1017/S0714980817000022

Gil, K. M., Mishel, M. H., Belyea, M., Germino, B., Porter, L. S., and Clayton, M. (2006). Benefits

of the uncertainty management intervention for African American and white older breast cancer survivors: 20-Month outcomes. *International Journal of Behavioral Medicine*, *13*(4), 286–294. https://doi.org/10.1207/s15327558ijbm1304_3

Greeff, M. (2013). Disclosure and stigma: A cultural perspective. In *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective* (pp. 71-95). Springer, Dordrecht.

Hoth, K. F., Wamboldt, F. S., Strand, M., Ford, D. W., Sandhaus, R. A., Strange, C., Bekelman, D. B., and Holm, K. E. (2013). Prospective impact of illness uncertainty on outcomes in chronic lung disease. *Health Psychology*, *32*(11), 1170–1174. https://doi.org/10.1037/a0032721

Jiang, X., and He, G. (2012). Effects of an uncertainty management intervention on uncertainty, anxiety, depression, and quality of life of chronic obstructive pulmonary disease outpatients. *Research in Nursing and Health*, *35*(4), 409–418. https://doi.org/10.1002/nur.21483

Kmet, L., Lee, R., Cook, L., Lee, C., and Lee, R. (2004). *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields*. Institute of Health Economics. https://www.ihe.ca/advanced-search/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields

Kremer, H., Ironson, G., Schneiderman, N., and Hautzinger, M. (2006). To Take or Not to Take: Decision-Making About Antiretroviral Treatment in People Living with HIV/AIDS. *AIDS Patient Care and STDs*, *20*(5), 335–349. https://doi.org/10.1089/apc.2006.20.335

Kuang, K., and Wilson, S. R. (2017). A Meta-Analysis of Uncertainty and Information Management in Illness Contexts. *Journal of Communication*, *67*(3), 378–401. https://doi.org/10.1111/jcom.12299

Lazarus, R. S., and Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing.

Leblanc, N. M., Mitchell, J. W., and De Santis, J. P. (2017). Negotiated safety - components, context and use: an integrative literature review. *Journal of Advanced Nursing*, *73*(7), 1583–1603. https://doi.org/10.1111/jan.13228

LeFort, S. M. (2000). A test of Braden's Self-Help Model in adults with chronic pain. *Journal of Nursing Scholarship, 32*(2), 153–160. https://doi.org/10.1111/j.1547-5069.2000.00153.x

Levine, D. N. (1985). *The flight from ambiguity : essays in social and cultural theory*. University of Chicago Press.

Loutfy, M. R., Sherr, L., Sonnenberg-Schwan, U., Walmsley, S. L., Johnson, M., and Monforte, A. D. A. (2013). Caring for women living with HIV: Gaps in the evidence. In *Journal of the International AIDS Society*. https://doi.org/10.7448/IAS.16.1.18509

Lynch, S. G., Kroencke, D. C., and Denney, D. R. (2001). The relationship between disability and depression in multiple sclerosis: the role of uncertainty, coping, and hope. *Multiple Sclerosis Journal*, *7*(6), 411–416. https://doi.org/10.1177/135245850100700611

Maikranz, J. M., Steele, R. G., Dreyer, M. L., Stratman, A. C., and Bovaird, J. A. (2006). The Relationship of Hope and Illness-Related Uncertainty to Emotional Adjustment and Adherence Among Pediatric Renal and Liver Transplant Recipients. *Journal of Pediatric Psychology*, *32*(5), 571–581. https://doi.org/10.1093/jpepsy/jsl046

May, M. T., Ingle, S. M., Costagliola, D., Justice, A. C., de Wolf, F., Cavassini, M., Monforte, A. D. A., Casabona, J., Hogg, R. S., Mocroft, A., Lampe, F. C., Dabis, F., Fätkenheuer, G., Sterling, T. R., del Amo, J., Gill, M. J., Crane, H. M., Saag, M. S., Guest, J., Sterne, J. A. C. (2014). Cohort profile: Antiretroviral therapy cohort collaboration. *International Journal of Epidemiology*, *43*(3), 691–702. https://doi.org/10.1093/ije/dyt010

McCormick, K. M. (2002). A Concept Analysis of Uncertainty in Illness. *Journal of Nursing*

Scholarship, *34*(2), 127–131. https://doi.org/10.1111/j.1547-5069.2002.00127.x

Mishel, M. H. (1990). Reconceptualisation of the uncertainty in illness theory. *Journal of Nursing Scholarship*, *22*(4), 256–262. https://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H. (1997). *Uncertainty in Illness Scales Manual*. [Unpublished manuscript]. Department of Nursing. University of North Carolina.

Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E., Robertson, C., and Mohler, J. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects. *Cancer*, *94*(6), 1854–1866. https://doi.org/10.1002/cncr.10390

Mishel, M. H., Padilla, G., Grant, M., and Sorenson, D. S. (1991). Uncertainty in Illness Theory. *Nursing Research*, *40*(4), 236???240. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Moher, D., Liberati, A., Tetzlaff, J., and Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. In *BMJ (Online)* 339(2535), 1–8. https://doi.org/10.1136/bmj.b2535

National AIDS Trust UK. (2018). *Changing Perceptions:Talking about HIV and our needs*. https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing

National AIDS Trust UK. (2020). *HIV in the UK statistics - 2018*. https://www.nat.org.uk/about-hiv/hiv-statistics

Neville, K. L. (2003). Uncertainty in illness: An integrative review. *Orthopaedic Nursing*, *22*(3), 206–214. https://doi.org/10.1097/00006416-200305000-00009

Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., Aschman, D. J., and Holmberg, S. D. (1998). Declining Morbidity and Mortality among Patients with Advanced Human Immunodeficiency Virus Infection. *New England Journal of Medicine*, *338*(13), 853–860. https://doi.org/10.1056/NEJM199803263381301

Perrett, S. E., and Biley, F. C. (2013). Negotiating Uncertainty: The Transitional Process of Adapting to Life With HIV. *JANAC: Journal of the Association of Nurses in AIDS Care*, *24*(3), 207–218. https://doi.org/10.1016/j.jana.2012.06.007

Pluye, P., and Hong, Q. N. (2014). *Combining the Power of Stories and the Power of Numbers : Mixed Methods Research and Mixed Studies Reviews*. https://doi.org/10.1146/annurev-publhealth-032013-182440

Public Health England. (2018). *Progress towards ending the HIV epidemic in the United Kingdom*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/821273/Progress_towards_ending_the_HIV_epidemic_in_the_UK.pdf

Ratneshwar, S., Warlop, L., Mick, D. G., and Seeger, G. (1997). Benefit salience and consumers' selective attention to product features. *International Journal of Research in Marketing*, *14*(3), 245–259. https://doi.org/10.1016/s0167-8116(97)00007-4

Reich, J. W., Johnson, L. M., Zautra, A. J., and Davis, M. C. (2006). Uncertainty of illness relationships with mental health and coping processes in fibromyalgia patients. *Journal of Behavioral Medicine*, *29*(4), 307–316. https://doi.org/10.1007/s10865-006-9054-7

Rosenfeld, D., Ridge, D., and Von Lob, G. (2014). Vital scientific puzzle or lived uncertainty? Professional and lived approaches to the uncertainties of ageing with HIV. *Health Sociology Review*, *23*(1), 20–32. https://doi.org/10.5172/hesr.2014.23.1.20

Sajjadi, M., Rassouli, M., Bahri, N., and Mohammadipoor, F. (2015). The Correlation Between Perceived Social Support and Illness Uncertainty in People with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome in Iran. *Indian Journal of Palliative Care*, *21*(2), 231–235. https://doi.org/10.4103/0973-1075.156508

Santacroce, S. J. (2000). Support from health care providers and parental uncertainty during the

diagnosis phase of perinatally acquired HIV infection. *JANAC: Journal of the Association of Nurses in AIDS Care*, *11*(2), 63–75. https://doi.org/http://dx.doi.org/10.1016/S1055-3290%2806%2960287-2

Schneider, S. (2000). *The Influence of Uncertainty in Illness, Stress Appraisal, and Hope on Coping in Survivors of Breast Cancer*. https://doi.org/10.1097/00002820-200012000-00004

Selder, F. (1989). Life transition theory: the resolution of uncertainty. *Nursing and Health Care : Official Publication of the National League for Nursing*, 10(8), 437-440.

Selvarajah, S., Abi Deivanayagam, T., Lasco, G., Scafe, S., White, A., Zembe-Mkabile, W., and Devakumar, D. (2020). Categorisation and minoritisation. *BMJ Global Health,* 5(12), e004508.

Shannon, M., and Lee, K. A. (2008). HIV-infected mothers' perceptions of uncertainty, stress, depression and social support during HIV viral testing of their infants. *Archives of Women's Mental Health*, *11*(4), 259–267. https://doi.org/http://dx.doi.org/10.1007/s00737-008-0023-8

Siegel, K., Dean, L., and Schrimshaw, E. W. (1999). Symptom ambiguity among late-middle-aged and older adults with HIV. *Research on Aging*, *21*(4), 595–618. https://doi.org/http://dx.doi.org/10.1177/0164027599214004

SJ, S. (2000). Support from health care providers and parental uncertainty during the diagnosis phase of perinatally acquired HIV infection. *JANAC: Journal of the Association of Nurses in AIDS Care*, *11*(2), 63–75.

Solomon, P., O'Brien, K., Wilkins, S., and Gervais, N. (2014). Aging with HIV and disability: The role of uncertainty. *AIDS Care*, *26*(2), 240–245. https://doi.org/10.1080/09540121.2013.811209

UNAIDS. (2020). *Global HIV & AIDS statistics*. UNAIDS. Retrieved November 10, 2020, from

https://www.unaids.org/en/resources/fact-sheet

United States Department of Health and Human Services. (2019). *Do People Living with HIV Have Other Health Conditions?* HIV.gov. Retrieved November 10, 2020, from https://www.hiv.gov/hiv-basics/staying-in-hiv-care/other-related-health-issues/other-health-issues-of-special-concern-for-people-living-with-hiv

Weitz, R. (1989). Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behavior*, *30*(Sep 89), 270–281.

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., and Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing*, *29*(3), 250–257.

World Health Organization. (2020). *HIV AIDS: Key Facts*. World Health Organization. Retrieved November 10, 2020, from https://www.who.int/news-room/fact-sheets/detail/hiv-aids

Wright, L. J., Afari, N., and Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports*, *13*(2), 133–138. https://doi.org/10.1007/s11916-009-0023-z

Wringe, A., Roura, M., Urassa, M., Busza, J., Athanas, V., and Zaba, B. (2009). Doubts, denial and divine intervention: understanding delayed attendance and poor retention rates at a HIV treatment programme in rural Tanzania. *AIDS Care*, *21*(5), 632–637. https://doi.org/10.1080/09540120802385629

Yarbrough, S., Cole, L., and Holtzclaw, B. (2001). "Riding it out": living with uncertainty of HIV-related fever at home. *Southern Online Journal of Nursing Research*, *2*(2), 1–23.

Zhang, Y. (2017). Uncertainty in illness: Theory review, application, and extension. *Oncology Nursing Forum*, *44*(6), 645–649. https://doi.org/10.1188/17.ONF.645-649

Riccardo Zito BSc Hons BFA MSc

Section B: Empirical study

The social environment, illness related uncertainty and quality of life of people living with HIV

Word Count: 7324

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background and aims: Illness uncertainty is related to worse health outcomes of individuals with chronic conditions. Theory and research suggest social support and adverse social experiences may play important roles in the experiences of illness uncertainty. Because people living with HIV are more likely to carry a burden of multiple stigmatised identities it was the aim of this research to explore the relationships between measures of discrimination and social support to illness uncertainty and in turn, to explore their predictiveness of quality of life.

Methods: 125 people living with HIV completed an online questionnaire containing measures of quality of life, illness uncertainty, social support, frequency of discrimination, and count of attributed stigmatised characteristics. Demographic data were also collected. Two sets of regressions controlling for demographics were carried out: a hierarchical regression was used to identify correlates of illness uncertainty; a multiple regression was adopted to model predictors of the previous regression and illness uncertainty on quality of life.

Results: The first regression showed positive moderate relationships of both measures of discrimination and an inverse moderate relationship of social support to illness uncertainty. In the second regression model, Illness uncertainty showed a negative moderate relationship to quality of life and was found to be a stronger predictor than social support.

Conclusions: People living with HIV subjected to multiple forms of discrimination can experience higher levels of illness uncertainty, thus potentially impacting their health outcomes.

Further research needed and clinical implications are discussed.

Keywords: Illness uncertainty, HIV, Stigma, Discrimination, Social support

Introduction

Living with HIV-related Uncertainty

Treatment of the human immunodeficiency virus (HIV) has made impressive progress over the last decades radically improving life expectancy (Palella et al., 1998) and quality of life (Liu et al., 2006) of people living with HIV (PLWHIV). The development of highly active antiretroviral treatment (HAART) has meant that HIV can now be treated as a chronic condition and that PLWHIV can expect the same life-expectancy as their HIV-negative peers, provided they access treatment early enough and can adhere to it (May, Gompels, et al., 2014). In spite of these improvements, PLWHIV have to contend with complex decisional dilemmas and sources of uncertainty related to the management of the condition and the multiple unfolding impacts it can have on their lives (Bravo et al., 2010). These sources of uncertainty related to illness can range from struggling to make sense of physical symptoms (Yarbrough et al., 2001), to managing conflicting information from health care providers and other sources of authority (Brashers et al., 2000; Furlotte and Schwartz, 2017). Other forms of uncertainty can originate from personal aspects of living with the condition, such as potential impacts on career progression (Brashers et al., 2003) and financial trajectories (Brashers et al., 1999; Solomon et al., 2014) or also family planning (Crossley, 1998). Furthermore, an important source of IU for PLWHIV is having to manage the stigma associated with the condition and the uncertainty around negotiating disclosure of one's HIV-positive status (Brashers et al., 2003; Davis et al., 2006).

Quantitative research across a variety of chronic conditions has consistently shown IU to be strongly related to mental and physical outcomes of wellbeing (Wright, Afari, and Zautra, 2009). Greater levels of IU have shown to be linked to increased levels of depression and anxiety, to higher levels of avoidant forms of coping, which in turn are also related to lower levels of quality

of life (Guan et al., 2020; Hoth et al., 2013; Mullins et al., 2017; Padilla et al., 1992; Pahlevan Sharif et al., 2017; Reich et al., 2006; Schiele et al., 2019). Furthermore, a longitudinal study was able to show that IU predicted clinical outcomes of individuals suffering from chronic obstructive pulmonary disease (Hoth et al. 2013). This literature describes the important role that IU plays in the experiences of people living with chronic conditions and indicates new areas of possible clinical intervention.

Uncertainty in Illness Theory (UIT) was proposed by Mishel (1988, 1990) and has been the most prominent theory in explaining uncertainty in chronic and acute illnesses (Wright et al., 2009). UIT defines uncertainty as "the inability to determine the meaning of illness related events that occurs in situations where the decision-maker is unable to assign definite values to objects and events and /or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel et al., 1991, 256). The theory suggests that the extent to which an individual will experience difficulty in making sense of an illness event will depend on how predictable the illness course is and how familiar or ambiguous the symptoms are. The model also suggests that an individual's cognitive capacity and aspects of their support systems (i.e. the availability, quality and complexity of services as well as forms of social support) will influence their ability to make sense of the illness event. As an example, ambiguous symptoms that change in presentation and intensity over time and are incongruent with a person's expectations, coupled with a complex health care system and poor social support, could be expected to decrease the person's ability to form a stable cognitive representation of the illness event. According to UIT this would result in the cognitive state we experience as illness uncertainty (IU). The model also describes how an individual's appraisal of IU as either beneficial or a threat is linked to different forms of coping that can impact outcomes such as the person's quality of life and disease progression (Padilla et al., 1992). Based

on her model, Mishel developed the Mishel Uncertainty in Illness Scale (MUIS) (Mishel, 1981, 1997) which has been used widely to study the effects of IU in chronic and acute conditions.

Social Context and Illness Uncertainty

Consistent with UIT, positive experiences of social support have been found to be related to lower levels of IU (Brashers et al., 2004; Hoth et al., 2015; Sajjadi et al., 2015; Sammarco, 2001; Shannon and Lee, 2008). UIT posits that this is due to the role that supportive social networks can play in providing individuals with new illness related information and in supporting them process it, while also providing structural support (Brashers et al., 2004). Interventions aiming to support access to social support have shown efficacy in lowering IU (Brashers et al., 2017). Nevertheless, not all social interactions are experienced positively, and some studies exploring the impact of adverse social interactions have found these to be related to higher levels of IU (Shannon and Lee, 2008). In a study by Hoth et al., (2015) for instance, perceived criticism from family was found to be positively associated with IU in people suffering from chronic obstructive pulmonary disease. In a study investigating the relationship between illness related stigma and IU, Blake et al., (2018) were able to show that individuals living with sickle cell anaemia reporting higher levels of illness related stigma also reported higher levels of IU. These results suggest that adverse social experiences such as stigma and discrimination are related to higher levels of IU and could be important in further elucidating the mechanisms leading to negative health outcomes. These mechanisms could be of particular importance for individuals living with chronic conditions that are subject to varied and intense forms of stigma.

Intersectional Stigma and HIV-related Uncertainty

Goffman describes stigma as a process where a person or group is denied full social acceptance due to an attribute or behaviour that is discredited by the dominant culture (Goffman,

1974). Stigma encompasses prejudices, discriminatory behaviours, practices and policies aimed at reproducing systems of inequality and maintaining privileges of the dominant sections of society. Research in the social sciences has investigated the ways in which characteristics such as race, gender or health impact privilege and disadvantage of both individuals and communities (Turan et al., 2019). While much of this research has focused on exploring the impacts of singular forms of stigma, individuals often embody several memberships to stigmatised groups. The concept of 'intersectional stigma' has emerged in order to thematise and explore the effects and consequences of living with multiple forms of stigma and is particularly relevant to the experiences of PLWHIV (Turan et al., 2019).

In high-income countries, HIV has been overrepresented in populations particularly vulnerable to stigma, such as: men that have sex with men (Public Health England, 2018; Purcell et al., 2012); men and women from minoritised ethnic groups (National AIDS Trust UK, 2014; Prejean et al., 2011); people who inject drugs (Prejean et al., 2011; Public Health England, 2018), and people that identify as trans (Herbst et al., 2008; Public Health England, 2018). Studies exploring the convergence of multiple stigmatised identities have underscored the relative severity of HIV-stigma while also confirming the cumulative potential of different forms of stigma. Identifying an individual as HIV-positive and in addition as IV-drug user or sex-worker increased the level of stigma attributed by students (Crandall, 1991) and by health care workers (Chan et al., 2008; Mannetti and Pierro, 1991; Rogers et al., 2014). Furthermore, the cumulative experiences of racial discrimination with HIV-related stigma was found to be related to reduced disclosure and reduced treatment adherence (Bogart et al., 2010; Fletcher et al., 2016) Similar results were found in a sample of transgender women, where lower access to HIV-related health care compared to cis-gender individuals was attributed to transphobia (Sevelius et al., 2014).

In fact, stigma is known to be a primary cause of social exclusion (Popay et al., 2008) and to have a deterring effect on help-seeking behaviours (Clement et al., 2015). For example, in a UK survey exploring the experiences of PLWHIV individuals that also identified as trans reported more frequently being excluded from family gatherings and experiences of being delayed or refused healthcare (Hibbert et al., 2018). It could be argued that because of the experience of active forms of social exclusion, individuals experiencing higher levels of stigma and discrimination would likely have reduced access to social resources. According to UIT, reduced social resources would then lead to experiencing higher levels of IU. This would be particularly true for individuals vulnerable to multiple forms of stigma who could potentially find accessing social support that feels safe, more difficult.

In their review of intersectional stigma in health, Turan et al. (2019) described different quantitative approaches in the exploration of intersectional stigma. A common approach has been that of adopting constructs that measure experiences of stigma and discrimination related to multiple stigmatised identities. An example of this are measures that allow respondents to report both multiple stigmatised identities attributable to their experiences of discrimination as well as the frequency of these incidents (Williams et al., 1997).

Study Aims and Hypothesis

PLWHIV have to manage numerous uncertainties related to living with the condition. This can be of particular importance due to evidence showing that IU is related to quality of life and potentially to illness progression. Furthermore, while social support has been shown to reduce measures of IU, evidence suggests that adverse social experiences, such as health stigma, are related to higher levels of IU. Because PLWHIV are more likely to carry a burden of multiple stigmatised identities, exploring the relationship between multiple forms of stigma and IU is warranted. It is in fact likely,

that individuals with a higher stigma burden will experience higher levels of social exclusion, thus presenting higher vulnerability to IU. Because the social environment is so instrumental in the meaning making process leading to the cognitive state of IU, it was the aim of this study to explore the relationships between social support, stigma and IU. A further aim of the study was to replicate previous findings regarding the relationship between IU and quality of life in a sample of PLWHIV. Based on these objectives the following hypothesis were formulated.

Because numerous studies reported the protective effect of social support on IU it is expected that:
H.1 higher levels of reported social support are associated to lower levels of reported illness uncertainty.

Individuals that experience multiple forms of stigma are at higher risk of social exclusion and thus likely have reduced access to social resources. According to UIT, reduced social resources would lead to experiencing higher levels of IU. Thus, it is hypothesised that:
H.2 A higher number of reported stigmatised characteristics are associated to higher levels of illness uncertainty.

Similarly, it would be expected that reports of frequent experiences of discrimination would also be related to higher levels of social exclusion, which would result to higher levels of illness uncertainty. Thus, it is hypothesised that:
H. 3 Experiencing frequent incidents of discrimination be associated to higher levels of illness uncertainty.

Lastly, based on the extant literature linking lower levels of IU to better quality of life it is hypothesised that:

H. 4 Lower levels of illness uncertainty are associated to higher levels of reported quality of life.

Methods

Design

A cross-sectional study design was adopted based on convenience sampled survey data. Each participant carried out one battery of measures.

Procedure

The study protocol was approved by the Salomons Institute's Ethics Panel (appendix F). The Code of Human Research Ethics of the British Psychological Society was adhered to (British Psychological Society, 2014).

Hyperlinks to the internet survey were distributed and advertised online through third sector agencies, social media (Appendix M) and HIV related forums. Survey questionnaires were stored online and delivered through Qualtrix. On accessing the online survey participants were provided with a participant information sheet (appendix G). Participants were assured of the privacy and anonymity protecting the information they submitted and were informed of the opportunity to decline participation up to the point of survey completion. On deciding to participate, participants accessed a consent sheet (appendix H) which they agreed to by pressing on a 'continue' button. No incentives were provided for completing the questionnaire. The measures were presented in a randomised sequence. To be included in the analysis participants had to complete and submit the questionnaire.

Participants

A total of 125 participants completed and submitted their questionnaires. Individuals were excluded from the study if they: were under 18 years of age; had not been diagnosed with HIV for at least over a year; had not shared their diagnosis with at least a friend or family member; were not proficient in reading English; did not live in either Australia, Canada, Ireland, New Zealand, the United Kingdom or the United States.

Measures

All measures adopted in the study can be viewed in appendix I

Demographic Data

Participants were asked to share the following demographic data: age, gender, ethnicity[2], number of years of completed education, employment status, relationship status[3], number of years since being diagnosed with HIV.

Illness Uncertainty

Uncertainty was measured with the community version of the Mishel Uncertainty in Illness Scale (MUIS-C) (Mishel, 1981, 1997). The measure consists of 23 items that are rated on a 5-point Likert type scale ranging from 1 = 'strongly disagree' to 5 = 'strongly agree'. The items explore areas in which individuals experience various forms of uncertainty (e.g. if they can tell when the illness is getting better or worse, if symptoms change unpredictably, the level of treatment and health care system complexity, the effectiveness of treatment, the clarity of communication with health care professionals etc.)

---

[2] The national statistics ethnicity coding frameworks of each respective country were adopted. To aid statistical analysis these categories were collapsed into White, Black, Asian and other ethnic background.
[3] To aid statistical analysis categories were collapsed into 'single' and 'in a relationship'.

The scale is a modified version of the Adult version of the MUIS (MUIS-A) and has been adapted for use with persons living with chronic conditions by deleting 10 items which referred to hospitalization and medical intervention. Items are summed to form the total score which can range from 23 to a maximum of 115. As the total score increases so does the level of illness related uncertainty. The internal consistency of the MUIS-C ranged from .74 to .92 in 18 studies based on individuals with a range of chronic conditions (Mishel, 1997).

The MUIS-C shares all of its items with the MUIS-A which was reviewed by a panel of experts during its development stages. Evidence for the construct validity of the MUIS-A was also reported following a factor analysis of data based on a sample of 616 participants yielding four constructs: ambiguity of symptoms, complexity, inconsistency of information and unpredictability (Mishel, 1997). Similarly, Reinoso and Türegün (2016) also identified a two-factor structure to the MUIS-C and high internal consistency at .91 thereby providing further evidence for the validity and reliability of the measure. No studies exploring convergent or divergent validity were reported. The construct has shown to preserve psychometric properties in Spanish, Norwegian and Chinese populations (Hagen et al., 2015; Torres-Ortega and Peña-Amaro, 2015)

Perceived Social Support

Social support was measured with the Multidimensional Scale of Perceived Social Support (Zimet et al., 1990). This measure consists of twelve items that are rated on a 7-point likert-type scale ranging from 1 = 'strongly disagree' to 7 = 'very strongly agree'. Items are summed and divided by their number to form the total score which can range from 1 to 7. As the total score increases so does the level of perceived social support. Some evidence for the construct validity of the measure was provided through a factor analysis. Three factors were identified in different studies and consistently reflected the three sub-groups of social support the measure was designed to query

i.e. family, friends and significant others. The internal consistency of the scale was reported to range from .85 to .95 (Canty-Mitchell and Zimet, 2000). Several studies have replicated psychometric properties in different cultural contexts (Mantuliz and Castillo, 2002; Wang et al., 2017; Wongpakaran et al., 2018)

Quality of Life

The Medical Outcome Study HIV (MOS-HIV) (Wu et al., 1997) consists of 35-item measure that are rated with 3,5 and 6-point Likert-type response responses. Subscale items are transformed to form scores that range from 0 to 100 with higher scores representing better quality of life and health. A final total score is computed by adding subscales and dividing them by their number. The MOS-HIV assesses several dimensions of quality of life: general health perceptions, physical function, role function, social function, pain, mental health, fatigue, health distress and transition[4]. Several studies reported internal consistency to range between .75 and .94 across different subpopulations of PLWHIV (Henderson et al., 2010; Wu et al., 1997). Multi-trait analysis also brought forward evidence for convergent and divergent validity of the measure across different stages of the illness (Wu et al., 1997).

Experiences of Discrimination

The Everyday Discrimination Scale (EDS) (Williams et al., 1997) consists of two sets of items: 'discrimination frequency' and 'discrimination attributions'. Discrimination frequency consists of nine items that are rated on a likert-type scale ranging from 1 = 'never' to 6 = 'almost every day'. The measure queries generic experiences of discrimination a respondent may have encountered over the period of 12 months (e.g. "You are called names or harassed"). The item scores are then

---

[4] The health transition item assess whether the participant has had a self-perceived change in health status over the last four weeks.

summed to create a frequency score of experiences of discrimination that ranges from 6 to 54. Higher scores indicate a higher frequency of experiences of discrimination.

For 'discrimination attributions', participants are asked: "What do you think are the main reasons for these experiences [of discrimination]? Participants can then choose from a list of 10 characteristics the main reasons they attribute to having been discriminated against. Participants can also choose the option 'other' to include characteristics that were not included in the list. The count of attributed characteristics is then computed.

The EDS has consistently demonstrated good internal consistency (Reeve et al., 2011; Shariff-Marco et al., 2011) and construct validity (Krieger et al., 2005), retaining psychometric properties and validity across different cultural groups (Chan et al., 2012; Gonzales et al., 2016)

Data Analysis

Data were analysed with SPSS version 21. Categorical sample characteristics were summarised and compared to national statistics to gauge sample representativeness. Averages and distributions of the measures adopted in the study were computed together with reliability coefficients. Because recruitment took place at the start of the COVID-19 pandemic, the relationship between IU and sampling time was also explored by computing a scatterplot and a linear regression of IU on sampling time. Relationships between variables employed in the study were initially explored with bivariate correlations. In order to control for confounding effects, demographic variables exhibiting significant moderate correlations with outcome variables were included as covariates in inferential analysis.

Hypothesis were tested with two linear regressions: a) a hierarchical linear model, and b) a linear multiple regression. Assumptions for linear regression modelling were tested.

a) Hierarchical regressions can be employed to build on previous research. This type of regression allows the introduction of variables at different stages of analysis and compares the change in explanatory power of a regression model. Covariates and predictors adopted in previous research are initially added to the model followed by new predictors. Following this procedure, IU was regressed in a stepwise manner on social support followed by experiences of discrimination (frequency of discrimination, and count of characteristics attributed) in order to confirm previous research linking social support to IU (i.e hypothesis 1) and to explore the predictiveness of discrimination on IU (i.e. hypothesis 2 and 3). This process is described in the following steps:

Model 1.

$$illness\ uncertainty = intercept + \beta_{1a}\ covariate_1 \ldots + \beta_{na}\ covariate_n + error$$

Model 2.

$$illness\ uncertainty = intercept + \beta_{1b}\ covariate_1 \ldots + \beta_{nb}\ covariate_n +$$
$$\beta_{ib}\ social\ support\ + error$$

Model 3.

$$illness\ Uucertainty = intercept + \beta_{1c}\ covariate_1 \ldots + \beta_{nc}\ covariate_n +$$
$$\beta_{ic}\ social\ support + \ \beta_{jc}\ discrimination\ attributions + error$$

Model 4.

$$illness\ uncertainty =$$

$$intercept + \beta_{1d}\ covariate_1\ ... + \beta_{nd}\ covariate_n +\ \beta_{id}\ social\ support$$

$$+ \beta_{jd}\ discrimination\ attributions +\ \beta_{kd}\ discrimination\ frequency$$

$$+\ error$$

b) A second multiple regression regressed quality of life on IU in order to confirm hypothesis four. This regression included covariates and all measures adopted in the study so to allow for comparison of predictiveness of the different variables.

$$Quality\ of\ Life$$

$$= intercept + \beta_{1e}\ Covariate_1\ ... + \beta_{ne}\ covariate_n +\ \beta_{ie}\ social\ support$$

$$+ \beta_{je}\ illness\ uncertainty + \beta_{ke}\ discrimination\ attributions$$

$$+\ \beta_{le}\ discrimination\ frequency + error$$

Statistical Power and Sample Size

Sample size was estimated in order to ensure the analysis would have 95% probability of detecting a medium size effect (f^2=.15) if present. The program G*Power was employed for this computation (Erdfelder et al., 2009). Alpha was set at .05 and a necessary sample size of 119 participants was returned for a linear regression model with eight predictors. In order to prevent familywise error inflation with the use of regression, Mundfrom et al. (2006) recommend adopting a multiple comparisons test. Midway et al. (2020) suggest the use of Bonferroni corrections for planned comparisons based on parametric data. A Bonferroni correction based on the number of hypotheses being tested and the number of comparisons being carried out was calculated:

Bonferroni corrected Alpha = Alpha / (Total number of hypotheses tested)

$$= .05/7 = .007$$

The Bonferroni corrected Alpha was adopted to test for significance of inferential statistics.

Results

Demographics

Table 1 summarises the demographic characteristics of participants that completed the survey.

Table 1

Participant demographics (N=125)

	M	Median	SD	Skewness	Kurtosis	Range
Age (Years)	46.7	49.0	11.5	-.85	-.91	18-71
Education (Years)	15.9	16.0	5.5	-.30	.15	2-29
Year since tested HIV+	13.9	11	9.9	.78	-.49	1-35
	n	%				
Gender						
Female	12	9.6				
Male	106	84.8				
Gender diverse	6	4.8				
Prefer not to say	1	.8				
Ethnicity						
White	98	78.4				
Asian	2	1.6				
Black	9	7.2				
Other	14	11.2				
Prefer not to say	2	1.6				
Employment status						
Employed in last 12 months	90	72.6				
Not employed in last 12 months	33	26.6				
Prefer not to say	2	.16				
Relationship status						
Single	53	42.4				
Married/Civil partner.	30	24.0				
Living with partner	23	18.4				

In a relationship	8	6.4	
Divorced/Separated	7	5.6	
Widowed	1	.8	
Prefer not to say	3	2.4	

Sexual orientation

Heterosexual	15	12.0	
Gay or Lesbian	91	72.8	
Bisexual	11	8.8	
Other	6	4.8	
Prefer not to say	2	.16	

Country of residence

Australia	6	4.8	
Canada	7	5.6	
Ireland	2	1.6	
United States	36	28.8	
United Kingdom	74	59.2	

One hundred and twenty-five participants had been diagnosed HIV-positive for a mean average of 13.9 years, they were predominantly male (n = 106), middle aged (median = 49 years) of white ethnic background (n=98) and non-heterosexual (n = 108). The majority of participants had some form of employment (72.6 %) and while half was single, divorced or separated (48.0%) the other half was involved in some form of long-term relationship (48.8%). The large majority of participants lived in the UK (n = 74) and the United States (n = 36).

In comparing UK National demographics to the demographics of the UK sub-sample of this study (see Table 2), it becomes apparent that the UK sub-sample is not nationally representative as it under-represents women and black and ethnic minorities. Age distribution in the sample appears to be more reflective of national statistics though older age individuals (i.e.65 and over) are not represented in this sub-sample.

Table 2

Comparison of UK sample characteristics with UK national statistics of people living with HIV

	UK National Statistics[5]	Sample
	%	%
Gender		
Female	30.9	4.1
Male	68.9	93.2
Ethnicity		
White	54.4	86.5
Asian	3.8	1.4
Black	34.1	5.4
Other	5.5	6.8
Age		
25-34	13.1	24.3
35-49	44.2	41.4
50-64	33.8	34.3
64 and over	6.0	

Descriptive Statistics

A missing data analysis was carried out and eight values were found to be missing across five variables. The small rate of missing values poses little threat of bias to the analysis and a multiple imputation was regarded unnecessary. In order to include all cases in the analysis and to minimise effects of listwise deletion missing values were replaced with corresponding means (Acock, 2012). As shown in Table 3, internal consistencies computed returned comparable values to the ones reported in previous research and provided further evidence of the reliability of all measures.

---

[5] National AIDS Trust UK (2020).

While means and distributions of the scores are dependent on the sample, descriptive statistics of the measures employed in this study were found to be within the same ranges as to those of previous research. Means and standard deviations computed for the MUIS-C were comparable to the descriptive statistics of several studies cited in Mishel (1997). Similarly, subscale means and standard deviations of the MOS-HIV were found to be comparable to those reported in Wu et al. (1997) and, as would be expected, showed higher means when compared to studies based on symptomatic clinical samples Wu et al. (1992)[6]. Means for the EDS are bound to differ depending on the subpopulation explored by a given study. However, studies showed similar distribution properties (Clark et al., 2004). Means and standard deviations of the MSPSS were comparable those reported in Zimet et al. (1990).

Table 4 shows bivariate correlations between the variables explored in the study. As would be expected from theory and previous research, statistically significant and strong negative relationship were found between a) the MUIS-C and MOS-HIV and b) between the MSPSS and the MUIS-C. All directions of statistically significant correlations reported in Table 4 were in line with theory and previous research. Both the MOS-HIV and the MUIS-C presented similar correlation coefficients in strength to four variables: years since tested positive, relationship status, employment status and education history. Variable means for UK and USA sub-samples were computed in the form of a bar chart and returned overlapping confidence intervals (see appendix J). The bar chart suggests there are no major differences between the groups that could confound statistical analysis.

Data harvesting started on the 7th of February 2020 and took place over a period of 77 days. The World Health Organization declared a global pandemic on the 11th of March 2020 (World

---

[6] As cited in Wu et al (1997)

Health Organization, 2020a). It is plausible that a pandemic breakout might impact the way participants score on IU. Figure 1 shows a scatterplot of scores of the MUIS-C across sampling time in days. The scatterplot seems to suggest a drop in scores across sampling time. A linear model regressing the MUIS-C on the sampling time was computed. Sampling time came close to being predictive of IU (MUIS-C), β=-.155, t (124)=-1.74 at p=.084 and the model explained 2.4% of variance in MUIS-C scores. While not statistically significant at p<.05, this model indicates sampling time could potentially act as confounding variable in the analysis.

Figure 1

Scatterplot of MUIS-C scores across time (days)

- 62 -
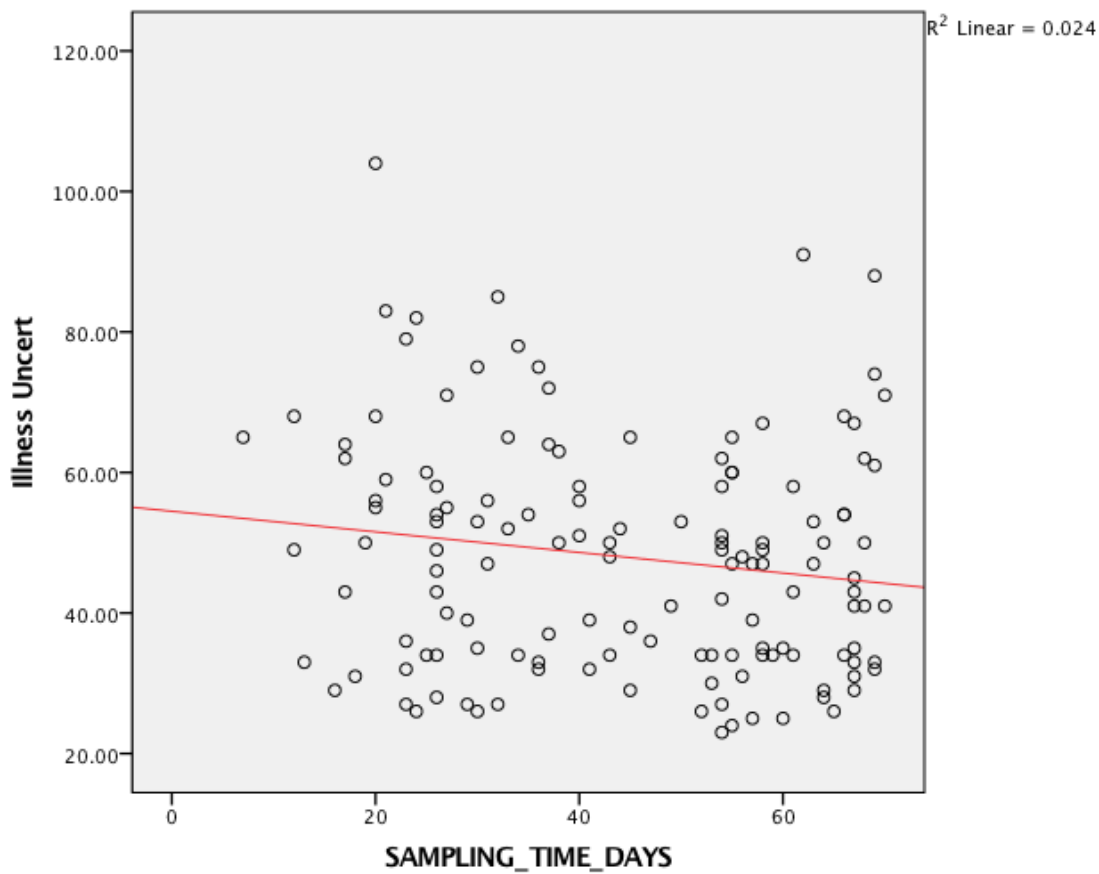
Table 3

Descriptive statistics of measures (N=125)

Measure	M	Median	SD	Range	Skewness (SE)	Kurtosis (SE)	Chronbach's Alpha
MUIS-C	47.8	47.0	17.4	23-104	.70 (.22)	.02 (.43)	.94
EDS							
Frequency	21.4	19.0	10.85	9.0-54.0	1.11 (.22)	.69 (.43)	.94
Attributions	2.14	2.0	1.59	0-11	2.03 (.22)	6.97(.43)	
MOS-HIV	61.74	66.7	18.7	17.0-91.4	-.67 (.22)	-.51 (.43)	.95
MSPSS	5.0	5.2	1.53	1-7	-.73 (.22)	-.18 (.43)	.94

Table 4

Bivariate correlations of variables (N=125)

		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1	**Gender**												
2	**Ethnicity**	.05											
3	**Age**	-.273**	-.143										
4	**Years since tested positive**	-.059	.096	.459**									
5	**Sampling time**	.114	-.099	-.03	-.057								
6	**Relationship Status**	-.022	-.109	.024	-.039	.217*							
7	**Employment**	-.017	.06	-.375**	-.282**	.148	.203*						
8	**Education history**	-.058	-.005	.173	.109	.078	.187*	.167					
9	**QoL (MOS-HIV)**	-.058	.042	.019	-.257**	.132	.251**	.414**	-.255**				
	Discrimination (EDS):												
10	Frequency	.111	.125	-.195*	.094	-.132	-.270**	-.182*	.229*	-.573**			
11	Attributions	.343**	.247**	-.168	.134	.031	-.230*	-.064	.125	-.375**	.509**		
12	**Perceived Social Supp (MSPSS)**	.123	.034	-.095	-.176*	.138	.452**	-.218*	-.245**	.551**	-.441**	-.202*	
13	**Illness Uncertainty (MUIS-C)**	.094	-.021	.084	.225*	-.155	-.254**	.338**	.247**	-.727**	.603**	.406**	-.530**

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis Testing

Hierarchical Multiple Regression on Illness Uncertainty

The hierarchical linear regression model presented in this analysis is based on several assumptions. For linear regressions to compute unbiased parameters it is necessary that residuals are normally distributed. The probability plot of standardised regression residuals against the standardised predicted values in appendix L suggests a mostly even distribution around 0. Furthermore, Lumley et al. (2002) was able to show that, linear regression models based on least square methods are robust to breaches of normality. The probability plots also indicate that neither heteroscedasticity nor non-linearity were of particular concern in this sample (Field, 2009). Furthermore, a Durbin-Watson test of 1.843 was computed to test for independence of errors. As the value is close to 2 the assumption of independence of errors was held (Savin and White, 1977). Multicollinearity statistics indicated a small degree of multicollinearity. Table 4 did not show strong correlation coefficients between predictors. Variance inflation factors computed in the analysis ranged between 1.068 and 1.645 which is below the critical value of 10 (Daoud, 2018). Furthermore, all tolerance levels computed in the analysis were > .2 (Daoud, 2018) indicating the absence of problematic multicollinearity.

Table 5 summarizes the results for the hierarchical linear regression model for IU. The change in R^2 was significant across all steps of the hierarchical regression, indicating that after adjusting for covariates (i.e. relationship and employment status, educational history, and time since receiving an HIV diagnosis), adding the predictors social support, discrimination attributions and discrimination frequency produced a statistically significant improvement in predicting IU. Specifically, the model at step four was statistically significant ($F_{(7, 124)}=18.77$, $p<0.0001$) and explained 48.2% of the variance in IU.

H. 1 High levels of social support are associated to lower levels of illness uncertainty.

In line with previous research, social support was moderately associated with IU. The model shows that PLWHIV reported higher levels of social support if they reported lower levels of IU (b=-3.366, SE=.894, p=.0001), hypothesis one was therefore supported.

H. 2 Experiencing multiple forms of discrimination is associated to higher levels of illness uncertainty.

Discriminations attributions was moderately associated to IU at step three of the hierarchical regression. PLWHIV that attributed a higher number of stigmatised characteristics to their experiences of discrimination reported higher levels of IU (b=3.245, SE =.773, p= .0001), hypothesis three was therefore supported.

However, introducing discrimination frequency to the model at step four, reduced the relative importance of discrimination attributions in explaining variance of IU (as can be observed from the drop in β-coefficient from step three to step four) and rendered it statistically non-significant (b=1.569, SE =.818, p= .058). In light of these results and the moderate bivariate correlation between discrimination frequency and discrimination attributions (r(123)=.51, p=.0001) it is suggested that discrimination frequency may partially mediate the effect between discrimination attributions and uncertainty in illness.

H. 3 Frequency of discrimination experiences are associated to higher levels of illness uncertainty.

Reporting higher frequency experiences of discrimination (i.e. discrimination frequency) was moderately associated to higher scores of self-reported IU (b=.567, SE =.131, p= .0001. In fact, discrimination frequency was the strongest predictor in the model (β=.359) overall, even more so than social support (β = -.302).

SPSS v.21 output also provides coefficient estimates of excluded variables at various stages of the hierarchical regression. In the absence of discrimination attributions, at step two, the standardised coefficient of discrimination frequency rises to $\beta=.434$. This means that assuming all other predictors are kept constant, one standard deviation increase in discrimination frequency will result in a .43 standard deviation increase in IU.

Overall, these results support hypothesis three and suggest that discrimination frequency accounts for more variance in IU than any other predictor in the model.

Table 5

Results of hierarchical linear regression model predicting illness uncertainty[7] (N = 125)

	Step 1				Step 2				Step 3				Step 4			
	b	(SE)	β	sig.	b	(SE)	β	sig.	b	(SE)	β	sig.	b	(SE)	β	sig.
Years since tested positive	.314	.15	.181	.038	.186	.138	.107	.179	.116	.13	.067	.375	.138	.121	.079	.259
Relationship status																
Single	Reference				Reference				Reference				Reference			
In a relationship	-5.536	2.917	-.16	.06	.645	2.897	.019	.824	2.107	2.736	.061	.443	2.068	2.55	.06	.419
Employment																
Not employed	Reference								Reference				Reference			
Employed	-8.235	3.424	-.212	.018	-7.185	3.109	-.185	.023	-7.751	2.916	-.2	.009	-6.653	2.73	-.171	.016
Years of education	-.634	.266	-.202	.019	-.382	.246	-.122	.123	-.291	.231	-.093	.212	-.202	.217	-.064	.352
Social support					-5.008	.96	-.45	.0001	-4.663	.903	-.419	.0001	-3.366	.894	-.302	.0001
Discrimination																
Attribution									3.245	.773	.303	.0001	1.569	.818	.146	.058
Frequency													.567	.131	.359	.0001
Change statistics																
R2 Change	.2				.149				.085				.078			
Sig. of change in R2	.0001				.0001				.0001				.0001			
Adjusted R2	.173				.321				.404				.482			

---

[7] The following effect size heuristics were employed in the interpretation of the results: "β < 0.20 is considered a weak effect, β between 0.2 and 0.5 is considered a moderate effect, and β >0.5 is considered a strong effect" (Acock, 2014, p.727)

Characteristics Attributed to Experiences of Discrimination.

Table 6

EDS count of attributed characteristics by ethnicity (N=125)

	White n (within%)	Asian n (within%)	Black n (within%)	Other ethnic background n (within%)
Attributed Characteristics				
Nationality	7 (7.1)	0	4 (44.4)	8 (57.1)
Gender	14 (14.3)	0	3 (33.3)	2 (14.3)
Race	4 (4.1)	2 (100)	7 (77.8)	4 (28.6)
Age	22 (22.4)	0	1 (11.1)	0
Religion	2 (2.0)	0	1 (11.1)	2 (14.3)
Weight	13 (13.3)	0	2 (22.2)	0
Physical appearance	11 (11.2)	0	3 (33.3)	3 (21.4)
Sexual orientation	53 (54.1)	0	3 (33.3)	8 (57.1)
Education or income level	12 (12.2	0	2 (22.2)	2 (14.3)
HIV status	41 (41.8)	0	5 (55.6)	6 (42.9)
Other	19 (19.4)	0	0	2 (17.1)
Ranking				
1	Sexuality	Race	Race	Sexuality/
2	HIV-stat.		HIV-status	Nationality
3	Age		Nationality	
4	Other			HIV status
5	Gender		Gender/	Race
6	Weight		Sexuality/	Phys. app.
7	Education		Phys. app.	Other
8	Physical app.			
9	Race		Education/	Education/
10	Nationality		Weight	Religion/
11	Religion			Gender
			Age/	
			Religion	

One hundred twenty-one participants (i.e. 96.8 % of the participants to this study) reported experiences of discrimination. A median of two stigmatised characteristics were attributed to these experiences. Table 6 shows the count of characteristics attributed to experiences of discrimination

by ethnicity. As can be seen from the table the top-ranking characteristics attributed were 'race'

for Black and Asian ethnic groups and 'sexuality' for White and 'other' minoritised ethnic groups.

Nationality was also the second and third top-ranking attributed characteristic for black and 'other'

ethnicities respectively. 'HIV-Status' was the second top ranking attributed characteristic for

White and Black ethnicities and third top ranking for 'other' ethnic minorities. PLWHIV that also

selected 'other characteristic' reported being discriminated against also because of their: mental

health, disability and self-confidence. These results provide insight into some of the experiences

of discrimination of PLWHIV constituting this sample but are unlikely to represent other sections

of the population under-represented here (e.g. women, trans men and women, gender diverse

individuals etc.). What is evident from this sample, however, is that experiences of discrimination

of PLWHIV are varied and reflect a multitude of systematic societal oppressors.

Multiple Regression on Quality of Life

Table 7

Results of linear regression model predicting quality of life (N = 125)

	b	(SE)	β	sig.
Years since tested positive	-.106	.117	-.056	.368
Relationship status				
Single	Reference			
In a relationship	1.881	2.451	.05	.444
Employment				
Not employed	Reference			
Employed	7.672	2.681	.181	.005
Years of education	.129	.208	.038	.538
Social support	2.504	.907	.206	.007
Illness Uncertainty	-.464	.089	-.426	.0001
Discrimination				
Attributions	-.782	.796	-.067	.328
Frequency	-.272	.135	-.158	.046

Adjusted R2	.599
Sig.	.0001

Table 7 summarises the results of a second linear regression that was computed on quality of life to test hypothesis four. Assumptions of linearity, normality and homoscedasticity were investigated through the inspection of residual against predicted value probability plots (appendix M). The assumptions were confirmed. Multicollinearity was assessed by inspecting variance inflation factors (1.151 to 1.909) and tolerance levels (.489 to .869) which were all within the acceptable range. A Durbin-Watson test confirmed the condition of independence of residual error (d = 2.037). The model explains 59.9% of the variance in quality of life of PLWHIV and was found to be highly significant ($F_{(8, 124)}$=24.187, p<0.0001). PLWHIV that reported working in the last 12 months (b=7.672, SE =2.681, p= .005) and having access to social support (b=2.504, SE =.907, p= .007) reported higher levels of quality of life.

H. 4 Lower levels of illness uncertainty are associated to higher levels of reported quality of life.

A moderate strength association was found between IU and quality of life. PLWHIV that reported experiencing lower levels of IU (b=-.464, SE =.089, p= .0001) reported higher levels of quality of life. Hypothesis four was thus supported. Neither discrimination attributions (b=-.782, SE =.796, p= .328) nor discrimination frequency (b=-.272, SE =.135, p= .046) were significant predictors of quality of life in this regression model.

Standardized coefficients enable the comparison of the relative strength of the variable in predicting quality of life. As can be seen from Table 7 IU accounts for most of the variance in quality of life in this model. In fact, one standard deviation increase in IU is shown to be associated

with a .43 standard deviation decrease in quality of life, assuming all other variables are kept

constant.

Figure 1 presents a visual summary of the results of both regressions.

Figure 2

Visual summary of inferential statistics showing standardised coefficients (β) and significance
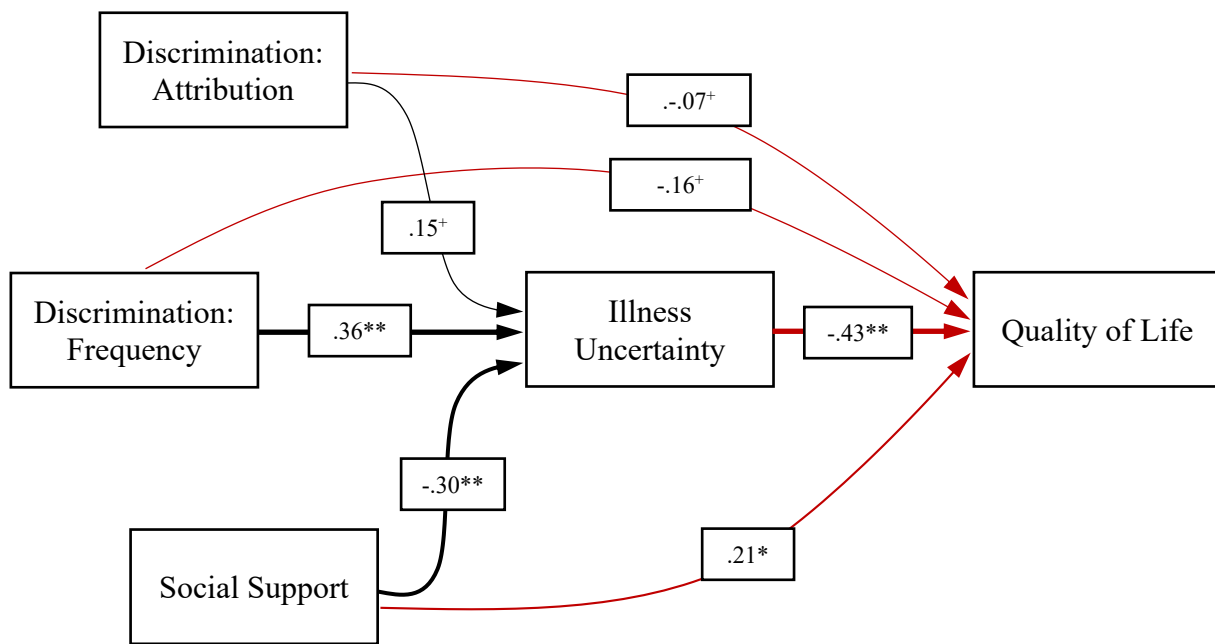
▬	Hierarchical regression on illness uncertainty: Model 4, Adjusted R Squared = .482
▬	Regression on quality of life, Adjusted R squared = .599

+ = statistically non-significant i.e. p > .007
* = statistically significant at p = .007
** = statistically significant at p = .0001

Discussion

The main aim of this study was to explore how the social environment of PLWHIV may be related to their experiences of IU. Specifically, to explore the relationship between stigma, social support and IU. Further, this study also aimed to replicate in a population of PLWHIV, findings showing an inverse relationship between IU and quality of life.

Main Findings

This study found that higher levels of reported social support were related to lower levels of reported IU. These findings are in line with previous research exploring this relationship in different populations of individuals living with chronic conditions (Hoth et al., 2015; Lien et al., 2009; Sammarco, 2001) and PLWHIV (Sajjadi et al., 2015). They are also in line with UIT and provide further support for the notion that supportive family members, friends and partners play an important role in the experiences of IU of individuals living with chronic conditions, such as HIV. Conversely, reports of higher levels of stigma were found to be related to higher levels of reported IU. Specifically, PLWHIV attributing discrimination to multiple stigmatised identities tended to report higher levels of IU. Furthermore, reporting a higher frequency of instances of discrimination was also associated to reports of higher IU. However, frequency of discrimination experiences was found to be a better predictor of IU compared to counts of discrimination attributions, as it explained much larger portions of variance in IU. Though no hypothesis was put forward in this study as to which sub-measure of stigma would present a stronger relationship to IU, this finding poses the question of why this difference was so stark. While the results suggested that frequency of discrimination may partially mediate the relationship between discrimination attributions and IU, there may be alternative explanations as to why frequency of discrimination was a better linear predictor of IU.

In their study, Seng et al. (2012) argued that relying on the sum of discrimination attributions can be simplistic and may not capture the valences and potential combination effects present in the attribution of discrimination to more than one stigmatised identity. In essence, they suggest that the experiences of discrimination attributed to one form of stigma may not be equivalent when attributed to another form and may thus impact individuals differently. For instance, it could be postulated that, PLWHIV experiencing homophobia and HIV-stigma, may be more able to access supportive communities, than individuals that experience HIV-stigma and racism. While this example is based on conjecture, it would be a plausible hypothesis considering the historical involvement of gay communities in HIV anti-stigma campaigning (Clews, 2017). The same level of support may not be available for individuals also experiencing racism. Identifying such combination effects could be relevant in addressing particular target groups more vulnerable to the effects of stigma on IU. At any rate, these results suggest that stigma and discrimination may play an important role in the experiences of IU of PLWHIV and that, as shown in Table 6, the episodes of discrimination PLWHIV experience are varied and not originating exclusively from HIV-stigma. Of particular note is the comparative predictive strength of discrimination frequency compared to social support, a predictor whose relevance to IU has been established through multiple studies. In fact, based on these results and UIT it could be postulated that experiences of discrimination could moderate access to social support, and through this process influence the formation of cognitive states that result in IU. The findings in this study, however, do not give us insight into such moderation hypotheses. Indeed, others have suggested the relationship between health stigma and IU could be explained through different mechanisms, such as increased arousal and hypervigilance related to discriminatory experiences which could in

turn affect the cognitive processes that lead to IU (Gamwell et al., 2020). These hypotheses require further testing.

Finally, this study was able to replicate previous findings reporting moderate strength relationships between IU and quality of life in samples of individuals living with chronic conditions (Fortier et al., 2013; Guan et al., 2020; Hoth et al., 2013; Parker et al., 2013; Wonghongkul et al., 2006b). Self-reported IU showed a moderate strength relationship to quality of life in PLWHIV and explained twice as much variance in quality of life as self-reports of social support. These findings provide further support for the relevance of IU in the quality of life of PLWHIV. Of note, when viewing the summary of results of both regression analyses (see Figure 1), are the small non-significant relationships of the two sub-measures of stigma to quality of life in spite of numerous studies reporting moderate relationships (Bergeron et al., 2020; Chapman Lambert et al., 2020; Logie et al., 2018). The non-significance of these weak relationships could in fact be due to a shared covariance of measures of discrimination with IU, as illustrated by the bivariate correlation matrix in Table 4. These results could suggest that IU partially mediates the relationship between stigma and quality of life. However, a full mediation analysis was not completed in this study and Wu and Zumbo (2008) remind us that mediation analysis is a causal analysis that should not, ideally, rest on cross-sectional designs as this one.

Strengths and Limitations

This study provides a nuanced exploration of the relationship between social environment and IU in PLWHIV. To our knowledge, this is the first study that has explored the relationship between multiple forms of stigma and IU. However, the fact that the stigma measure employed here was not specifically developed for PLWHIV, could mean that many experiences of health-related stigma were left uncaptured. This could have resulted in the under-representation of participant's

experiences of health-related stigma and arguably, may have encouraged those who felt unable to report their experiences, to discontinue participating to the survey.

The study made use of convenience sampling which has resulted in a sample of PLWHIV that appears not to be representative of the wider population. In fact, the UK sub-sample of this study, is under-representing women, people from Black and Asian ethnic backgrounds and Trans people. The effects of self-selection are also likely to have been particularly strong in this sample due to the well documented relationship between IU and avoidant coping (Guan et al., 2020). Furthermore, it is possible, that experiences of discrimination might systematically impact individual's motivation to participate to the study, thus potentially impacting the sample's composition. It should also be noted that collecting data through the internet excludes individuals that may not have online access which in the UK, for example, account for 10% of the population (Office for National Statistics, 2019). Self-report measures are known to be vulnerable to social-desirability and acquiescence (Barker et al., 2002) and in combination with a non-representative sample this could have resulted in the alteration of significance and magnitude of some relationships. The study did not control for such extraneous variables as illness progression or the presence of other conditions. These sources of bias require that caution be used in the interpretation and generalization of the results. Caution should also be used in inferring causality of the relationships due to the cross-sectional nature of the design employed here.

Finally, sample size and consequently statistical power posed limitations to the extent of inferential statistics that could be employed in this study. For example, the inclusion of interaction terms in the multiple regressions would have required much larger sample sizes (Shieh, 2009).

Future Research

Based on the limitations inherent to this study and its main findings, several directions of future research have emerged. These results warrant further exploration of the relationships between measures of stigma, social support and IU. Specifically, determining if there is a significant interaction between measures of stigma and social support on measures of IU would be an initial step in exploring the hypothesis that the relationship between social support and IU is moderated by stigma and experiences of discrimination.

Furthermore, this study raises the question of whether discrimination frequency mediates a potential effect of discrimination attributions on IU and whether different combinations of discrimination attributions may be differentially related to IU. An idiographic approach to the study of these relationships would be more appropriate as it would allow their exploration within groups of individuals that share similar characteristics and experiences (Bergman et al., 2003).

Finally, the results of this study also warrant further exploration of the relationship between experiences of stigma and quality of life and the potential mediating role of IU in this relationship.

Clinical Implications

Findings of the current study indicate that PLWHIV might be more vulnerable to IU due to the burden of multiple stigmas that this population is confronted with. Though conclusions can only be tentative, these results and previous research allow for the following hypothesis. Individuals that experience high levels of stigma, potentially experience higher levels of social exclusion and, as a consequence, find it more difficult to form coherent cognitive representations of their illness related events; This in turn could lead to higher levels of IU; As has been shown by much research in the field, IU can often be appraised as threat and lead to affective responses that result in avoidant coping styles, such as treatment non-adherence. This hypothesis describes a vicious cycle

that can result in continually worsening health outcomes for the individuals experiencing high levels of stigma. However, it also offers different sites of intervention. First of all – it identifies potential target populations more vulnerable to IU. According to UIT health care professionals are central in helping individuals form coherent cognitive representations of illness related events. Clinicians have thus the opportunity to identify individuals that are more vulnerable to stigma and support them in making sense of their illness events. They can do this in many of the ways that have already been discussed elsewhere in nursing literature (Clayton et al., 2018), such as supporting them in the reappraisal of uncertainty from stressful to hopeful, or more simply, providing information that meet the communication needs of specific patient groups.

An alternative site of intervention would be to provide forms of peer-support based on a multifaceted understanding of the person's identity. Buddy programs oriented by the individual's prior experiences of stigma, could for instance facilitate access to social support that might otherwise feel threatening. Indeed, interventions based on buddy programs for PLWHIV have already been trialled by Brashers et al. (2017). A future adaptation of such program could see potential participants express their preference in terms of shared experience they would need to have with their buddy, including those that might be related to identifying with one or more stigmatised identities.

Other sites of intervention are related to staff training at HIV clinical services and could consist in sensitising staff to sources of uncertainty that are specific to stigmatised groups of individuals and how to support such individuals in managing these uncertainties. Such training would naturally be specific to the area and community in which the service was active and would need to be rich in service-user knowledge and involvement.

Conclusions

This study expands and builds on previous research evidencing the role of the social environment in the experiences of IU of people living with chronic conditions. Specifically, the results showed that in a non-representative sample of PLWHIV, frequency of experiences of discrimination and counts of attributed stigmatised characteristics were related to higher levels of IU. Furthermore, social support was also found to be moderately and inversely related to IU. This study provides further support for UIT and its applications. The results suggest that addressing experiences of stigma and discrimination in minoritised people living with HIV could impact the level of IU they experience, and potentially improve their quality of life. The results also provide further support for the use of individual's social context as site of intervention for the management of IU. However, further research exploring the mechanisms involved in these relationship is warranted in order to ascertain causality and gain further understanding of the role that social support may play in them.

References

Acock, A C. (2012). What to do About Missing Values. In P. Harris Cooper (Ed.), *APA Handbook of Research Methods in Psychology*. (pp. 27–50). American Psychological Association. https://doi.org/10.1037/13621-002

Acock, Alan C. (2014). *A Gentle Introduction to Stata* (4th ed.). Stata Press.

Arechabala Mantuliz, M. C., and Miranda Castillo, C. (2002). Validacion de una escala de apoyo social percibido en un grupo de adultos mayores adscritos a un programa de hipertension de la region metropolitana. *Ciencia y Enfermeria*, *8*(1), 49–55.

Barker, C., Pistrang, N., Elliott, R., and Barker, C. (2002). *Research methods in clinical psychology : an introduction for students and practitioners*. J. Wiley.

Bergeron, G., Lundy De La Cruz, N., Gould, L. H., Liu, S. Y., and Levanon Seligson, A. (2020). Association between racial discrimination and health-related quality of life and the impact of social relationships. *Quality of Life Research*, *29*(10), 2793–2805. https://doi.org/10.1007/s11136-020-02525-2

Bergman, L. R., Magnusson, D., and El-Khouri, B. M. (2003). Studying individual development in an interindividual context: A person-oriented approach. In *Paths through life*. Lawrence Erlbaum Associates Publishers.

Blake, A., Asnani, V., Leger, R. R., Harris, J., Odesina, V., Hemmings, D. L., Morris, D. A., Knight-Madden, J., Wagner, L., and Asnani, M. R. (2018). Stigma and illness uncertainty: adding to the burden of sickle cell disease. *Hematology*, *23*(2), 122-130. https://doi.org/10.1080/10245332.2017.1359898

Bogart, L. M., Wagner, G. J., Galvan, F. H., and Klein, D. J. (2010). Longitudinal relationships between antiretroviral treatment adherence and discrimination due to HIV-serostatus, race,

and sexual orientation among African-American men with HIV. *Annals of Behavioral Medicine*, *40*(2), 184-190. https://doi.org/10.1007/s12160-010-9200-x

Brashers, D. E., Basinger, E. D., Rintamaki, L. S., Caughlin, J. P., and Para, M. (2017). Taking Control: The Efficacy and Durability of a Peer-Led Uncertainty Management Intervention for People Recently Diagnosed With HIV. *Health Communication*, *32*(1), 11–21. https://doi.org/10.1080/10410236.2015.1089469

Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., Haas, S. M. (1999). "In an important way, I did die": uncertainty and revival in persons living with HIV or AIDS. *AIDS Care*, *11*(2), 201–219. https://doi.org/http://dx.doi.org/10.1080/09540129948090

Brashers, D. E., Neidig, J. L., and Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication*, *16*(3), 305–331.

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., and Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs*, *67*(1), 63–84. https://doi.org/http://dx.doi.org/10.1080/03637750009376495

Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., Garland, M., McCartney, B., and Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing*, *24*(5), 497–522. https://doi.org/10.1080/01612840305292

Bravo, P., Edwards, A., Rollnick, S., and Elwyn, G. (2010). Tough decisions faced by people living with HIV: a literature review of psychosocial problems. *AIDS Reviews*, *12*(2), 76–88.

British Psychological Society. (2014). *Code of Human Research Ethics*. https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy - Files/BPS Code of Human

Research Ethics.pdf

Canty-Mitchell, J., and Zimet, G. D. (2000). Psychometric properties of the multidimensional scale of perceived social support in urban adolescents. *American Journal of Community Psychology*, *28*(3), 391–400. https://doi.org/10.1023/A:1005109522457

Chan, K. T. K., Tran, T. V., and Nguyen, T. N. (2012). Cross-Cultural Equivalence of a Measure of Perceived Discrimination Between Chinese-Americans and Vietnamese-Americans. *Journal of Ethnic and Cultural Diversity in Social Work*, *21*(1), 20–36. https://doi.org/10.1080/15313204.2011.647348

Chan, K. Y., Stoové, M. A., and Reidpath, D. D. (2008). Stigma, social reciprocity and exclusion of HIV/AIDS patients with illicit drug histories: A study of Thai nurses' attitudes. *Harm Reduction Journal*, *5*(1), 28. https://doi.org/10.1186/1477-7517-5-28

Chapman Lambert, C., Westfall, A., Modi, R., Amico, R. K., Golin, C., Keruly, J., Quinlivan, E. B., Crane, H. M., Zinski, A., Turan, B., Turan, J. M., and Mugavero, M. J. (2020). HIV-related stigma, depression, and social support are associated with health-related quality of life among patients newly entering HIV care. *AIDS Care*, *32*(6), 681–688. https://doi.org/10.1080/09540121.2019.1622635

Clark, R., Coleman, A. P., and Novak, J. D. (2004). Brief report: Initial psychometric properties of the everyday discrimination scale in black adolescents. *Journal of Adolescence, 27(3), 363-368.* https://doi.org/10.1016/j.adolescence.2003.09.004

Clayton, M. F., Dean, M., and Mishel, M. (2018). Theories of uncertainty in illness. In *Middle Range Theory for Nursing, Fourth Edition*. https://doi.org/10.1891/9780826159922.0004

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., Morgan, C., Rüsch, N., Brown, J. S. L., and Thornicroft, G. (2015). What is the impact of

mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. In *Psychological Medicine*, *45*(1), 11-27. https://doi.org/10.1017/S0033291714000129

Clews, C. (2017). The AIDS Coalition to Unleash Power (ACT UP). In *Gay in the 80s : from fighting for our rights to fighting for our lives* (pp. 255–259). Troubador Publishing.

Crandall, C. S. (1991). Multiple stigma and AIDS: Illness stigma and attitudes toward homosexuals and IV drug users in AIDS-related stigmatization. *Journal of Community and Applied Social Psychology*, *1*(2), 165-172. https://doi.org/10.1002/casp.2450010210

Crossley, M. (1998). "Sick role" or "empowerment"? The ambiguities of life with an HIV positive diagnosis. *Sociology of Health and Illness*, *20*(4), 507–531.

Daoud, J. I. (2018). Multicollinearity and Regression Analysis. *Journal of Physics: Conference Series*, *949*(1), 12009. https://doi.org/10.1088/1742-6596/949/1/012009

Davis, Mark, Frankis, J., Paul;, F., Flowers, P., Paul;, F., and Flowers, P. (2006). Uncertainty and "technological horizon" in qualitative interviews about HIV treatment. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *10*(3), 323–344. https://doi.org/http://dx.doi.org/10.1177/1363459306064489

Davis, Mary, Ventura, J. L., Wieners, M., Covington, S. N., Vanderhoof, V. H., Ryan, M. E., Koziol, D. E., Popat, V. B., and Nelson, L. M. (2010). The psychosocial transition associated with spontaneous 46,XX primary ovarian insufficiency: Illness uncertainty, stigma, goal flexibility, and purpose in life as factors in emotional health. *Fertility and Sterility*. *93*(7), 2321-2329. https://doi.org/10.1016/j.fertnstert.2008.12.122

Erdfelder, E., FAul, F., Buchner, A., and Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*,

41(4), 1149–1160. https://doi.org/10.3758/BRM.41.4.1149

Field, A. (2009). *Discovering statistics using SPSS.* Sage Publications Limited.

Fletcher, F., Ingram, L. A., Kerr, J., Buchberg, M., Bogdan-Lovis, L., and Philpott-Jones, S. (2016). She Told Them, Oh That Bitch Got AIDS: Experiences of Multilevel HIV/AIDS-Related Stigma among African American Women Living with HIV/AIDS in the South. *AIDS Patient Care and STDs*, *30*(7), 349-356. https://doi.org/10.1089/apc.2016.0026

Fortier, M. A., Batista, M. L., Wahi, A., Kain, A., Strom, S., and Sender, L. S. (2013). Illness uncertainty and quality of life in children with cancer. *Journal of Pediatric Hematology/Oncology*, *35*(5), 366-370. https://doi.org/10.1097/MPH.0b013e318290cfdb

Furlotte, C., and Schwartz, K. (2017). Mental Health Experiences of Older Adults Living with HIV: Uncertainty, Stigma, and Approaches to Resilience. *Canadian Journal on Aging*, *36*(2), 125–140. https://doi.org/10.1017/S0714980817000022

Gamwell, K. L., Roberts, C. M., Espeleta, H. C., Baudino, M. N., Hommel, K. A., Grunow, J. E., Jacobs, N. J., Gillaspy, S. R., Mullins, L. L., and Chaney, J. M. (2020). Perceived stigma, illness uncertainty, and depressive symptoms in youth with inflammatory bowel disease: The moderating effect of mindfulness, *25*(9), 1037-1048. *Psychology, Health and Medicine*. https://doi.org/10.1080/13548506.2020.1714062

Goffman, E. (1974). *Stigma: Notes on the management of spoiled identity.* Touchstone. https://doi.org/10.2307/2575995

Gonzales, K. L., Noonan, C., Goins, R. T., Henderson, W. G., Beals, J., Manson, S. M., Acton, K. J., and Roubideaux, Y. (2016). Assessing the Everyday Discrimination Scale among American Indians and Alaska Natives. *Psychological Assessment*, *28*(1), 51–58. https://doi.org/10.1037/a0039337

Guan, T., Santacroce, S. J., Chen, D. G., and Song, L. (2020). Illness uncertainty, coping, and quality of life among patients with prostate cancer. *Psycho-Oncology*, 29(6), 1019-1025. https://doi.org/10.1002/pon.5372

Hagen, K. B., Aas, T., Lode, K., Gjerde, J., Lien, E., Kvaløy, J. T., Lash, T. L., Søiland, H., and Lind, R. (2015). Illness uncertainty in breast cancer patients: Validation of the 5-item short form of the Mishel Uncertainty in Illness Scale. *European Journal of Oncology Nursing*, *19*(2), 113–119. https://doi.org/10.1016/j.ejon.2014.10.009

Henderson, W. A., Schlenk, E. A., Kim, K. H., Hadigan, C. M., Martino, A. C., Sereika, S. M., and Erlen, J. A. (2010). Validation of the MOS-HIV as a measure of health-related quality of life in persons living with HIV and liver disease. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *22*(4), 483–490. https://doi.org/10.1080/09540120903207292

Herbst, J. H., Jacobs, E. D., Finlayson, T. J., McKleroy, V. S., Neumann, M. S., and Crepaz, N. (2008). Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. In *AIDS and Behavior*, *12*(1), 1-17. https://doi.org/10.1007/s10461-007-9299-3

Hibbert, M., Wolton, A., Crenna-Jennings, W., Benton, L., Kirwan, P., Lut, I., Okala, S., Ross, M., Furegato, M., Nambiar, K., Douglas, N., Roche, J., Jeffries, J., Reeves, I., Nelson, M., Weerawardhana, C., Jamal, Z., Hudson, A., and Delpech, V. (2018). Experiences of stigma and discrimination in social and healthcare settings among trans people living with HIV in the UK. *AIDS Care, 30(7), 836-843.* https://doi.org/10.1080/09540121.2018.1436687

Hoth, K. F., Wamboldt, F. S., Ford, D. W., Sandhaus, R. A., Strange, C., Bekelman, D. B., and Holm, K. E. (2015). The Social Environment and Illness Uncertainty in Chronic Obstructive Pulmonary Disease. *International Journal of Behavioral Medicine*, *22*(2), 223–232.

https://doi.org/10.1007/s12529-014-9423-5

Hoth, K. F., Wamboldt, F. S., Strand, M., Ford, D. W., Sandhaus, R. A., Strange, C., Bekelman, D. B., and Holm, K. E. (2013). Prospective impact of illness uncertainty on outcomes in chronic lung disease. *Health Psychology*, *32*(11), 1170–1174. https://doi.org/10.1037/a0032721

Krieger, N., Smith, K., Naishadham, D., Hartman, C., and Barbeau, E. M. (2005). Experiences of discrimination: Validity and reliability of a self-report measure for population health research on racism and health. *Social Science and Medicine*, *61*(7), 1576–1596. https://doi.org/10.1016/j.socscimed.2005.03.006

Lien, C. Y., Lin, H. R., Kuo, I. T., and Chen, M. L. (2009). Perceived uncertainty, social support and psychological adjustment in older patients with cancer being treated with surgery. *Journal of Clinical Nursing*, *18*(16), 2311-2319. https://doi.org/10.1111/j.1365-2702.2008.02549.x

Liu, C., Ostrow, D., Detels, R., Hu, Z., Johnson, L., Kingsley, L., and Jacobson, L. P. (2006). Impacts of HIV infection and HAART use on quality of life. *Quality of Life Research*, *15*(6), 941-949. https://doi.org/10.1007/s11136-005-5913-x

Logie, C. H., Wang, Y., Lacombe-Duncan, A., Wagner, A. C., Kaida, A., Conway, T., Webster, K., de Pokomandy, A., and Loutfy, M. R. (2018). HIV-related stigma, racial discrimination, and gender discrimination: Pathways to physical and mental health-related quality of life among a national cohort of women living with HIV. *Preventive Medicine*, *107*, 36–44. https://doi.org/10.1016/j.ypmed.2017.12.018

Lumley, T., Diehr, P., Emerson, S., and Chen, L. (2002). The importance of the normality assumption in large public health data sets. *Annual Review of Public Health*, *23*, 151–169.

https://doi.org/10.1146/annurev.publhealth.23.100901.140546

Mannetti, L., and Pierro, A. (1991). Health care workers' reactions to AIDS victims: Perception of risk and attribution of responsibility. *Journal of Community and Applied Social Psychology*. *1*(2), 133-142. https://doi.org/10.1002/casp.2450010207

May, M. T., Gompels, M., Delpech, V., Porter, K., Orkin, C., Kegg, S., Hay, P., Johnson, M., Palfreeman, A., Gilson, R., Chadwick, D., Martin, F., Hill, T., Walsh, J., Post, F., Fisher, M., Ainsworth, J., Jose, S., Leen, C., Glabay, A. (2014). Impact on life expectancy of HIV-1 positive individuals of CD4R cell count and viral load response to antiretroviral therapy. *AIDS*, *28*(8), 1193-1202. https://doi.org/10.1097/QAD.0000000000000243

Midway, S., Robertson, M., Flinn, S., and Kaller, M. (2020). Comparing multiple comparisons: practical guidance for choosing the best multiple comparisons test. *PeerJ*, *8*, 1-26 https://doi.org/10.7717/peerj.10387

Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30(5), 259-263.

Mishel, M. H. (1988). Uncertainty in Illness. *Image: The Journal of Nursing Scholarship*, *20*(4), 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H. (1990). Reconceptualisation of the uncertainty in illness theory. *Journal of Nursing Scholarship*, *22*(4), 256–262. https://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H. (1997). *Uncertainty in Illness Scales Manual*. [Unpublished manuscript]. Department of Nursing. University of North Carolina.

Mishel, M. H., Padilla, G., Grant, M., and Sorenson, D. S. (1991). Uncertainty in Illness Theory. *Nursing Research*, *40*(4), 236-240. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Mullins, A. J., Gamwell, K. L., Sharkey, C. M., Bakula, D. M., Tackett, A. P., Suorsa, K. I.,

Chaney, J. M., and Mullins, L. L. (2017). Illness uncertainty and illness intrusiveness as predictors of depressive and anxious symptomology in college students with chronic illnesses. *Journal of American College Health*, *65*(5), 352-360. https://doi.org/10.1080/07448481.2017.1312415

Mundfrom, D. J., Perrett, J. J., Schaffer, J., Piccone, A., and Roozeboom, M. (2006). Bonferroni Adjustments in Tests for Regression Coefficients. *Multiple Linear Regression Viewpoints*, 32(1), 1-6.

National AIDS Trust UK. (2014). *HIV and Black African Communities in the UK*. https://www.nat.org.uk/sites/default/files/publications/NAT-African-Communities-Report-June-2014-FINAL.pdf

National AIDS Trust UK. (2020). *HIV in the UK statistics - 2018*. https://www.nat.org.uk/about-hiv/hiv-statistics

Office for National Statistics. (2019). *Exploring the UK's digital divide*. moz-extension://b62955a2-ed0c-9546-9486-c29e190fa283/enhanced-reader.html?openAppandpdf=https%3A%2F%2Fwww.risual.com%2Fwp-content%2Fuploads%2F2019%2F03%2FExploring-the-UK-s-digital-divide-compressed.pdf

Padilla, G. V., Mishel, M. H., and Grant, M. M. (1992). Uncertainty, appraisal and quality of life. *Quality of Life Research*, *1*(3), 155–165. https://doi.org/10.1007/BF00635615

Pahlevan Sharif, S., Ahadzadeh, A. S., and Perdamen, H. K. (2017). Uncertainty and quality of life of Malaysian women with breast cancer: Mediating role of coping styles and mood states. *Applied Nursing Research*, *38*, 88-94. https://doi.org/10.1016/j.apnr.2017.09.012

Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A.,

Aschman, D. J., and Holmberg, S. D. (1998). Declining Morbidity and Mortality among Patients with Advanced Human Immunodeficiency Virus Infection. *New England Journal of Medicine*, *338*(13), 853–860. https://doi.org/10.1056/NEJM199803263381301

Parker, P. A., Alba, F., Fellman, B., Urbauer, D. L., Li, Y., Karam, J. A., Tannir, N., Jonasch, E., Wood, C. G., and Matin, S. F. (2013). Illness uncertainty and quality of life of patients with small renal tumors undergoing watchful waiting: a 2-year prospective study. *European Urology*, *63*(6), 1122–1127.

Popay, J., Escorel, S., Hernandez, M., Johnston, H., Mathieson, J., and Rispel, L. (2008). Understanding and tackling social exclusion: final report to the WHO Commission on Social Determinants of Health from the Social Exclusion Knowledge Network. In *WHO Commission on the Social Determinants of Health*.

Prejean, J., Song, R., Hernandez, A., Ziebell, R., Green, T., Walker, F., Lin, L. S., An, Q., Mermin, J., Lansky, A., and Hall, H. I. (2011). Estimated HIV incidence in the United States, 2006-2009. *PLoS ONE*, 6(8), 1-13 https://doi.org/10.1371/journal.pone.0017502

Public Health England. (2018). *Progress towards ending the HIV epidemic in the United Kingdom*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/821273/Progress_towards_ending_the_HIV_epidemic_in_the_UK.pdf

Purcell, D. W., Johnson, C. H., Lansky, A., Prejean, J., Stein, R., Denning, P., Gau1, Z., Weinstock, H., Su, J., and Crepaz, N. (2012). Estimating the Population Size of Men Who Have Sex with Men in the United States to Obtain HIV and Syphilis Rates. *The Open AIDS Journal*, 6(1), 98-107. https://doi.org/10.2174/1874613601206010098

Reeve, B. B., Willis, G., Shariff-Marco, S. N., Breen, N., Williams, D. R., Gee, G. C., Alegría, M., Takeuchi, D. T., Stapleton, M., and Levin, K. Y. (2011). Comparing cognitive interviewing

and psychometric methods to evaluate a racial/ethnic discrimination scale. *Field Methods*, *23*(4), 397–419. https://doi.org/10.1177/1525822X11416564

Reich, J. W., Johnson, L. M., Zautra, A. J., and Davis, M. C. (2006). Uncertainty of illness relationships with mental health and coping processes in fibromyalgia patients. *Journal of Behavioral Medicine*, *29*(4), 307–316. https://doi.org/10.1007/s10865-006-9054-7

Reinoso, H., and Türegün, M. (2016). Examining the factor structure of MUIS-C scale among baby boomers with hepatitis C. *Applied Nursing Research*, *32*, 111–116. https://doi.org/10.1016/j.apnr.2016.06.007

Rogers, S. J., Tureski, K., Cushnie, A., Brown, A., Bailey, A., and Palmer, Q. (2014). Layered stigma among health-care and social service providers toward key affected populations in Jamaica and the Bahamas. *AIDS Care*, *26*(5), 538-546. https://doi.org/10.1080/09540121.2013.844762

Sajjadi, M., Rassouli, M., Bahri, N., and Mohammadipoor, F. (2015). The Correlation Between Perceived Social Support and Illness Uncertainty in People with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome in Iran. *Indian Journal of Palliative Care*, *21*(2), 231–235. https://doi.org/10.4103/0973-1075.156508

Sammarco, A. (2001). Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. *Cancer Nursing*, *24*(3), 212–219.

Savin, N. E., and White, K. J. (1977). The Durbin-Watson Test for Serial Correlation with Extreme Sample Sizes or Many Regressors. *Econometrica*, *45*(8), 1989. https://doi.org/10.2307/1914122

Schiele, S. E., Emery, C. F., and Jackson, J. L. (2019). The role of illness uncertainty in the relationship between disease knowledge and patient-reported outcomes among adolescents

and adults with congenital heart disease. *Heart and Lung*, *48*(4), 325-330. https://doi.org/10.1016/j.hrtlng.2018.10.026

Seng, J. S., Lopez, W. D., Sperlich, M., Hamama, L., and Reed Meldrum, C. D. (2012). Marginalized identities, discrimination burden, and mental health: Empirical exploration of an interpersonal-level approach to modeling intersectionality. *Social Science and Medicine*, *75*(12), 2437–2445. https://doi.org/10.1016/j.socscimed.2012.09.023

Sevelius, J. M., Patouhas, E., Keatley, J. G., and Johnson, M. O. (2014). Barriers and facilitators to engagement and retention in care among transgender women living with human immunodeficiency virus. *Annals of Behavioral Medicine*, *47*(1), 5-16. https://doi.org/10.1007/s12160-013-9565-8

Shariff-Marco, S., Breen, N., Landrine, H., Reeve, B. B., Krieger, N., Gee, G. C., Williams, D. R., Mays, V. M., Ponce, N. A., Alegrí, M., Liu, B., Willis, G., and Johnson, T. P. (2011). Measuring everyday racial/ethnic discrimination in health surveys: How Best to Ask the Questions, in One or Two Stages, Across Multiple Racial/Ethnic Groups? *Du Bois Review*, *8*(1), 159–177. https://doi.org/10.1017/S1742058X11000129

Shieh, G. (2009). Detecting Interaction Effects in Moderated Multiple Regression With Continuous Variables Power and Sample Size Considerations. *Organizational Research Methods*, *12*(3), 510–528. https://doi.org/10.1177/1094428108320370

Solomon, P., O'Brien, K., Wilkins, S., and Gervais, N. (2014). Aging with HIV and disability: The role of uncertainty. *AIDS Care*, *26*(2), 240–245. https://doi.org/10.1080/09540121.2013.811209

Torres-Ortega, C., and Peña-Amaro, P. (2015). Adaptación cultural de la escala de incertidumbre de Mishel en el paciente tratado con hemodiálisis. *Enfermeria Clinica*, *25*(1), 9–18.

https://doi.org/10.1016/j.enfcli.2014.09.002

Turan, J. M., Elafros, M. A., Logie, C. H., Banik, S., Turan, B., Crockett, K. B., Pescosolido, B., and Murray, S. M. (2019). Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Medicine*, *17*(1), 7-22. https://doi.org/10.1186/s12916-018-1246-9

Wang, Y., Wan, Q., Huang, Z., Huang, L., and Kong, F. (2017). Psychometric properties of multi-dimensional scale of perceived social support in Chinese parents of children with cerebral palsy. *Frontiers in Psychology*, 8, 1-6. https://doi.org/10.3389/fpsyg.2017.02020

Williams, D. R., Yu, Y., Jackson, J. S., and Anderson, N. B. (1997). Racial differences in physical and mental health: Socio-economic status, stress and discrimination. *Journal of Health Psychology*, *2*(3), 335–351.

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., and Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing*, *29*(3), 250–257. https://doi.org/10.1097/00002820-200605000-00014

Wongpakaran, T., Wongpakaran, N., Sirirak, T., Arunpongpaisal, S., and Zimet, G. (2018). Confirmatory factor analysis of the revised version of the Thai multidimensional scale of perceived social support among the elderly with depression. *Aging and Mental Health*, *22*(9), 1149-1154.https://doi.org/10.1080/13607863.2017.1339778

World Health Organization. (2020). *Coronavirus disease (COVID-19) pandemic*. https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19

Wright, L. J., Afari, N., and Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports*, *13*(2), 133–138. https://doi.org/10.1007/s11916-009-0023-z

Wu, A. D., and Zumbo, B. D. (2008). Understanding and Using Mediators and Moderators. *Social*

Indicators Research, *87*(3), 367–392. https://doi.org/10.1007/s11205-007-9143-1

Wu, A. W., Lichter, L., and Richardson, W. (1992). Quality of life in patients receiving clarithromycin for mycobacterium avium complex infection and AIDS. *VIII Internetional Conference on AIDS/III STD World Congress*.

Wu, A. W., Revicki, D. A., Jacobson, D., and Malitz, F. E. (1997). Evidence for reliability, validity and usefulness of the Medical Outcomes Study HIV Health Survey (MOS-HIV). *Quality of Life Research*, *6*(6), 481–493. https://doi.org/10.1023/A:1018451930750

Yarbrough, S., Cole, L., and Holtzclaw, B. (2001). "Riding it out": living with uncertainty of HIV-related fever at home. *Southern Online Journal of Nursing Research*, *2*(2), 1–23.

Zimet, G. D., Powell, S. S., Farley, G. K., Werkman, S., and Berkoff, K. A. (1990). Psychometric Characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *55*(3–4), 610–617. https://doi.org/10.1080/00223891.1990.9674095

Appendices

Appendix A. Terms adopted in systematic search

HIV or Human Immunodeficiency Virus or AIDS or Acquired Immune Deficiency Syndrome
AND uncert* or insecur* or unpredictab* or Ambigu* or certain* or doubt* or incertit* or ceritud* or indecis*

Appendix B. Summary of quality assessment: qualitative studies

	Question / objective sufficiently described?	Study design evident and appropriate?	Context for the study clear?	Connection to a theoretical framework / wider body of knowledge?	Sampling strategy described, relevant and justified?	Data collection methods clearly described and systematic?	Data analysis clearly described and systematic?	Use of verification procedure(s) to establish credibility?	Conclusions supported by the results?	Reflexivity of the account?	Quality score (%)
Weitz (1989)	0	2	2	2	2	2	2	1	2	2	85
Katz (1996)	2	2	2	2	2	1	2	2	2	1	90
Crossley (1998)	2	2	2	2	2	2	1	1	2	0	80
Brashers et al. (1999)	1	2	2	2	2	1	2	2	2	0	80
Siegel et al. (1999)	0	2	2	2	2	2	1	2	2	0	75
Brashers et al. (2000)	2	2	2	2	2	2	2	2	2	0	90
Yarbrough et al. (2001)	2	2	2	2	2	1	1	1	2	0	75
Brashers et al. (2003)	2	2	2	2	2	2	2	2	2	0	90
Cochrane (2003)	2	2	2	2	1	2	2	2	2	1	90
Brashers et al. (2004)	2	2	2	2	2	2	2	2	2	0	90
Davis et al. (2006)	2	2	2	2	2	2	1	1	2	0	80
Wringe et al. (2009)	2	2	2	1	2	2	2	2	2	1	90
Bernays and Rhodes (2009)	2	1	2	2	2	2	2	1	2	0	80
Campbell et al. (2010)	2	2	2	2	2	2	2	1	2	1	90
Perrett et al. (2013)	2	2	2	2	2	2	2	1	2	0	85

Rosenfeld et al. (2014)	2	2	2	2	2	2	2	1	2	0	85
Solomon et al. (2014)	2	2	2	2	2	2	2	2	2	0	90
Furlotte and Schwartz (2017)	2	2	2	2	2	2	2	1	2	0	85

Appendix C. Summary of quality assessment: quantitative studies

	Question / objective sufficiently described?	Study design evident and appropriate?	Method of subject/comparison group selection or source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Quality score (%)
Santacroce (2000)	2	2	2	n/a	n/a	n/a	n/a	2	1	2	2	0	2	1	80
Frain et al. (2008)	1	2	2	n/a	n/a	n/a	n/a	2	1	2	2	0	2	2	80
Shannon and Lee (2008)	1	2	2	n/a	n/a	n/a	n/a	2	1	2	2	0	2	2	80
Sajjadi et al. (2015)	1	1	2	n/a	n/a	n/a	n/a	2	1	2	2	0	2	2	75
Brashers et al. (2017)	2	1	2	2	2	n/a	n/a	2	2	1	2	2	1	1	83

Appendix D. Summary of sudies included in the review ordered by year of publication

Study	Country	Sample	Design	Illness uncertainty measure	Relevant findings	Quality assessment
Weitz (1989)	US	N= 23 Men, 2 Women Age= 30-39 Sexual orientation: > Gay Ethnicity: White Sampling: Snowball sampling Sampling location: HIV Project contact list, mainstream press Time since diagnosis: / Disease progression: diagnosed with AIDS	Qualitative longitudinal Analysis: Grounded Theory Interviews lasted 2 to 5 hours. Data were obtained through transcribed semi structured interviews. Interviewees were invited for a second interview 4-6 months after the first. 2 declined, 2 moved address and 8 died.	n/a	The author identified uncertainties around: why the person had contracted HIV, how the illness would affect their lives, which professionals to trust and what information. The study also elucidates how individuals cope by generating "normative frameworks" to comprehend their situation in illness, and how this is related to coping tactics such as "taking a day at a time".	Strengths: This is the first study to report experiences of uncertainty in PLWHIV. Bias was discussed explicitly. Sample includes people that lived in non-highly urbanised areas. The sample was reported to be in some respect representative of demographics of PLWHIV in that state. The author provides examples to support findings. Weaknesses: No clear statement of study aim made. Only one coder adopted during the analysis thus increasing potential for bias.
Katz (1996)	CA	N= 9 Men, 1 Women Age= 27-50 Sexual orientation: / Ethnicity: / Sampling: purposive sampling Sampling location: HIV clinic, Urban area Time since diagnosis: / Disease progression: Asymptomatic	Qualitative cross sectional Analysis: Grounded theory Interviews conducted with each participant were recorded and transcribed. Participants, health care providers were asked to review and give feedback of results. The material was also		Adjustment to uncertainty involves gaining a new life perspective through experiencing survival of the diagnosis, developing ways of self-care, living in the present, seeking support networks and appreciating positive changes that HIV diagnosis has brought.	Strengths: Results were discussed with clinical staff and interviewees for feedback. The analysis was also audited by external researcher thus increasing the credibility of the results. Weaknesses: Very little data about sample demographics making it difficult to gage whose perspectives were being voiced.

			audited by external researcher.			
Crossley (1998)	UK	N= 31 Men, 4 Women Age x̄ = 38.5 Sexual orientation: / Ethnicity:/ Sampling: purposive sampling Sampling location: Peer group Time since diagnosis: /	Qualitative cross sectional Analysis: Thematic analysis 90min interviews were carried out between 1994 and 1996. Interviews were semi-structured and designed to address physical, psychosocial and existential dimensions of LWHIV. Verbatim transcripts were coded.		Participants explained their experiences of uncertainty related to a general skepticism towards medical knowledge and a tendency of health care professionals to refuse lay knowledge.	Strengths: The article is rich in transcript extracts to support the extraction of themes. This is the only study reported that included participants living with hemophilia. Weaknesses: little description regarding participant demographics recruitment and selection. Bias is not addressed or explicitly discussed. Coding process is not described in detail.
Brashers et al. (2000)	US	N= 18 men, 3 women Age x̄ = 38 Sexual orientation: >gay Ethnicity: > White, 5 ethnic minority Sampling: purposive sampling Sampling location: HIV clinic, Urban Time since diagnosis: 5.5 years Disease progression: diagnosed with AIDS	Qualitative cross sectional Analysis: constant comparison technique Data collected through focus groups 1.5-2 hours in length. One researcher facilitated while other noted order of speaking to aid transcription. Data was independently coded and then compared to then agree on set of categories and continue with coding. Iterative	n/a	Revival emerged as a major source of uncertainty. Uncertainty related to hope around the future effectiveness of medication; the uncertainty about "re-entering" life into old social roles as a person with a chronic illness; the uncertainty around re-entering old relationships; the financial cost of lifelong medication dependence; uncertainty around the level of quality of life.	Strengths The study selected a subpopulation of individuals at a more advanced stage of the disease, at a historically relevant moment i.e. following introduction of HAART. This insured homogeneity of illness progression in the sample. The authors provided several examples of raw data linked to themes. Researches initially coded data independently aiding validity of findings. Weaknesses Researcher biases and theoretical positioning were not addressed. Few records of discordant reports were included.

			process followed till completion.			
Siegel et al. (1999)	USA	N= 48 men, 19 women Age=50-69 Sexual orientation:/ Ethnicity: > Ethnic minority background Sampling: Representative case sampling Sampling location: community based health and social organizations, advocacy groups and clinics, Urban Time since diagnosis: range from 1 month to 12 years, x̄= 6 years Disease progression: 57% diagnosed with AIDS, 30% asymptomatic.	Qualitative cross sectional Analysis: Thematic analysis Representative case sampling was adopted. Recruitment took place across a variety of HIV specialist centres across New York City. Data collection took place from 1996 to 1997. Semi-structured interviews were carried over two meetings. Two members of the team carried out a thematic analysis of interview transcriptions.		Ambiguity /confusion about many common symptoms were frequent issues for older people LWHIV. The study found a tendency for participants to normalize symptoms – hypothesizing this was a form of emotional coping. HIV poses an existential threat, and patients were caught between a tension to seek more information and to take informed health-promoting actions and the need to believe they are healthy. Some participants were found to prefer this ambiguity especially if symptom cause might be a sign of illness progression. On the other hand authors argued that the swifter use of health services was prompted by a desire to resolve uncertainty.	Strengths: Use of design was justified by authors. Recruitment and data collection procedures were explained in great detail and appropriate. Weaknesses: There was no clear statement of the aim of the study. Two coders were employed but there was no consideration of how bias was reduced, nor explanation of how categories and themes were derived. Thereby impacting on overall credibility of the results.
Brashers et al. (2000)	USA	N= 29 men, 4 women Age x̄ = 37.1 Sexual orientation: >gay Ethnicity: > White Sampling: purposeful sampling Sampling location: Clinical trial Unit Disease progression: 21 diagnosed with AIDS	Qualitative cross sectional Analysis: Constant comparative techniques Data were collected from six focus groups. Two researchers present where one moderated and the other		Danger appraisal appeared to be related to uncertainty reduction strategies: information seeking Opportunity appraisal Appraisal of Chronic Illness Managing information.	Strengths: Aim and thorough rational for design and methodology were given. An interview schedule was provided giving details of interview procedure. Detailed explanation of coding procedures were outlined. Coding reliability was calculated and reported (Cohens K=.96). Study results were shared with participants and feedback was sought.

			recorded speaking order. Open ended questions were asked to elicit accounts of uncertainty. Coding and development of categories was carried out by 6 researchers. Results were reported to participants to receive feedback.			Weaknesses: In spite of rigor of analysis reporting and measures adopted to reduce bias, researcher - participant relationship and potential influence were not explicitly discussed.
Santacroce (2000)	USA	N= 25 women Age x̄ = 30 Sexual orientation:/ Ethnicity: > Ethnic minority background Sampling: Convenience sampling Sampling location: HIV pedriatic clinic, Urban Time since diagnosis: /	Quantitative: Cross sectional survey Analysis: Regression	Mishel Uncertainty in Illness Scale – Community form to measure parent's own illness uncertainty. - Parent perception of Uncertainty Scale to measure parent's uncertainty about child's potential illness.	For the seropositive women who participated in this study, uncertainty about their HIV was found to mediate the relationship between health care practitioner support and parental uncertainty.	Strengths: Aims, methods and analysis are well described and appropriate. Weaknesses: The authors of this study assume causality though the study's design does not allow for this to be inferred. Sample size is small and results are difficult to generalise to wider population.
Yarbrough et al. (2001)	USA	N= 36 men, 2 women Age x̄ = 39 Sexual orientation:/ Ethnicity:/ Sampling: purposive sampling Sampling location: Hospital Time since diagnosis:/	Qualitative cross sectional Analysis: Content analysis Analysis of near-verbatim nursing records of telephone		Participants described three levels of fever rated according to level of threat. The most threatening were the ones participants associated to AIDS. Participants coping strategies were related to uncertainty management –	Strengths: Clear aims of the study stated. Detailed description of design, context and procedure of data recording. Weaknesses: conversations were not audio recorded and transcribed. This may have lead to bias through the recording of the conversations, in

		Disease progression: diagnosed with AIDS	conversations with patients focusing on experiences of fever episodes. Telephone conversations took place in 1996. Data saturation was tested by testing themes against new interviews with two participants.		i.e. participants seemed to prefer maintaining uncertainty (e.g. thinking "maybe is it is just a light fever") and not take proactive action (e.g. temperature monitoring).	the type of questions asked by different nurses. The authors don't discuss bias in the study. Little demographic information is available making it difficult to know whose voice is being represented. Analysis was not described in detail. No evidence shared to illustrate process leading from categories to themes. Data saturation was discussed but not exhaustively.
Brashers et al. (2003)	USA	N= 29 men, 4 women Age x̄ = 37.1 Sexual orientation: >gay Ethnicity: > White Sampling: purposeful sampling Sampling location: Clinical trial Unit Time since diagnosis: x̄=4.9 years Disease progression: diagnosed with AIDS	Qualitative cross sectional Analysis: "Constant comparative techniques" were used to analyse interview transcripts. Data was collected from six focus groups. Two researchers present where one moderated and the other recorded speaking order. Open ended questions were asked to elicit accounts of uncertainty. Coding and development of categories was carried out 6 researchers. Results were reported to participants to receive feedback.		Several sources of uncertainty were identified: ambiguous symptom patterns, illness progression and prognosis, financial implications, HIV-stigma and disclosure of diagnosis.	Strengths: Aim and thorough rational for design and methodology were given. An interview schedule was provided giving details of interview procedure. Detailed explanation of coding procedures were outlined. Coding reliability was calculated and reported (Cohens K=.96). Study results were shared with participants and feedback was sought. Weaknesses: In spite of rigor of analysis reporting and measures adopted to reduce bias, researcher - participant relationship and potential influence were not explicitly discussed.
Cochrane (2003)	UK	N= 5 men, 1 woman Age= 37-62 Sexual orientation:/ Ethnicity:/	Qualitative cross sectional Analysis:		The major theme emerging from the analysis was the experience of unpredictability of illness trajectory. Participants	Strengths: The author addresses issues of ethics and confidentiality while considering the importance of having the voice of PLWHIV represented. There is some

		Sampling: purposive sampling Sampling location: HIV Clinic Time since diagnosis: x̄ =9.9 years	phenomenological research methodology Data collection took place in participants homes. Participants' views were obtained through semi-structured interviews that were tape-recorded.		recounted experiencing periods of being very ill alternated with period of recovery resulting in a "roller coaster" ride effect.	consideration of the impact of researcher-participant relationship bias. Feedback about the results was received from participants. Weaknesses: Information was lacking about sampling process. Analytical bias was addressed via the aid of self-reflective diaries. The analysis only involved one researcher. The sample is small and not representative.
Brashers et al. (2004)	USA	N= 29 men, 4 women Age x̄ = 37.1 Sexual orientation: >gay Ethnicity: > White Sampling: purposeful sampling Sampling location: Clinical trial Unit Time since diagnosis: x̄=4.9 years Disease progression: diagnosed with AIDS	Qualitative cross sectional Analysis: Constant comparative technique data was collected from six focus groups. Two researchers present where one moderated and the other recorded speaking order. Open ended questions were asked to elicit accounts of uncertainty. "Constant comparative techniques" were used to analyse interview transcripts. Coding and development of categories was carried out by two researchers.		The study elucidated some of the processes that link illness uncertainty to social support – specifically how social support may help or may not help manage illness uncertainty. The analysis also revealed costs and dilemmas associated to accessing social support, which can bring added uncertainties to PLWHIV. The paper reports strategies identified in managing these costs and dilemmas: developing active vs self-advocating orientation; reframing supportive relationships, withdrawing from unhelpful social situations, selection of support person, maintaining boundaries.	Strengths: Aim and thorough rational for design and methodology were given. An interview schedule was provided giving details of interview procedure. Detailed explanation of coding procedures were outlined. Coding reliability was calculated and reported (Cohens K=.96). Study results were shared with participants and feedback was sought. Weaknesses: In spite of rigor of analysis reporting and measures adopted to reduce bias, researcher - participant relationship and potential influence were not explicitly discussed.
Davis et al. (2006)	UK	N= 20 men Age = 28-55	Qualitative cross sectional		Uncertainties related to HIV infection have not	Strengths: Detailed description of interviews, data collection and

					been erased by HAART. The concept of "technological horizon" surfaced to describe a way PLWHIV deal with the uncertainties of technological/medical advancements. PLWHIV spoke of delaying HAART and managing change in a way that maximizes benefits to them.	sampling provided. Ethical issues discussed in the paper. The study identified participants that were diagnosed pre-HAART.
Sexual orientation: gay Ethnicity: > White, 3 ethnic minority background Sampling: purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis: 9 were diagnosed prior to 1996		Analysis: Constant comparative technique Individual semi-structured interviews were conducted between 2001 and 2002. Interviews were transcribed. Constant comparison was used to generate themes.				Weaknesses: Little description of analytical process was provided. Analytical bias was discussed briefly in the paper and no reflexive account of researcher-participant relationship was given. There is little mention of researchers seeking to verify credibility of the findings. The study does not include women.
Frain et al. (2008)	USA	N= 110 men, 15 women Age= 21-50 Sexual orientation: gay Ethnicity:/ Sampling: Convenience sampling Sampling location: Online recruitment, flyers, personal ads Time since diagnosis: > 8 years	Quantitative cross sectional survey Analysis: Regression	-The Mishel Uncertainty in Illness Scale (see previous descriptions)	Uncertainty and optimism accounted for 61% of variance in the model that predicted participant quality of life. Family variables added in on the third step to hierarchical regression explained only 1% of variance.	Strength: the study integrated subjective definitions of family, thus allowing the exploration of impacts of family support on QoL, in across different understandings of family. Weakness: Beta values of single predictors were not reported. This means that the individual contribution/ effect sizes of the predictors could not be investigated. Sample was recruited online only thus introducing bias. Sample is not representative.
Shannon and Lee (2008)	USA	N= 21 women Age= 21-50 Sexual orientation: / Ethnicity: 60% Ethnic minority, White 40% Sampling: Convenience sampling Sampling location: HIV pedriatic clinic, Urban Time since diagnosis: x̄ =8.7 years	Quantitative longitudinal survey Analysis: Repeated measures ANOVA Took place from 2004 to 2007. Six measuring points starting at third trimester of pregnancy. Final measurement was	Parent perception of Uncertainty Scale to measure parent's uncertainty about child's potential illness.	Negative HIV test result of child resulted in decrease of Parental uncertainty. A strong negative correlation was found between of parental illness uncertainty and social support and a strong positive correlation with social network conflict.	Strengths: longitudinal study design. Weaknesses: The aim of the study was somewhat unclear. No hypothesis put forward though theory and past research would have enabled this. Small sample size – results are not generalizable. Two of the women did not know they were

			taken 4 weeks after the infant's HIV viral test at 18 months of age.			HIV positive at beginning of pregnancy potentially bringing some confounding effects. .
Wringe et al. (2009)	Tanzania	N= 16 men, 29 women Age= 19-43 Sexual orientation:/ Ethnicity: Black African Sampling: purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis:	Qualitative cross sectional Analysis: Thematic analysis 42 "in depth interviews" were carried out and 4 sex and residence specific focus groups were conducted exploring factors influencing HIV clinic attendance. Data was transcribed and coded.		Uncertainty about the veracity of HIV diagnosis (competing illness explanations e.g. virus vs. being bewitched vs. god has healed me) impacted attendance to clinic and treatment adherence. A desire to seek certainty by monitoring disease progression was associated with adherence/attendance.	Strengths: study gives very clear description of setting and how data was collected. Data was independently coded by a second researcher and compared. Sample was relatively large covered persons living in rural and urbanized areas. Weaknesses: researcher bias not explicitly discussed.
Bernays and Rhodes (2009)	Serbia and Montenegro	N= 30 Age= 22-78 / Sexual orientation:/ Ethnicity:/ Sampling: purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis:	Qualitative cross sectional Analysis: Thematic analysis Interviewers transcribed verbatim and coded.		In context of fragile delivery of treatment, perceived poor quality of information exacerbated sense of uncertainty. Three strategies identified in managing uncertainty: fostering network and resources to ensure optimum access to information and treatment. To ration contact with other PLWHIV to avoid alarming rumours. The third strategy was to stop taking treatment as precarity of situation was seen as more risk than gain.	Strengths Large sample recruited through networks and different governmental and non-governmental agencies, thus increasing representability. Translators were used to aid inclusion of minority participants. A sample of translations was cross checked to assert accuracy. Weaknesses Analytical bias was addressed but not in detail. Credibility of the findings was not discussed. Limited sample demographics provided.

Campbell et al. (2010)	UK	N= 3 boys, 3 girls Age= 13-15 Sexual orientation:/ Ethnicity: Ethnic minority background Sampling: purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis:	Qualitative cross sectional Analysis: Thematic analysis Telephone or in person interviews took place. Participants were asked 4 questions related to their experiences in an HIV management group for youths. Responses were transcribed and analysed by two researchers. Themes were reviewed with interviewers.		Helpful experiences were: "being with others who are the same is helpful"; Discussing disclosure (voluntary or not), discussing pros and cons of medication. And uncertainty in the future while being hopeful.	Strengths: this was the only study that reported experiences of uncertainty in young people living with HIV. Provides some evidence to effectiveness of peer-support in young people. Weaknesses: Small sample. Little detail of interviews were provided. Little discussion around bias.
Perrett et al. (2013)	UK	N= 24 men Age= 24-57 Sexual orientation:/ Ethnicity: >Ethnic minority background, 8 White British. Sampling:purposive sampling Sampling location: Genitourinary Clinic, Urban Time since diagnosis: 3-20 years	Qualitative Longitudinal Analysis: Thematic analysis Semi-structured interviews using constant comparison method. Each participant carried out two interviews at 6 months apart to gain understanding of adaptation. Transcriptions of audio records were made and coded by two researchers		"Negotiating uncertainty" emerged as the core concept. Main category consists of adaptation to uncertainty following diagnosis through: finding strength through hope, gain control of the virus, seizing opportunities. Relativizing ones illness to others, planning for the future, and "adapting to the fact that there is nothing to adapt to" allowing one to make plans for the future.	Strengths: Thorough description of coding methods. Two interviews carried out at 6 months apart to investigate adjustment trajectory. Weaknesses: Evidence from transcripts was sometimes missing. Only men were included in the study

Perrett et al. (2013)	UK	N= 39 men, 16 women Age= >50 Sexual orientation:/ Ethnicity: claim of demographic representability Sampling:purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis: 1 – 28 years	Qualitative cross sectional Analysis: Thematic analysis Data gathered through focus groups with the first sample were analysed with the aim of producing topic guides for life-history interviews with the second sample. Individual life-history interviews posed open ended questions. A mixture of inductive and deductive thematic analysis was used to analyse the interview data.		Aging with HIV as "unchartered territory" was a major theme in the interviews and the concerns surrounding symptom identification (is it aging or HIV?), premature mortality and health practices also emerged. There were also concerns of the impacts aging with HIV would have on the participant's children. Interviews with women also raised to attention themes which were specific to sex such aging with HIV and the menopause.	Strengths: the study relies on a two-stage process which based on different stakeholders – potentially broadening thematic scope and informing interview content. The sample employed was large and in some respects representative of older age population of PLWHIV in the UK. Weaknesses: The study does not specify how many coders were involved in analysis and what measures were introduced to minimise bias.
Solomon et al. (2014)	Canada	N= 29 men, 20 women Age= >50 Sexual orientation:/ Ethnicity: >white, 22% ethnic minority Sampling: purposive sampling Sampling location: HIV Clinic, Urban Time since diagnosis: x̄=13.5 years	Qualitative cross sectional Analysis: Grounded theory Semi-structured interviews took place face to face or over the telephone by a research assistant. Data was transcribed. Three investigators coded transcripts. Iterative analysis was carried out till saturation.		Uncertainties related to aging were: uncertainty around the source of their health problem (i.e. is it HIV or aging?); uncertainty around health care professional knowledge of aging with uncertainty given the historically new phenomenon; financial uncertainty related to the fact many had not expected to live a long life; difficulties in transitioning into a pension; uncertainties around who would care for them in the	Strengths: three raters were adopted for coding. Excerpts were used frequently to demonstrate coherence of themes and exceptions were also integrated in the results. Weaknesses: mean age was 56. Bias was not explicitly discussed in the study.

					future; uncertainty around long term housing; and uncertainty around the episodic nature of HIV related health events.	
Sajjadi et al. (2015)	Iran	N= 49 men, 31 women Age x̄ = 36 Sexual orientation:/ Ethnicity: / Sampling: Convenience sampling Sampling location: HIV Clinic, Urban Time since diagnosis: x̄= 4.7 years	Quantitative cross sectional survey Analysis: Regression	Persian translation of the Mishel's Uncertainty Scale – Adult version.	The study showed that individuals that scored higher on perceived social support scored lower on illness uncertainty. The model showed that a .26 unit increase in perceived social support predicted 1 unit drop in illness uncertainty.	Strenght: The study provides some cross-cultural validation for the relationship between social support and illness uncertainty in PLWHIV. Weaknesses: Small opportunity sample is not generalisable to the wider population.
Furlotte and Schwartz (2017)	Canada	N= 9 men, 2 women Age= >50 Sexual orientation:/ Ethnicity: >White Sampling:purposive sampling Sampling location: Local AIDS services, Urban Time since diagnosis: x̄ =10 years Disease progression: Asymptomatic n=6, Diagnosed with AIDS=1	Qualitative cross sectional Analysis: Thematic analysis Semi-structured interviews were transcribed. Theoretically driven coding was based on knowledge of stigma, uncertainty, and resilience. These were used to identify central themes of the study. Peer-debriefings were conducted between authors to discuss interpretation and consensus of themes		Themes of uncertainty in older adults arose around unexpected survival, symptom interpretation and medical uncertainty. Some of the stories in the study brought to light some of the ways in which uncertainty and stigma can contribute to poor mental health.	Strength: The study focuses on the experiences of older adults. Weaknesses: - only one researcher coded the recordings. - Theoretically driven coding could be argued to have increased bias. - Sample is unlikely to be representative due to size and recruitment. - biased was not addressed.

| Brashers et al. (2017) | USA | N= 83 men, 14 women
Age x̄ = 36.25
Sexual orientation: >gay, 19 heterosexual
Ethnicity:
Sampling: purposive sampling
Sampling location: AIDS Clinical trial unit
Time since diagnosis: newly diagnosed HIV+ | Randomised Controlled Trial

Analysis:
Multilevel Modelling

Experimental pre-test–post-test design was employed. Participants were randomly assigned to experimental group or waiting-list control group. Treatment consisted of a peer educator delivering skill-development tools focusing on: managing uncertainty, finding information, communication skills, and accessing community resources. | | The intervention led to a steeper decline in uncertainty and depression. It is argued that tactical communication skills e.g. such as in disclosure of HIV status helped participants maintain their support networks. | Strengths
Randomization.
Pre-test post-test design gives some support to causality.

Weaknesses
Participants are mostly men and were recruited from the one location, thus not representative.

Social support construct was not a validated measure.

Effect sizes were not reported.

How much of the effect was due to peer-support delivery – and how much was it due to skills training is not possible to discern from the design. |

Appendix E. Thematic table with selection of participant's quotes

Organizing theme	Basic theme	Sub-theme	Participant quote
		Global theme: Sources of uncertainty	
Medical sources of uncertainty	**Making sense of symptoms**		This morning when I was getting up ... I wasn't that sure footed. Is it age or is it AIDS? (Solomon et al., 2014)
	Disease progression		I was on a protease for three months and my viral load was near undetectable and then my CD4 counts did nothing they just stay around 60, 70, and uh, the doctor calls me up and says, `you know your viral load is almost undetectable' . Two days later I'm in the hospital with pneumonia. So you spend two days celebrating and then you think like `well, what' s up with this?' You know, `what is going on? (Brashers et al., 1999)
	Health care systems and competing sources of knowledge	Uncertainty of treatment delivery	Now my treatment is available at the pharmacy but I don't know for how long (Bernays and Rhodes, 2009)
		Uncertainty of available medical knowledge	I'm really just trying to deal with today because I don't know what the long-term effects of all these new treatments are going to be yet. (Brashers et al., 1999)

Personal	Financial	Economically [growing older] is a bit scary because .. . in a certain sense ... , I haven't put away [any money] and I haven't been able to put away. You know, choices you make and then the realities that affect those choices (Solomon et al., 2014) I've done all kinds of things planning on my death. And, if I don't die, I owe an awful lot of people an awful lot of money (Brashers et al., 1999)
	Interpersonal roles and identity	Then sometimes I want to say "but wait a minute, I am here and I am positive too. Don't forget me". Because sometimes they do treat me as though I am just OK. Which is fine, I don't want to be treated like an invalid. (Brashers et al., 2003)
	Professional identity	I was always independent. Now, all of a sudden, I'm asked to learn this. This is devastating. I don' t like being on welfare, going and collecting food stamps, you know. I've been on disability, on SSDI, for a year. And yeah, I want to get back into nursing. What is going to happen if I do go back to work? Am I going to get so stressed out I'm going to end up in the hospital again?

		(Brashers et al., 1999)
Stigma and disclosure		I certainly feel restricted talking about both issues … but if I am going to open up about anything, I'm probably going to open up about my HIV status more than my mental health status. I find, for me, I have self-stigmatized, I guess, on mental health more than HIV (Furlotte and Schwartz, 2017)

Global theme: managing illness uncertainty

Seeking information		I'm well aware of the risks that are involved . . . to keep on top of those risks I have myself monitored more often and make sure I know the results and what have you. (Davis et al., 2006)
Avoiding information		I didn't want to find out I had AIDS. Even though I kind of figured I did, I didn't want to know. I wanted to live a normal life for as long as I could. (Weitz, 1989)

Accepting uncertainty

 What doesn't kill you, makes you stronger' sort o' thing. You know so what I'm saying there is that if you don't have any control over it, why bother worrying about it?

Time is the factor on a lot of HIV people. And if anything, time gives you hope as well, believe it or not . . . I deal with that bridge when I cross it'

(Davis et al., 2006)

I look forward. I feel insecure but I am OK with it
(Campbell et al., 2010)

Accessing social support

So I thought, "if all else fails, go back to what you know." So I went back to what I knew. And I called my parents on the phone and I said "I have 64 T cells." Mom says "well how many are you supposed to have?" And I said, "Thousands!" She says "quit your job and come home." You know, she said "you and Peter pack up and you just come home." So I called my boss and I said "I quit."

(Brashers et al., 2004)

I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation

(Campbell et al., 2010)

Canterbury
Christ Church
University

Salomons Centre for Applied Psychology

Exploring the relationships between experiences of discrimination, illness-related uncertainty and quality of life in people living with HIV

Who are we?

My name is Riccardo Zito and I am a Doctoral Candidate in Clinical Psychology at the Salomons Institute for Applied Psychology in the United Kingdom. This study is supervised by Dr Stuart Gibson (Barts Health NHS Trust) and Prof Margie Callanan (Salomons, Canterbury Christ Church University).

I would like to invite you to take part in a study which will form part of my doctoral thesis.

What is the study about?

Results from research suggest that people living with HIV can express various degrees of uncertainty relating to life with the disease. This study will explore how general wellbeing in living with HIV is related to such 'illness uncertainty' and the experience of discrimination. This could be important in helping to identify people who are more vulnerable to the effects of illness uncertainty so we can develop better ways of supporting them in the future.

Who can participate?

You can participate in this study if you:

- are 18 years of age or older;

- were diagnosed with HIV at least more than one year ago;

- have disclosed your HIV status to at least one person who is not a health care professional;

- are living in one of the following countries: Australia, Canada, Ireland, New Zealand, United

States, United Kingdom;

- are not acquainted with the researchers conducting this study.

Unfortunately, this study does not have resources to translate the questionnaires into different languages. As a result, participants will need to be able to read English.

What will happen to me if I take part?

Participation in this study is anonymous.

You will be asked to provide some demographic and other personal non-identifiable information. This will only take about one minute.

If you meet the participation criteria, you will be asked to respond to a set of questionnaires exploring your experiences of illness related uncertainty, discrimination, general wellbeing and social support.

Participating typically takes between 15 to 25 minutes. We will not need to contact you again once you have completed the survey.

Are there any benefits in taking part?

Unfortunately, we do not have the resources to pay participants for their time.

What are the risks of taking part?

There are no known risks for you in participating in the survey. Though some of the questions may lead you to remember some unpleasant experiences in your life, answering them is not expected to cause you any harm or distress.

Online related activity always poses risk of a security breach. Although this is highly unlikely, it cannot be ruled out. When participating in this survey, it is important for you to feel safe. Please chose a private place for you to read and respond to questions of a personal nature. When filling out the survey online, it

is also advisable to make sure you are using a secure internet connection (e.g. your own home internet connection).

What will happen to the data I submit?

Some parts of the anonymized data collected for this study will be seen by authorized persons from Canterbury Christ Church University. But this will only take place when the results are being analysed by statistical consultants.

Your anonymous answers will be saved securely for 10 years. After this time, all information will be disposed of securely. During this time all precautions will be taken to keep the information you have submitted safe.

You can always decide to stop being a part of this study while you are completing the survey. However, as the contributions will be anonymous, it is not possible to withdraw once you complete and submit your survey responses.

What will happen to the results of the research study?

The results of the survey will be presented as part of a Doctorate thesis at Canterbury Christ Church University. The findings will also be published in a scientific journal, and possibly presented at academic conferences.

Who has reviewed the study?

This research is organized and funded by Canterbury Christ Church University and was reviewed and authorized by Salomons Institute for Applied Psychology Ethics Panel. The purpose of the panel is to safeguard the interests of the individuals who accept to take part in research projects such as this one.

Further information and contact details

If you encounter any problems or you would like to speak to me and find out more about the research we are conducting, feel free to contact me by email:

Riccardo Zito, Trainee Clinical Psychologist

EMAIL: r.zito17@canterbury.ac.uk

Alternatively, if you have any complaints or concerns you can contact the head of research at the

Salomons Institute for Applied Psychology:

Dr. Fergal Jones, Research Director

EMAIL: fergal.jones@canterbury.ac.uk

Appendix G. Patient consent form

Canterbury
Christ Church
University

Salomons Centre for Applied Psychology

Title of Project: **Exploring the relationships between experiences of discrimination, illness related uncertainty and quality of life in people living with HIV**

Name of Researcher: **Riccardo Zito**

I confirm that I have read the information sheet for this study.

I understand that my participation is voluntary and that I may withdraw from the research at any time up until the submission of the questionnaire.

My data will be kept on a secure computer for the duration of the analysis and stored on an encrypted DVD in a locked cabinet on university grounds. The data will be deleted 10 years after the appearance of any related publication.

I give permission for the researchers of this study to have access to these data and to collect, store, analyze and publish information obtained from my participation in this study.

I understand that if I decide to submit my email addresses it will be kept separate from the research data I will submit, and that it will be kept confidential. The email address will only be used for the purpose of receiving the outcomes of the study.

By completing and submitting the questionnaire I am giving my consent for my data to be used for the outlined purposes of the present study. All questions that I have about the research have been satisfactorily answered.

I agree to participate to this study.

CONTINUE

Appendix H. Demographic items and constructs

This has been removed from the electronic copy.

Appendix I. Ethics board approval

This has been removed from the electronic copy.

Appendix J. Bar chart of means scores of predictors and outcomes by country showing 95% confidence intervals

Error bars: 95% CI
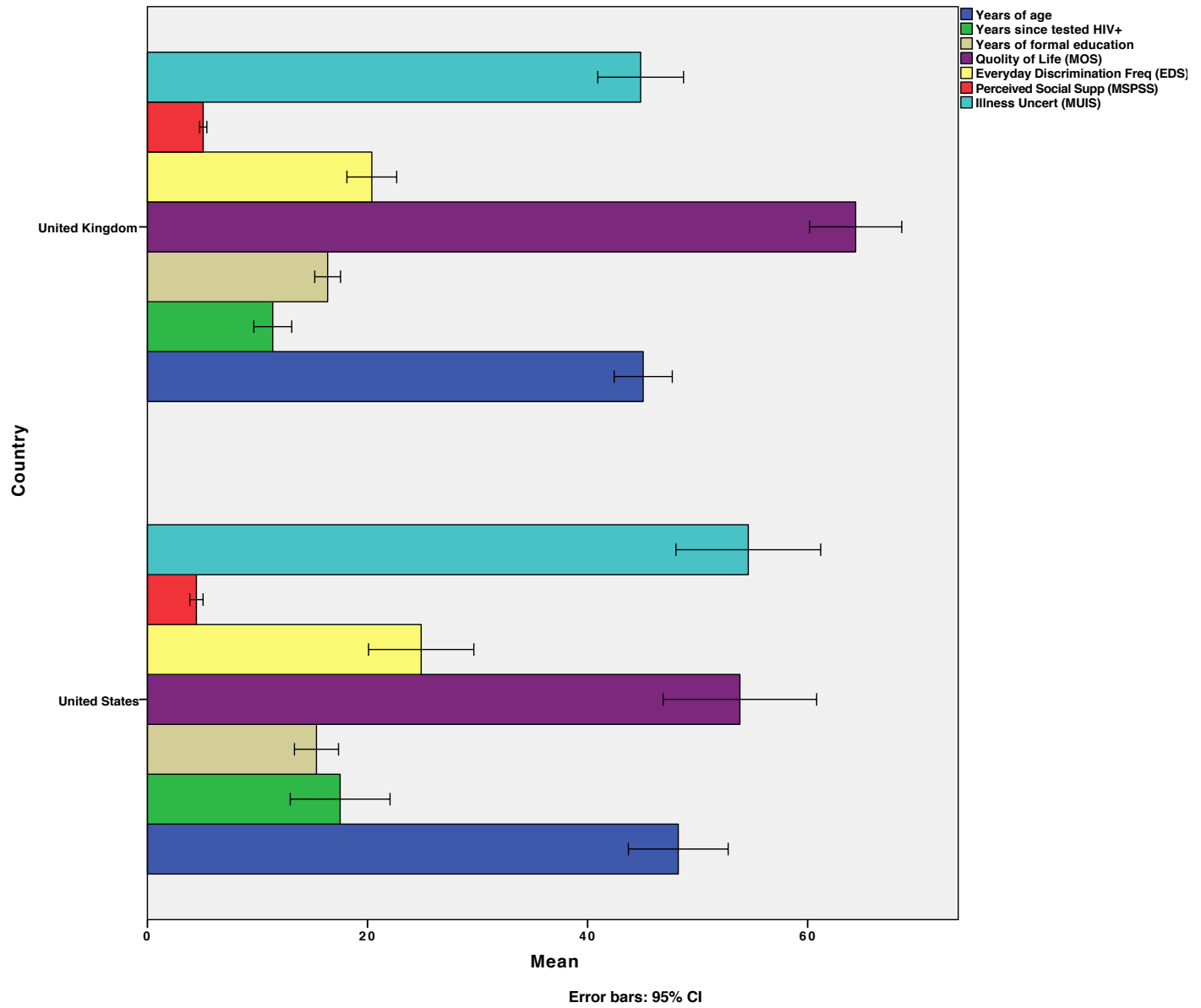
Appendix K. Scatter plot of standardized residual against standardised predicted value for the regression on illness uncertainty (model 4)

Scatterplot
Dependent Variable: Illness Uncert
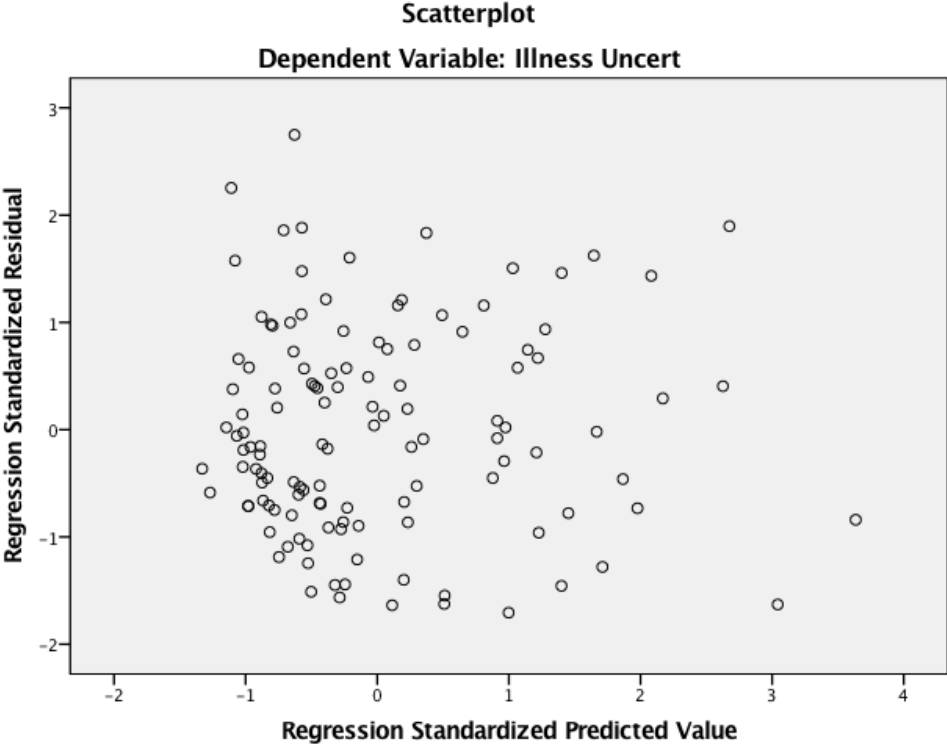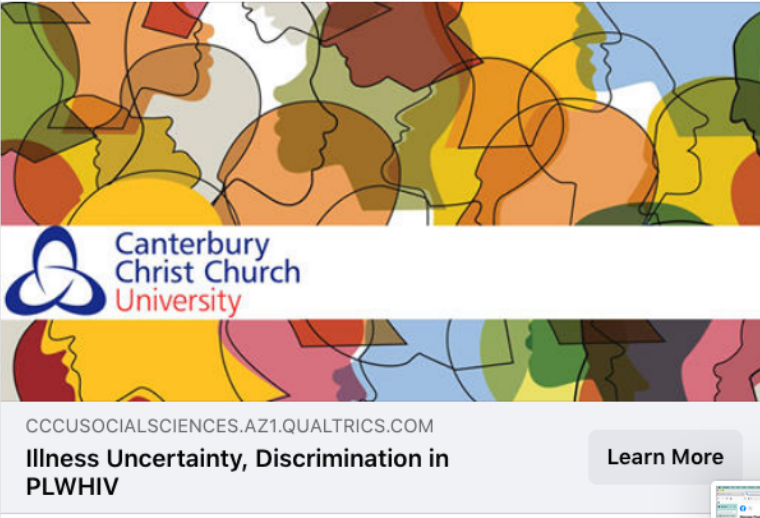
Appendix L. Scatter plot of standardized residual against standardised predicted value for the regression on quality of life

Scatterplot
Dependent Variable: MOS_Tot_Scaled
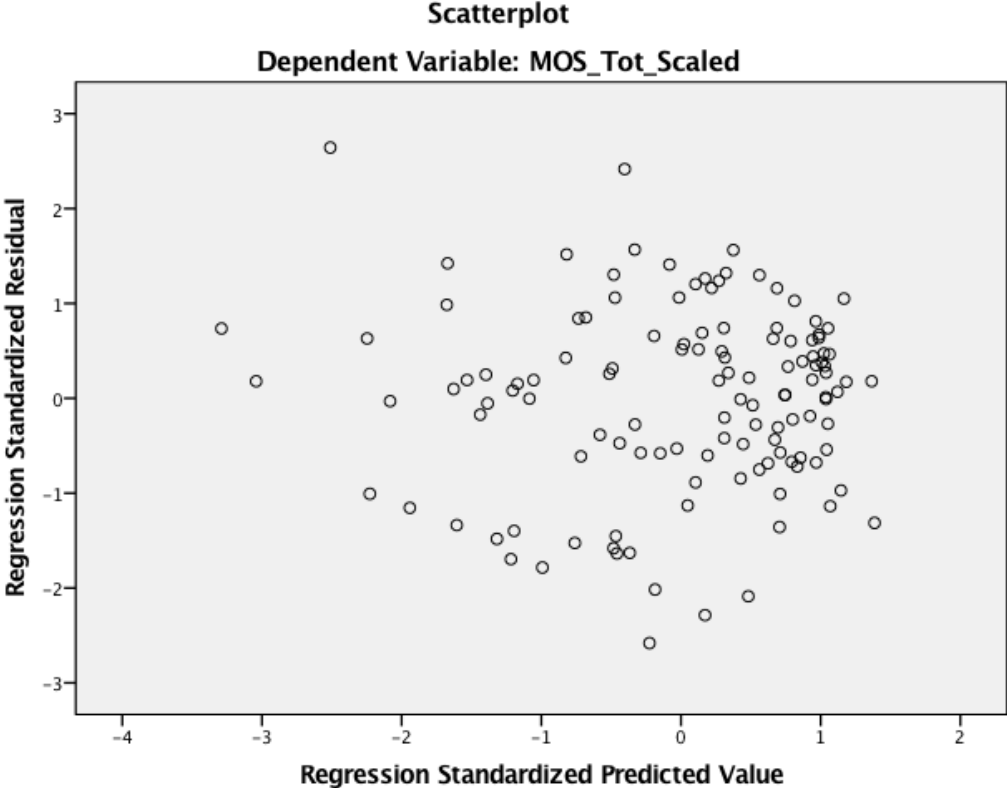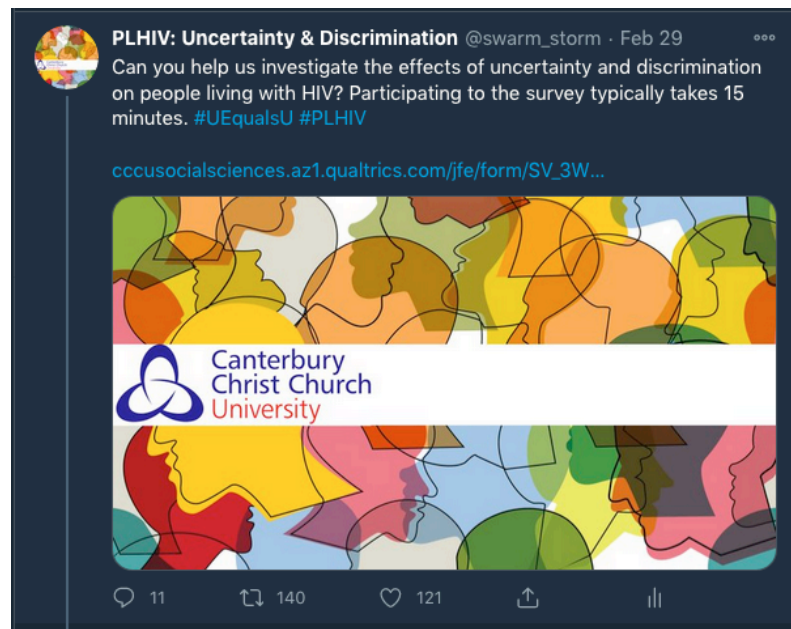
Appendix M. Social media advertisement

Can you help us investigate some of the effects of living with uncertainty and discrimination in people living with HIV? Participating to the survey typically takes 15 minutes.

https://cccusocialsciences.az1.qualtrics.com/.../SV...

Canterbury
Christ Church
University

CCCUSOCIALSCIENCES.AZ1.QUALTRICS.COM

Illness Uncertainty, Discrimination in PLWHIV

Learn More

PLHIV: Uncertainty & Discrimination @swarm_storm · Feb 29
Can you help us investigate the effects of uncertainty and discrimination on people living with HIV? Participating to the survey typically takes 15 minutes. #UEqualsU #PLHIV

cccusocialsciences.az1.qualtrics.com/jfe/form/SV_3W...

Canterbury
Christ Church
University

11   140   121

Appendix N. Resources for participants in distress

Australia

The following link provides a range of resources for people that have been recently tested positive for HIV:

https://www.afao.org.au/about-hiv/living-with-hiv/recently-diagnosed/

If you feel that you would like to talk to someone about how you feel or about any troubling experiences you may have had, the following link provides nation-wide counselling and therapy resources:

https://www.healthdirect.gov.au/mental-health-helplines

Canada

The following link provides a range of resources for people that have been recently tested positive for HIV:

https://www.catie.ca/en/practical-guides/just-diagnosed-hiv

If you would like to speak to someone about the medical and psychological implications of being diagnosed with HIV you can access a hotline at the following link:

https://www.catie.ca/en/about/inquiry-line

or call: 1-800-263-1638

The following link is a Canadian governmental website providing links for mental health support:

https://www.canada.ca/en/public-health/services/mental-health-services/mental-health-get-help.html

Ireland

The following link provides a range of resources for people that have been recently tested positive for HIV:

https://www.hivireland.ie/living-with-hiv/newly-diagnosed/

or access the Health Service Executive (HSE) HIV and sexual health Helpline on: 1800 459 459

More HSE contact details are available at the following link:

https://www.hse.ie/eng/services/list/5/addiction/drugshivhelpline/hiv-and-sexual-health-helpline/

The following link is an HSE website providing contacts for mental health support:

https://www2.hse.ie/services/mental-health/services-search/

New Zealand

The following link provides a range of resources for people that have been recently tested positive for HIV:

https://www.nzaf.org.nz/living-with-hiv/recently-diagnosed/

If you feel you need to speak to someone about how you feel or about any troubling experiences you may have had, these are a list of resources published on the NZ ministry of health website:

https://www.health.govt.nz/your-health/services-and-support/health-care-services/mental-health-services

UK

The following link provides a range of resources for people that have been recently tested positive for HIV:

https://www.tht.org.uk/hiv-and-sexual-health/being-diagnosed-hiv/newly-diagnosed

If you feel you need to speak to someone about how you feel or about any troubling experiences you may have had, this NHS link provides a series of counselling and therapy resources:

https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

USA

The following link provides a list of hotlines redacted by the Ryan White and Global HIV/AIDS program. The hotlines are organized according to state:

https://hab.hrsa.gov/get-care/state-hivaids-hotlines

The following link takes you to a governmental search engine which can search resources and HIV organizations in your area:

https://locator.aids.gov/

The following link is a US governmental website providing links for mental health support:

http://www.mentalhealth.gov/get-help/immediate-help

If you would like to get general information on mental health and locate mental health services in your area you can call toll free SAMHSA7 on: 1-877-726-4727

Appendix O. End of study summary sent to the Salomons Ethics Committee

Dear members of the Salomons Ethics Committee,

I am writing to inform you that I have completed the empirical research project approved by you on 30 October 2019. A brief summary of the research findings follows below.

Study title: **The social environment, illness related uncertainty and quality of life of people living with HIV**

Study background

Uncertainty related to illness has been shown to be linked to the mental and physical health of individuals living with chronic conditions, such as HIV. Theory and research both suggest that social support and adverse social experiences can greatly influence the level of illness uncertainty individuals experience. Positive social contact has been shown to be instrumental in managing illness related uncertainty. This is because interacting with supportive others can help individuals make sense of their illness, but also because supportive others can provide forms of material support that can help alleviate uncertainty. However, because people living with HIV are likely to experience different forms of discrimination, not only related to HIV-stigma (e.g. trans/homophobia, racism, ageism etc.), it is possible that they may at times find it difficult to access social support. This raises the question of whether stigma and discrimination may exacerbate the level of illness uncertainty individuals experience. It was the aim of this study to explore how experiences of discrimination and social support may be related to illness uncertainty of people living with HIV, and to explore how these, in turn, relate to their quality of life.

Results

One-hundred and twenty-five people living with HIV completed the online questionnaire. The analysis showed that participants who reported being subjected to multiple forms of discrimination or who reported experiencing discrimination more frequently, also experienced significantly

higher levels of illness uncertainty. In turn, those experiencing higher levels of uncertainty also reported lower levels of quality of life. As expected, participants reporting more social support reported experiencing less illness related uncertainty and better quality of life.

What do these results mean?

The data analysis reproduced results, similar to previous studies investigating uncertainty in other chronic conditions, such as the fact that people experiencing better social support tend to also experience less illness uncertainty and report higher levels of quality of life. In addition, this study presented new evidence suggesting that experiences of stigma and discrimination could potentially lead individuals to experience higher levels of illness uncertainty. If this were the case, the question of *how* stigma and discrimination might lead to increased experiences of illness uncertainty could be important in the way support is provided. It could be that people that are confronted with multiple forms of stigma have less opportunities to access social contexts that feel safe, and as a consequence, experience more illness uncertainty. An alternative explanation could be that because stigma and discrimination can lead people to experience higher levels of anxiety this may in turn lead individuals to focus more on worrisome experiences of illness, thereby increasing a sense of insecurity related to the illness. These hypothetical explanations are not mutually exclusive but have different implications in terms of the way effective support can be provided. In summary, this study brings forth evidence that people living with HIV that experience multiple forms of stigma and higher levels of discrimination are more likely to experience higher levels of illness uncertainty – this is also likely to impact their quality of life. Future research should focus on identifying who is more at risk and how support can be better tailored to individual needs.