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Psychosocial factors that impact maintaining health and wellbeing in women over 50 years living with HIV: a systematic review

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Abstract

Background: Women now carry half the burden of the HIV epidemic worldwide, and even more in certain developing countries. This study aimed to determine psychosocial factors impacting on the health and wellbeing of ageing women living with HIV

Method: Systematic literature review focusing on qualitative research method articles using interviews and focus groups of women aged >50 years and living with HIV. International literature in the English language was included.

Findings: A total of 11 studies in 15 articles were included in the review. The majority were conducted in the US, three in Canada and one in the UK, published 1998–2015.

Results: Overall eight key themes emerged from the review. The themes were grouped into those influenced by extrinsic factors and those influenced by intrinsic factors. Extrinsic themes: stigma and secrets, support, daily struggles and being a mother/grandmother. Intrinsic themes: loneliness and uncertainty, self-care, religion and spirituality, and self-acceptance and adjustment.

Conclusion: This review revealed women living with HIV aged >50 years have eight psychosocial factors that impact on their ability to maintain health and wellbeing and that their HIV condition changed the dimensions to the majority being HIV specific.

Keywords: HIV, women, psychosocial, wellbeing, older women

Background

Over recent years the proportion of women living with HIV worldwide has grown, what once followed a transmission pattern of predominantly men who have sex with men has now become a heterosexual pattern, and owing to anatomical differences, women are more vulnerable to HIV acquisition [1]. Women now carry half the burden of the HIV epidemic worldwide, and even more in certain developing countries [2]. In the UK there are currently 28,877 women living with HIV, many often diagnosed late into the illness resulting in poorer health outcomes [3,4].

With this specific population still emerging, there is limited knowledge of women's specific needs around support, care and treatment, therefore it remains that these aspects in older women living with HIV are relatively under researched [5–7].

With a gap in the evidence base there is a need for further research on this unfolding phenomenon to determine issues such as psychosocial factors impacting on the health and wellbeing of ageing women living with HIV.

A systematic review was completed which aimed to synthesise existing international qualitative research to answer the question: What are the psychosocial factors that impact on maintaining health and wellbeing in women aged >50 years living with HIV?

Methods

A systematic review investigation was chosen as it involves a specific and reproducible method to identify, select and appraise all studies to answer the research question. This method was selected due to its value in bringing together separately conducted studies in order to synthesise their findings and provide the evidence on which decisions can be based [8]. The review focused solely on qualitative research as it allows us to explain and describe behaviour in its context, and there is a growing recognition of the importance of systematically reviewing qualitative research when exploring a particular topic area [9].

Ethical requirements

As this is a systematic review of the literature relevant to the review question, no ethical approval was required. While a systematic review does perform secondary analysis of data it is unlike primary research that involves human subjects, either directly or indirectly. To complete this systematic review, a risk assessment document and a School of Health and Related Research (ScHARR) ethical declaration were completed, signed

Box 1. Inclusion and exclusion criteria

Inclusion criteria

1. International literature was included to enable examination of how issues such as culture and ethnicity could potentially change the psychosocial factors that impact on the health and wellbeing experienced by older women living with HIV.
2. Only English language articles were retrieved and included in the review.
3. The review used only qualitative research methods defined as interviews and focus groups for data collection and analysis.

Exclusion criteria

1. This review was specifically interested in women aged >50 years. To ensure the research question was answered the findings from women aged <50 years were excluded.
2. A year limitation was applied to this review, therefore literature published prior to the advent of widespread highly-active antiretroviral therapy (HAART) in 1996 will not be considered, as availability of HIV treatment changed the prognosis and quality of life for people living with HIV [28]. This review considered the psychosocial factors for those living in the post treatment era only.
3. This review excluded all studies where the gender identity and age of the participants could not be identified within the findings of the study to ensure that the correct qualitative data was analysed.

and approved by the reviewer and supervisor and presented in a separate dissertation.

Selection process

The inclusion and exclusion criteria used to assist with the selection process and to identify the studies are shown in Box 1.

Literature search: key concepts of the research question

A search tool was used to provide overall structure and to assist with defining the key components and search terms for the review [10]. The strategy tool SPIDER (Sample, Phenomenon of interest, Design, Evaluation, Research type) was chosen. The key components for the review were taken from the research question and are shown in Box 2.

To increase the sensitivity of the review each key concept of the research question was expressed in a number of ways to produce the search terms. The descriptors were developed primarily from the reviewer, considering each word and altering to international terms, alternative spellings, plurals, and synonyms to develop a more comprehensive list.

Boolean logic was then used to combine the relevant elements of the search and these entered into five preselected databases (MEDLINE, PsycINFO, CINAHL, EMBASE, Web of Science). The search was conducted in April 2016 and May 2016. The method of hand, citation and reference searching was then conducted on all studies selected for inclusion. The reviewer also had contact with clinicians and academics for grey literature.

Box 2. Key concepts of the research question and the review using the SPIDER tool

Sample	Women living with HIV aged >50 years
Phenomenon of interest	Psychosocial factors
Design	Qualitative research design methods
Evaluation	Impact on maintaining health and wellbeing
Research type	Qualitative research

Findings: search results

The systematic search of the electronic health databases resulted *n*=827 articles. This was reduced to *n*=696 articles following the removal of duplicated articles. A three-stage sifting process was completed, and finally a total of 11 studies reported in *n*=15 articles were included in the review. A quality assessment and sensitivity analysis on all the selected articles was then conducted and data were extracted onto a data extraction template.

The process of refining the search is explored in Figure 1.

Findings: summary of studies

A total of 11 qualitative studies provided outcomes in 15 articles on the psychosocial factors that impact on maintaining the health and wellbeing of women living with HIV aged >50 years of age.

The articles had a wide ranging publication date of 1998–2015, with the majority being conducted in the US, three in Canada and one in the UK. Of these, 12 had collected data via interviews, two via focus groups and one from both interviews and focus groups.

The length of interviews varied greatly from the shortest being 15 minutes to the longest being a single 11.5 hour interview, however it may be possible that this may be an error within the article, as a second article from the same study stated the length of the same interview was 1.5 hours. The majority of the studies were conducted over one or two occasions via face-to-face interviews. The location of interviews ranged from local AIDS organisational settings, participant's homes, researchers' offices, private function rooms or locations chosen by the participant, which included libraries and coffee shops. Ten studies reported offering participants compensation, such as money plus transport and refreshments. The articles reported a number of findings which have been documented in Table 1. Common findings included discrimination, stigma, concerns for the future, challenges, accepting, adjusting to life and the desire to live well with HIV.

Analysis methods: quality assessment

A quality of reporting assessment checklist developed by Carroll *et al* [11], was completed by the single reviewer on all articles. Overall the reviewer found the articles to be adequately reported. The majority

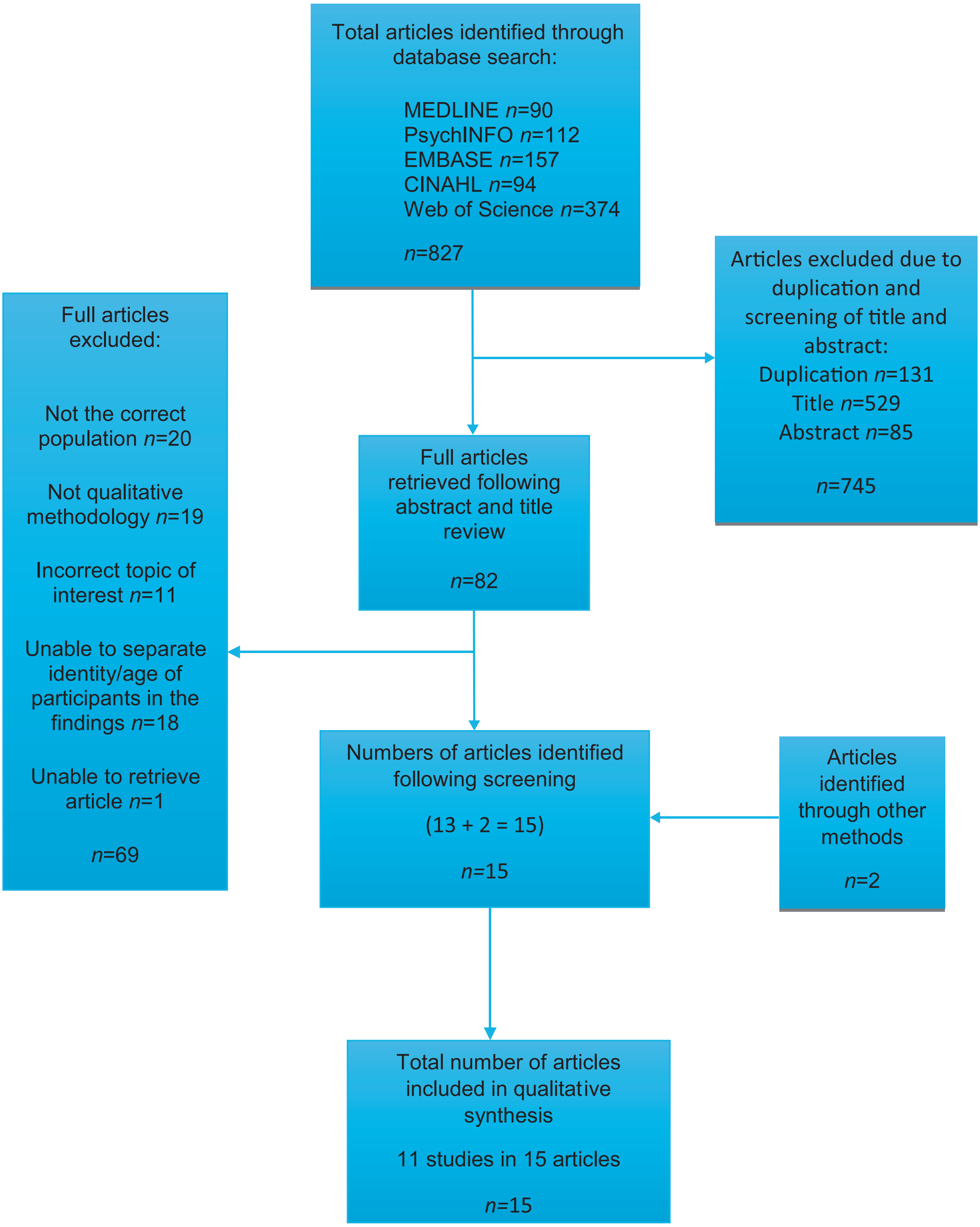

Figure 1: Study selection flow diagram

reported on the study question and design, the selection of participants, the methods of data collection and methods of analysis. The majority of articles gave a description of their design and question. Following the assessment no articles were excluded on quality grounds from the review.

Results

Thematic synthesis based upon thematic analysis was the chosen method to analyse and integrate the findings of the multiple qualitative studies. The thematic synthesis brings together data for a systematic review through the completion of three principle stages [12]. The three-stage process starts with the reviewer reading and coding line by line to identify the prominent themes in the individual studies. Second, from the coded themes the reviewer will organise the 'free codes' into summarised related areas in a structured manner. This developed descriptive key themes or subcategories to finally conclude with analytical themes [13]. This method of thematic analysis was chosen as it is suitable

Table 1: Main characteristics of the included articles

Article	Methodology	Overview	Key themes
Emlet *et al*. 'I'm not going to die from the AIDS': resilience in aging with HIV disease. 2011 [19]	Semi-structured interviews Constant comparative methodology	An understanding of the lived experiences of older women with HIV as it relates to strengths and resilience in dealing with the disease	Acceptance Optimism Will to live Generativity Self-management Relational living Independence
Warren-Jeanpiere *et al*. Taking it one day at a time: African American women aging with HIV and co-morbidities. 2014 [22]	Focus groups Constant comparative methodology	Highlights there is a link between HIV and comorbidities self-management in women and not to view HIV management as a single disease issue but to hope to achieve ideal health and wellbeing for women living with HIV.	Self-management commitments and importance of continued role as a mother Prioritising self Loneliness Lack of income Perseverance
Plach *et al*. Self-care of women growing older with HIV and/or AIDS. 2005 [23]	Repeated narrative interviews Multistage narrative analysis technique	An understanding of what constitutes self-care for older women living with HIV and what self-care actions older women who are living with HIV enact to enhance their mental and physical health.	Self-promotion of health and wellness Contending with symptoms Sustaining inner strength Sense of optimism Control to maintain self-care Having faith in God
Psaros *et al*. Reflections on living with HIV over time: exploring the perspective of HIV-infected women over 50. 2015 [17]	In-depth qualitative semi-structured Grounded theory approach content analysis	Explores the experiences of US women aged >50 years living with HIV to better understand how they make sense of their diagnosis and cope with their illness over time and during the ageing process.	Experiences at diagnosis Doubt over future health and disease course Accepting their situation Living well with HIV Caring for mind and body Changing negative relationships and environments Engaging in meaningful activities
Rosenfeld *et al*. Social support, mental health, and quality of life among older people living with HIV– findings from the HIV and later life (HALL) project. 2015 [16]	Focus groups and interviews Qualitative thematic data analysis thematic to generate codes through NVIVO software	Explores: the social support, mental health, and quality of life among older people living with HIV.	HIV stigma and knowledge Telling HIV status and social relations – fear of rejection Dating, romantic relationships and sharing status Sharing status with children and uncertainty with health Isolation and lack of financial support Loneliness and isolation in old age Separation from family and children
Siemon *et al*. A grounded theory of social participation among older women living with HIV. 2013 [18]	Grounded theory methodological approach	Explores the various aspects of social participation, including self-care, relationships with others, and access to health and social service for women living with HIV, aged ≥50 years.	Connecting with other Isolation Caring for others HIV stigma Social isolation Coping with HIV Being hopeful Unhappiness with self Living with mental health issues, employment Telling others of HIV Caring for others, being a parent, spirituality

Table 1: Main characteristics of the included articles (continued)

Article	Methodology	Overview	Key themes
Grodensky *et al.* 'I should know better': the roles of relationships, spirituality, disclosure, stigma, and shame for older women living with HIV seeking support in the south. 2015 [6]	In-depth qualitative semi-structured Continuous comparative analysis	Explores the important psychosocial factors impacting older women's living and coping with HIV, particularly in social and spiritual relationships.	Family Romantic partnerships Relationship with God. Telling others of HIV hinders women getting support Isolation Spirituality Support from family and friends
Wallach *et al.* Ageing with HIV/AIDS: a scoping study among people aged 50 and over living in Quebec. 2012 [25]	Interviews Phenomenological approach	Explores the impact of the intersection of HIV and ageing on the identities and lived experiences of people living with HIV aged >50 years, both on a psychological (ageing experience, body image, self-perception) and social (relational, professional, socio-economic) level.	Premature ageing Relationships Shrinking of social networks Fear of rejection Unable to return to work Deterioration of living conditions Fear of rejection Financial struggles
Beuthin *et al.* Storylines of aging with HIV: shifts towards sense making. 2015 [15]	Interviews Narrative analysis	Explores the experiences of ageing with HIV and learns more about the coming together of treatment, living long term and ageing with HIV.	Sense making Death and Loss Embodiment Stigma Identity Connection Stigma Being proactive, self-management, financial worries, forming relationships, self-esteem
Brown *et al.* Identifying HIV-infected women's psychosocial stressors: findings from a qualitative study. 2015 [20]	Focus groups Narrative analysis	Identifies the prominent psychosocial stressors experienced by women living with HIV and how they develop strategies to address the psychosocial challenges.	Telling others of HIV, discrimination treatment Adherence Fatigue adherence Mental health Caring for family, relationship Financial difficulties Substance misuse problems
Schrimshaw *et al.* Perceived barriers to social support from family and friends among older adults living with HIV/AIDS. 2003 [21]	Interviews Thematic analysis	Explores the perceived barriers to obtaining emotional and practical social support from friends and family among older adults aged >50 living with HIV.	Telling others of HIV Stigma Desire to be self-reliant Independent, not wanting to be a burden Unavailability of family Death of friends to AIDS Ageism Importance of support Loneliness Independence Daily struggles Self-care
Emlet. 'You're awfully old to have this disease': experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. 2006 [29]	Semi-structured interviews Constant comparative method	Explores how HIV stigma and ageism manifest in the lives of older adults with HIV.	Rejection Stigma Ageism Social discrimination

Table 1: Main characteristics of the included articles (continued)

Article	Methodology	Overview	Key themes
Siegal *et al.* The perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS. 2002 [26]	Interviews Thematic analysis	Explores the perceived benefits of religious and spiritual coping among older adults living with HIV.	Benefits of religion/spirituality influence adjustment to HIV by: Comforting emotions Eases of emotional burden of illness Empowering Control Strength Meaningful Acceptance by God Preserves health
Psaros *et al.* Intimacy and sexual decision making: exploring the perspectives of HIV positive women over 50. 2012 [30]	Semi-structured interviews Grounded theory approach	This study explores to how women with HIV, aged >50 years, experience living with HIV and age-specific factors that impacted intimate partner relationships and sexuality.	Desire for relationships Hopelessness due to stigma Dilemma of telling others of HIV Concerns over body image Fear of rejection/being hurt/ Stigma
Siegal *et al.* Perceived advantages and disadvantage of age among older HIV-infected adults. 1998 [24]	Semi-structured interviews Content analysis of narrative	Examines the ways in which older (aged >50 years) people living with HIV perceive age to influence one's feelings about living with HIV and the reactions of others, and their coping behaviour.	*Advantages:* Age comes wisdom Respect for health and life Self-management Greater respect for life and health Patience Contentment Moderation Less psychological threat for a disability and fatigue Ability to focus on own needs *Disadvantages*: Bodies are worn and less resilient Socially isolated Less sympathy Judged

for systematic reviews when addressing questions regarding people's experiences [14]. Thematic analysis was used to bring the findings of the articles together, the reviewer identified 52 'free codes' from the initial coding process. These emerging descriptive themes were then synthesised and eight themes were apparent. The evidence highlighted that the psychosocial factors of the women can be influenced by both extrinsic and intrinsic features. These influences then shape what the women express as their psychosocial factors from their own experience.

To present the synthesis, the reviewer has displayed the themes clearly in Figures 2 and 3.

It can be inferred that the themes under the extrinsic factors are influenced by the themes under the intrinsic factors and vice versa, therefore they can work either independently or in conjunction with each other. Each theme will now be discussed under its overarching heading of extrinsic and intrinsic influences, reviewer suggestions of where the factors work in conjunction with others will be highlighted. Quotes have been provided to strengthen the evidence.

Extrinsic influences

Stigma and secrets

A prominent theme throughout the review was stigma. For women living with HIV aged >50 years it can play a major role in their lives. The stigma experienced appeared to be heightened by negative association between 'risky sex' and HIV, and the effects of stigma can cause a sense of rejection due to the fear of sharing their HIV status.

Beuthin *et al.* highlight the impact of stigma and the older woman's reluctance to pursue a romantic relationship:

> *'The stigma of HIV is still so great. You live with fear that you might pass it on. And having HIV is not like having diabetes. You cannot date, and it now has criminal element and it is stigma personified. Your identity is changed forever.'* [15],

Figure 2: Overarching key themes: extrinsic factors. Includes four themes, stigma and secrets, support, daily struggles and being a mother/grandmother. Each key theme has further descriptive themes within. The findings have been categorised under the heading of extrinsic influences as each psychosocial factor encapsulated can be impacted by an outside influence.

HIV stigma can be driven by extrinsic factors, poor knowledge, outdated information or assumptions of HIV, which can escalate stigma and discrimination. Stigma can hinder social participation, therefore the environmental factor of stigma can influence the individual's intrinsic psychosocial factor of loneliness. Resulting in a merging of psychosocial factors across the synthesis findings.

Support

From the review, seven of the articles stated that support, either emotional or practical, from either friends or family was important [6,16–20] and provides a source of strength to the women [19].

The consequences of being supported was that women felt loved and wanted.

Intergenerational relationships also provided support [16], a participant from Grodensky *et al* 2009 stated:

> *'Well, I supposed to be living by myself. But my children and my grandkids … I never live alone,* [laughter] *Who I live with? I live with all my kids. I'm around somebody all of the time.'* [6]

The review also found that HIV organisations provide support to women.

While the majority of the older women in the review felt supported, a number felt there were barriers to seeking help. The women reported challenges such as not wanting to share their status, stigma and not wanting to be a burden. One women stated in Schimshaw and Siegal's 2003 study:

> *'I feel at my age, 53, that to ask people for help, they would feel that well, she should know how to do this or she should know where that's at. I just feel people expect me—expect me to know. So I do have a problem with asking for help.'* [21]

To summarise this theme, there are benefits to receiving support, however personal experiences and thoughts can hinder social engagement with others.

Daily struggles

The review highlighted a number of daily struggles, a prominent feature was the stress of financial concerns [16,20,22,]. For this theme there was a noticeable difference depending on where the studies were conducted. The US studies stated financial concerns with regards to healthcare bills and medical costs [20,22], while the UK study highlighted the women's concerns regarding the cost of utility bills [16].

Being a mother/grandmother

A factor unique to older women is care giving responsibilities. Caring for either children or even grandchildren was a strong theme in the review

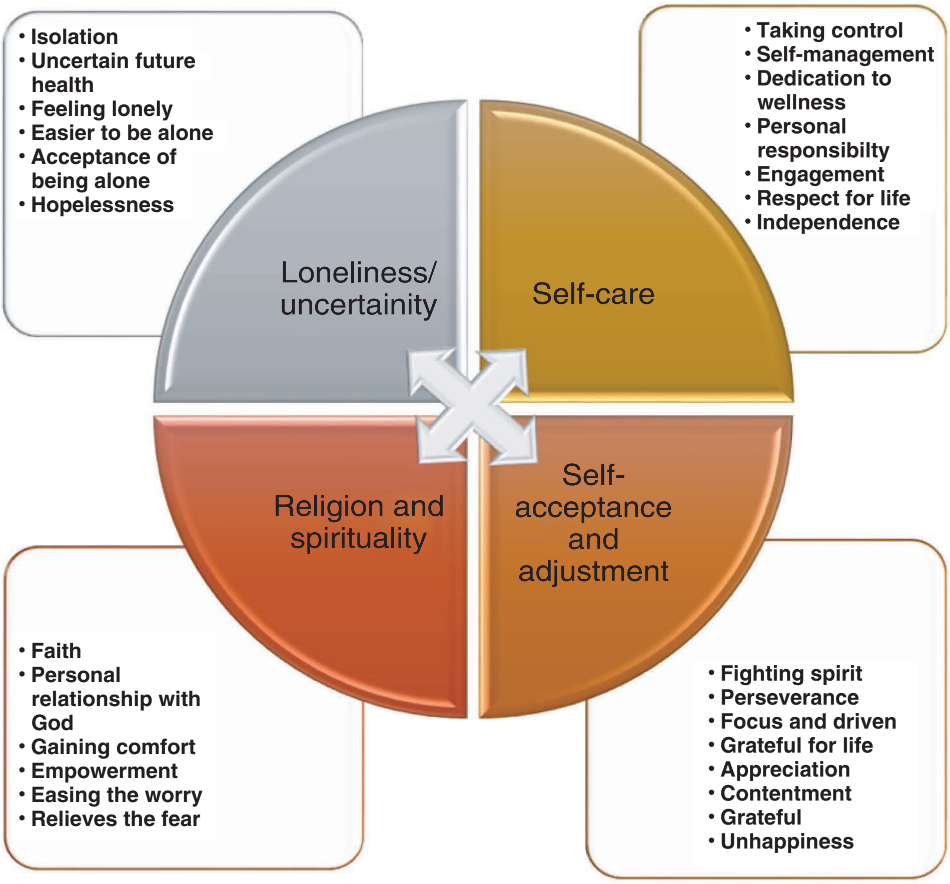

Figure 3: Overarching key themes: intrinsic factors. Includes four themes, loneliness and uncertainty, self-care, religion and spirituality and self-acceptance and adjustment with further descriptive themes within. These findings have been categorised under the heading of intrinsic influences as the psychosocial factors can be shaped by the individual.

[16,18,20,22]. These responsibilities impacted on the women's ability to self-manage their illness. Concerns were of the continuing support for their children if they died [16] or putting the child first before themselves [18]. The theme of 'children come first' was also evident with one women in Brown *et al's* 2015 study stating:

> *'We always put our health on the back burner because we take care, no matter how old our kids are, they could be 50 years old, you know and we still caring for them, caring for their children and everything else …'* [20]

This theme was placed under the extrinsic influence umbrella as it could be suggested depending on whether the women participating in the studies felt obliged to state they are good mothers and that their 'children come first'. There may, however, be pressure on all women not to voice anything other than positive parenting.

A further theme surrounding the aspect of being a mother was feeling fortunate to have had the opportunity to have children. It could be suggested that the extrinsic influence of being a mother or grandmother impacts on their ability to self-manage their HIV, but also the condition itself may cause psychosocial stress as it may prevent the individual from becoming a mother.

Intrinsic influences

Loneliness and uncertainty

The uncertainty appeared to be regarding the disease progression and the length of time health improvements would last. It was surprising to discover the participants in 2014/2015 had expressed a sense of uncertainty specifically around the long-term side effects of highly-active antiretroviral treatment (HAART), one participant states in Rosenfield *et al's* 2015 study:

> *'My concerns are long-term medication; is it okay or not. Maybe you have taken over 20 years. Will it work or will it not work? …'* [16]

Loneliness was a strong theme and was strongly linked to isolation. The personal journeys and the intrinsic influence of this emotion can be highlighted by a participant stating in Warren-Jeanpiere *et al's* 2014 study:

> *'But I'mma tell you what the main problem I personally was dealing with was loneliness. Not having brothers and sisters. Not having children. Not having a husband. Always feeling nobody would want me so the psychological aspects of living HIV was more devastating to me than the physical aspects … I do as much as I can to enjoy myself but I still have those lonely moments … '* [22]

Self-care

A prominent theme from the review was self-care [15,19,21–25]. Highlighting HIV self-management was important and a person's responsibility to be proactive, taking control, engaged, independent, show dedication to staying well and have respect for life. One participant stated within Plach *et al*'s 2005 study:

> *'I have been dedicated to my health. After I found out I had HIV that was the primary objective in my life. I was going to do everything and anything I had to do to get my health back. To me, health is everything. I went through experiences with it to know without health you have nothing…'* [23]

Self-acceptance and adjustment

The self-acceptance and adjustment theme showed inspiration to achieve. This psychosocial factor included a will to live, a fighting spirit, appreciation, being grateful for life and contentment [17,19,21,22,24].

Despite adversity the women voiced positivity, self-acceptance and perseverance, for example one woman stated in Psaros *et al*'s 2015 study:

> *'I would rather be HIV positive than have cancer or diabetes…'* [17]

The resilience expressed by the women in the US articles was strong as they spoke of adjustment to life with HIV and great acceptance, with one women from Plach *et al*'s 2005 stating:

> *'Even though he did what he did to me, gave me HIV, I couldn't hold no grudge against him. I didn't get up in his face and whoop and holler and scream, "Oh, you done killed me, you gave me AIDS," I said, "Well, what done is done now. I'm just grateful that you loved me enough to tell me."'* [23]

The emotional distress from women's personal experiences and life journeys may impact on their ability to accept life with HIV, which may affect their ability to seek help and support, thereby reducing the likelihood of them self-managing the disease. This cycle provides possible evidence that extrinsic influences can shape the intrinsic response of an individual impacting on their ability to maintain health and wellbeing.

Religion and spirituality

The final theme that emerged from the review was the impact of religion and spirituality on the lives of the women. This theme was particularly pertinent to the US articles [23,26].

The women voiced a personal relationship with God, gaining comfort, strength, emotion, and empowerment. One women from Plach *et al*'s 2005 stated:

> *'I pray every day, because without God, I wouldn't be here.'* [23]

A woman From Siegal and Schrimshaw's 2002 research findings stated:

> *'I've always liked the feeling of church. And since I got the virus, that's really, it's my church that has really helped me feel better…'* [26]

Discussion

Strengths of the review

This review goes someway to filling the gap in the evidence base. A particular strength of the review was the process of conducting the reporting of quality assessment and sensitivity analysis of the individual articles. The results highlighted that the articles included in the review were of good quality so the findings may be considered robust. Synthesising individual qualitative studies into a larger sample can provide a more powerful explanation than those single studies alone, this can be particularly important when concerning hard to reach populations and sensitive topics [27]. The review was potentially strengthened by the clinical experience of the reviewer, bringing a strong understanding of the disease and population though clinical experiences may have assisted with the process and depth of the synthesis applied.

Limitations of the review

This review does have limitations. Limiting the search to English language publications may have applied constraints and information bias on the search as publications from other languages may have provided an increased global representation. There is also implication on the choice of the time frame of the review, articles published prior to 1996 may have captured a wider scope of the psychosocial factors for women.

Most of the articles were from the US and Canada therefore dominating the review. A potential reason for a stronger representation from the US is their larger population living with HIV. The wealth of research regarding the medical aspects of HIV social research may take time to catch up outside of the US. However as the ageing population is growing research opportunities will be increasing.

Another limitation is that the review may not be generalisable beyond the review population due to the small numbers of participants, and the majority of the studies being conducted in the US with differences in the socioeconomic structures of the US and the UK. A final limitation was how the clinical role of the reviewers may have influenced the interpretations of the review findings. The reviewers remained mindful of this throughout the project. Reflexivity continued throughout the synthesis to be conscious of how the researcher's clinical experience could shape the findings and add a deeper layer to the process.

Recommendations for further research and clinical practice

As women living with HIV continue to age further research to explore the needs of older women living with HIV is required. HIV services need to consider how the current care setting reflects the needs of women living with HIV and what improvements could be made in order to increase health-related quality of life issues for them.

Conclusion

To conclude, the review revealed women living with HIV aged >50 years have eight psychosocial factors that impact on their ability to maintain health and wellbeing. These include stigma and secrets, support, daily struggles, being a mother/grandmother, loneliness and uncertainty, self-care, religions and spirituality, and self-acceptance and adjustment. While these could be described as general life psychosocial factors, the review findings highlighted that the participant's HIV condition impacted and changed the dimensions to the majority of the themes becoming HIV specific. Women living with HIV have unique life experiences which shape their psychosocial factors. Despite the advances in HIV medicine, stigma continues and the presented review revealed that HIV stigma increases the difficulties women face in adjusting to and self-managing their HIV.

Health and social care professionals need to consider that women are affected by individual HIV-specific psychosocial factors that services need to address in their care delivery.

Implications for practice

With the numbers of women living with HIV increasing there will be challenges faced by both the health and social care services. This review shows the need to improve engagement and inclusion opportunities for women, to create services for further support, and the need for education and interventions to reduce stigma and discrimination. Individualised care and support should be offered to assist women to live well with HIV.

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Conflicts of interest

The authors declare no conflicts of interests.

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