# THE UNIVERSITY OF HULL

# EXPLORING THE EXPERIENCES OF MISCARRIAGE AND HELP SEEKING AFTERWARDS AMONGST BLACK WOMEN

Being a Thesis submitted in partial fulfilment of the requirements for the degree of

Doctor of Clinical Psychology

In the University of Hull

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# Acknowledgements

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## **Overview**

This portfolio consists of: a systematic literature review, an empirical paper and supporting appendices. The thesis explored Black women's experiences of miscarriage and the help-seeking behaviours afterwards as well as barriers.

Part one is a systematic literature review evaluating the literature regarding Black women and mental health help seeking. The systematic search of databases yielded 7 papers all of which were evaluated using the NICE quality checklist. Thematic synthesis was used to analyse the studies. The findings are discussed and implications for further research and service provision proposed.

Part two is an empirical paper describing a qualitative study. The study explored the experiences that Black women had of their miscarriage(s), what support was sought and what barriers they encountered. Twelve women who self-identified as Black participated in a semi-structured interview and transcripts were analysed using thematic analysis. Findings described the key themes regarding the miscarriage experience for Black women, what support is helpful and what barriers arose that hinder support from being received. The findings are discussed and implications for future research and service provision proposed.

Part three consists of the appendices that support the systematic literature review and the empirical paper. Included is also an epistemological statement that describes the stance of the researcher and a reflective statement of the process of carrying out the systematic review and empirical paper.

Total word count: 17, 351(including tables, appendices and references)

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# Part One: Systematic Literature Review

This paper is written in the format ready the submission to the journal:

Clinical Psychology Review

Please see Appendix C for submission guidelines

Total word count: 7827 (including references, tables and figures)

# Barriers to Mental Health Help Seeking Amongst Black Women

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### <u>Abstract</u>

*Purpose of research:* This review aimed to explore data that emerged from both qualitative and quantitative literature surrounding Black Women's mental health help seeking behaviours in the UK and US. The nuanced challenges that Black women face in a white majority culture, and how they seek support are under researched.

*Method:* A systematic search was conducted; all articles identified by the search were screened by title and abstract. Articles were removed if they did not meet the inclusion criteria. The articles outstanding were then assessed for quality and data from the papers were analysed using thematic synthesis.

**Results:** Black women are faced with a multitude of barriers when seeking mental health support. Fear of stigmatisation, lack of money to access mental health support and the Strong Black Woman narrative all play a role in perpetuating barriers. Additional barriers of mistrust of services, role strain, lack of education regarding mental health symptoms and professional support seen as the last resort were also reported across studies.

*Conclusion:* This review provides a multitude of implications for clinical practice; by recognising the difficulties and barricades that Black women face when trying to seek or thinking about seeking support from clinical services, services can create systems and structures in which these barriers can be alleviated which in turn will see Black women engage in services that are needed more.

*Keywords:* Black women, African American women, mental health, help-seeking, barriers, systematic review

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#### **INTRODUCTION**

According to the 2011 UK government census there are approximately 1,864,890 (3.3%) individuals living in the UK who identify as black. (England and Wales census, 2011) and in the US approximately 13.4% individuals identify as black (United States Census Bureau, 2019). Studies over the recent years have begun to highlight the disparities seen between black and white people with regards to mental health.

Black Caribbean individuals are seven times more at risk of being diagnosed with psychosis compared to their white counterparts (Fearon, Kirkbride, Morgan, Dazzan, Morgan, Lloyd, Hutchinson, Tarrant, Fung, Holloway, Mallett, Harrison, Leff, Jones & Murray, 2006). Additionally, the "Count Me In" Census consistently reported higher than average admission and detention rates for Black groups from 2006 to 2010 (Care Quality Commission, 2010). Detention rates under the Mental Health Act between 2019 and 2020 in the UK were over 4 times higher for those within the black community compared to white individuals (National Institute for Mental Health, 2020). Between 2014 and 2015 approximately 5,000 individuals who identified as black/black British accessed mental health services (Mental Health Bulletin, 2015). Additionally 12.7% of black individuals in contact with both mental health and learning disability services had spent at least one night in hospital that year. These figures are double those found in the white population. The National Institute for Mental Health in England (2003) highlighted significant barriers for ethnic minorities, such as cultural and racial stereotyping, which in turn negatively affect help-seeking within these communities.

Recent research on mental health within the black community focuses on mental health in Black women. In the UK 29.3% of Black women experience a "common mental disorder" including anxiety, depression and obsessive compulsive disorder (OCD) in a week (National Institute for Mental Health, 2020). This figure is considerably higher than in both the White and other ethnic minority groups. Lacey, Parnell, Mouzon, Matusko, Head, Abelson and Jackson (2015) found that in the US Black women had high rates of mood disorders (16.7%), major depression (14.6%), anxiety (23.7%), PTSD (12.0%) and any other mental health disorder (39.9%). They concluded that factors such as discrimination, neighbourhood characteristics, severe physical intimate partner violence and socioeconomic status all impacted on Black women's mental health.

The black community, and more specifically Black women, experience higher levels of mental health difficulties compared to other ethnic minority and White women. (Race Disparity Audit, 2017). Health setting statistics show that black and ethnic minorities are underrepresented in primary mental health care and overly represented in crisis mental health care; suggesting that this group is only accessing services when distress is at its upmost (Race Disparity Audit, 2017). When thinking about Black women specifically, research into their experiences has been largely absent. Most published research focuses on ethnic minorities or the black community as a whole. The nuanced challenges that Black women face in a white majority culture, and how they seek support, are under researched. Therefore, this review aimed to explore data that emerged from both qualitative and quantitative literature surrounding Black Women's mental health help seeking behaviours in the UK and US.

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#### **METHODS**

### **Search Protocol**

A systematic search was conducted. The following databases were accessed via EBSCOhost: APAPsychInfo, Academic Search Premier, MEDLINE, CINHAL Complete, APA Psych Articles. Databases were searched up to and including October 2020. The "All Text" field was selected to certify that all relevant papers were included. The following search terms were used:

("help seek\*" OR "help-seeking" OR guidance OR support OR "mental health care")

AND

("black wom\*n" OR "african American wom\*n" OR "wom\*n of colo\*r" OR "black femal\*)

### AND

("mental health" OR "mental illness" OR "mental disorder" OR "psychiatric illness" OR depression OR anxiety)

Limiters were: English Language, Peer-Reviewed Journal and Full Text. These were applied afterwards.

### **Inclusion and Exclusion Criteria**

The inclusion criteria for the study were as follows:

- Participants are Black Women
- Study explores help seeking barriers in Black women

- Formal help-seeking for mental health difficulties
- Peer reviewed
- Qualitative or mixed methodology
- English written papers

The exclusion criteria for the study were as follows:

- Case studies
- Reviews
- Dissertations
- Not written in English
- Intervention studies
- Solely medical/ general health settings focused
- Participants including results of men and women where findings from women cannot be extracted.

All articles identified by the search were screened by title and abstract. Articles that did not meet all inclusion criteria or met one (or more) of the exclusion criteria were removed. Articles that were unclear on their suitability based on the title and abstract, were read in detail. These articles were then reviewed in full following the inclusion and exclusion criteria. A final sample of 7 studies remained (see Figure 1. PRISMA flow Diagram- Summary of the selection process)

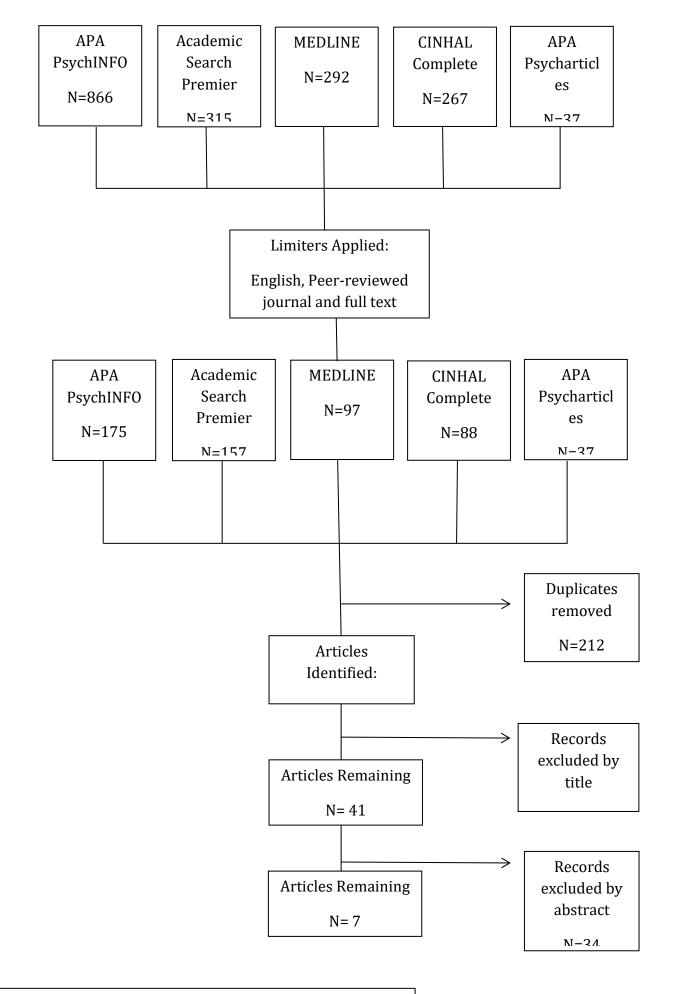


Figure 1. PRISMA Diagram-Summary of the selection process.

#### **Data Extraction**

The data from the articles were extracted using a data extraction form designed for the current review (Appendix D). Data extraction included the following topics:

- Study Title
- General
- Participants
- Methodology
- Findings and conclusions

#### **Quality Assessment**

The National Institute for Health and Clinical Excellence (NICE, 2012) checklist was used for both qualitative and quantitative measures. The checklist measures the quality, including validity, of each paper across different domains (e.g. theoretical approach, study design, data collection, trustworthiness, analysis and ethics). All papers included a qualitative methodology; therefore researcher bias was addressed when assessing the quality of the paper. With regards to the studies that had carried out a mixed methodology, two separate NICE quality assessment checklist were used to assess the quality of the quantitative aspect of the study and the quality of the qualitative aspect of the study. Both scores were then combined as the key and scoring were the same across checklists and an overall score agreed upon. The Additionally articles were reviewed using the quality checklist; scores were reported with a key to explain scores.

The highest, median and lowest scored papers were second rated by a clinician to ensure that the above process was reliable. Papers were independently scored on the same checklist; differences found in scores were discussed until a decision was agreed.

#### **Data Synthesis**

The data from the papers was analysed using thematic synthesis (Thomas & Harden, 2008). This allowed for themes across the chosen literature to be identified and grouped. The chosen themes were then synthesised to "go beyond" the content within the original studies. This allowed for analytical themes to be produced in order to further develop the concepts and findings from the studies being reviewed (Thomas & Harden, 2008).

Thematic synthesis follows three stages (Thomas and Harden 2008):

Stage 1: Coding the text, quotes, themes and results from each study.

Stage 2: Grouping codes together to develop descriptive themes and new codes developed added to capture the meaning of each code group.

Stage 3: Generating analytical themes by using the descriptive themes to answer the question. Considering how themes relate to each other in terms of barriers to help-seeking.

#### RESULTS

## **Characteristics of Included Studies**

The studies included in the literature review explored the experiences of Black Women's professional help-seeking and the barriers they encounter. Studies were carried out across two countries: England and the US. Most studies carried out qualitative interviews (including semi-structured interviews, ethnographic interviews; n=5); some studies combined this with quantitative measures such as surveys. The remaining studies utilised focus groups (n=2). Two studies employed mixed methodology (Ullman & Lorenz, 2020; Lacey, Jiwatram-Negron & Sears, 2021); in these

cases both the qualitative and quantitative data were extracted and reviewed. As the quantitative data was presented in a descriptive manner, the results were able to further support the themes found across studies. The remaining studies used only qualitative methodology. Type of analysis varied across both qualitative and mixed methods studies. Each paper explored barriers to help-seeking from professionals; however, they were varied in the help-seeking context (e.g. drug and alcohol abuse programmes, perinatal depression, intimate partner violence etc.). A detailed summary of each study's characteristics and findings can be found in Table1.

Table 1	Overview	of included studies
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Author(s) & Year Country (UK/USA)	Title of Study	Aims of Study	Methodology	Participants	Analysis	Main findings	Quality Assessment Score
Copeland & Snyder (2011) USA	Barriers to mental health treatment services for low- income African American women whose children receive behavioral health services: an ethnographic investigation.	Explore the barriers to receiving/ accessing mental health treatment.	Qualitative: Ethnographic interviews	Participants were African American women recruited from a larger study on "why mothers seek mental health treatment for their children" (n=32)	Content analysis	<ul> <li>Barriers to seeking formal mental health support include:</li> <li>1)Fear of losing their child- fear that if they shared difficult life experiences, the "system would remove their children"</li> <li>2) Economic stressors</li> <li>3) Role strain: "Tired and Drained"</li> <li>4) Perception of the system- women believed that "clinicians would be ineffective due to their lack of first-hand knowledge of what it's like to live in the shoes of these women". Fear of being hospitalized and placed on medication. Fear of being labelled.</li> <li>5) violence and</li> </ul>	++

						survivorship	
Edge & MacKian (2010) UK	Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among Black Caribbean women in the UK.	"Black Caribbean women's approaches to help seeking and secondly, their experiences of receiving help from professional 'help-givers'"	Qualitative: In- depth interviews	Participants were Black Caribbean women recruited from a larger study on "depression during and after pregnancy among Black Caribbean and White women" (n= 12)	Method of analysis unknown. Coding referenced in text.	Approaches to help seeking- community not seeing depressive feelings and symptoms of mental health difficulties. Formal mental health support is seen as last resort. Previous negative interactions with healthcare providers. Structural and professional barriers to receiving help- fear of psychiatric labelling and stigmatisation. Long waiting times, and inadequate childcare, inability to be seen by a black psychologist who "they believed would be more likely to understand and empathise with their lived experiences".	++
Jones, Hopson,	A Qualitative	To explore the	Qualitative:	Participants	Open and axial	Theme 1- "bias and	++
Warner,	Study of Black	experiences of	focus groups	were Black	coding	stigma are powerful	
Hardiman &	Women's	black women		women via		impediments to	

James (2015)	Experiences in	who have	substance	treatment"- stigma	
	Drug Abuse and	received	abuse	and bias from both	
USA	Mental Health	treatment for	programmes	the black community	
		substance	and community	and professional	
		abuse, mental	organisations	clinicians	
		health	that offer	<u>Theme 2</u> -	
		difficulties or	support for	"incompatible	
		both.	health, HIV,	perspectives of illness	
			mental health	and wellness between	
			and substance	consumer and	
			abuse (n=29)	provider"- mental	
				health difficulties not	
				taken seriously by	
				professionals. Placed	
				on medication	
				without in-depth	
				discussions regarding	
				mental health. 'Strong	
				Black women' label	
				placed on them by	
				professionals	
				Theme 3- "consumer	
				mistrust of both	
				service providers and	
				methods of	
				treatment"- distrust	
				of white clinicians due	
				to perceived lack of	
				understanding of	
				Black issues. Lack of	
				cultural competence	
				from clinicians.	

						Medication being prescribed when therapy is needed.	
Lacey, Jiwatram- Negron & Sears (2021) USA	Help-Seeking Behaviors and Barriers Among Black Women Exposed to Severe Intimate Partner Violence: Findings From a Nationally Representative Sample.	To explore barriers to help-seeking among US Black women (African American and Caribbean Black).	Mixed methods: National Survey of American Life (NSAL) Collaborative Psychiatric Epidemiology Survey (CPES). Telephone interviews (open responses)	Participants were African American and Caribbean Black women recruited via a national survey (n= 5191)	Quantitative data= Rao- Scott chi- square, multivariate logistic regression analysis, multivariate analysis Qualitative data=unknown	Barriers to help- seeking: -22.9% wanted to resolve problem on their own. -19.2% problem would get better by itself -14.9% thought it would not help -11.6% felt they did not need help or did not think they had a problem	+
Ullman & Lorenz (2020) USA	African American Sexual Assault Survivors and Mental Health Help-Seeking: A Mixed Methods Study.	To explore mental health help-seeking practices in a mixed sample of African American Sexual Assault survivors.	Mixed methods: quantitative survey, qualitative interview	Quantitative sample= African American women, aged 18-71 (n= 863) Qualitative sample= African American Women, aged 21-59	Qualitative data - thematic analysis	Cultural barriers, mistrust of mental health professionals, and stigma of needing mental health care. 61.3% of women did not seek mental health support 9.6% of women planned to seek help but still had not 8.5% of women sought counselling	++

		(n=unknown)	straight after the	
			assault	
			6.2& sought help	
			within 1 year post	
			assault	
			14.4% sought	
			counselling over 1	
			year post assault.	

Ward, Clark &	African American	To examine	Qualitative:	African	Common Sense	Barriers to seeking	++
Heidrich	Women's Beliefs,	African	semi-	American	Model (CSM)	formal mental health	
(2009)	Coping	American	structured	women aged	and	support included: 1)	
	Behaviours, and	women's	interviews	25-85 were	dimensional	Individual barriers-	
USA	Barriers to	beliefs about		recruited via	analysis	lack of knowledge on	
	Seeking Mental	mental illness,		posters and	<u>y</u>	where to seek mental	
	Health Services.	coping		snowballing		health support,	
		behaviours,		(n= 15)		embarrassment due	
		barriers to				to mental illness,	
		treatment				negative cultural	
		seeking and				views, discrimination	
		variations in				towards those with	
		beliefs, coping				mental illness and	
		and barriers				lack of awareness of	
		associated				mental illness. "In our	
		with aging.				society we don't spend	
		0.0				a lot of time talking	
						about mental illness".	
						2) Systemic barriers-	
						lack of access	
						including agency and	
						socioeconomic issues.	
						"A lot of systems that	
						are set up in poor	
						neighbourhoods are	
						overstretched; they	
						don't have adequate	
						resources." " A lot of	
						people simply don't	
						have that ability to	
						pay".	

Woods-	Superwoman	To develop the	Qualitative: 8	Participants	Thematic	1)"Obligation to	++
Giscombe,	Schema, Stigma,	superwoman	focus groups	were African	analysis	present an image of	
Robinson,	Spirituality, and	schema in		American		<i>strength"-</i> did not	
Carthon,	Culturally	order to		women		want society to see	
Devane-	Sensitive	further		recruited via		them as weak "African	
Johnson &	Providers:	understand		the local		American women do	
Corbie-Smith	Factors	the barriers to		community (n=		not go to therapy"	
(2016)	Influencing	care that		48)		2)"Obligation to	
	African American	African				supress emotions"	
USA	Women's Use of	American				3)"Resistance to being	
	Mental Health	women				vulnerable or	
	Services.	perceive.				depending on others"	
						4)"Determination to	
						succeed despite a lack	
						of resources"	
						5)"Obligation to help	
						others over self-care"	

# <u>Key:</u>

++	All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.
+	Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
-	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

#### **Methodological Quality**

When regarding the data set as a whole, only two studies explicitly stated that they considered bias in selection of participants and how participants remembered certain events (Jones et al, 2015; Ullman & Lorenz, 2020). Most studies collected data using one method (Jones et al, 2015; Ward et al, 2009; Copeland & Snyder, 2011; Edge & Mackian, 2010; Woods-Giscombe et al, 2010). The remaining studies used two methods (Ullman & Lorenz, 2020; Lacey et al, 2021).

With regards to the qualitative data set, only one took into consideration the relationship between the researcher and the participants (Ward et al, 2009). This criterion had the lowest score on the quality checklist. It is therefore important to acknowledge that most studies may show areas of bias, as the methodology leans towards subjectivity which has not been explicitly acknowledged by the researchers.

Just over half of the studies explicitly disclosed approval obtained by an ethics committee (Jones et al, 2015; Woods-Giscombe et al, 2016; Edge & Mackian, 2010; Ward et al, 2009). The remaining studies did not make reference to ethical approval (Ullman & Lorenz, 2020; Copeland & Snyder, 2011; Lacey et al, 2015) therefore questioning the sufficiency of ethical consideration.

The above information should be taken into account when interpreting the results of the studies. There are a number of potential variables with implications for the results. Despite various pieces of information not being reported, none of the papers were excluded from this systematic review based on methodological quality. As all of the papers scored high on the NICE Quality Assessment Tool, it was deemed that the collated results obtained from the selected papers would be significant in developing

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further understanding of formal mental health help-seeking and barriers Black women face.

#### Synthesis of Findings

The following 7 themes (see Table 2) extracted from the studies reflect the difficulties and barriers Black women described experiencing, when accessing mental health services.

Table 2. List of themes extracted from the studies

THEMES
Theme 1: Strong Black Woman
Theme 2: Stigma and bias
Theme 3: Lack of trust
Theme 4: Lack of education
Theme 5: Role strain
Theme 6: Financial strain
Theme7: Last resort

### Theme 1: Strong Black Woman

The majority of the studies highlighted the 'Strong Black Woman' narrative as a barrier to effective mental health help seeking. The 'Strong Black Woman' role caused women to view the deterioration of their mental health as less serious and they minimised any diagnosis they received.

"I think Black women are stronger when it comes to mental health. I think they'll fight it faster I think a White person would sink in and believe it. Like a Black woman would be like "nah, this can't be, nah." (Jones, Hopson, Warner, Hardiman & James, 2015; pg 7)

The preservation of the 'Strong Black Woman' identity was shared across studies as Black women spoke about the ways in which they manoeuvre dealing with mental health difficulties.

"... I had something really traumatic happen to me last month, and my roommate was like, 'You need to go to therapy.' You tell that to a black woman, and it's like 'Therapy?!' [laughs] You know what I mean?" (Woods-Giscombe et al, 2016; pg 7)

"We hold a lot in and try to fix it ourselves before we get help outside..." (Woods-Giscombe et al, 2016, pg 11)

"...You get depressed [depressive feeling], everybody does but, like I said, I think Black women don't allow themselves to get depressed [depressive illness]. They keep themselves on top of it..." (Edge & Mackian, 2010; pg 14)

Although there was a shared desire to maintain the image of the 'Strong Black Woman' across participants, there was also acknowledgement that holding this narrative close has major downfalls. So although the portrayal and belief of Black women being strong can be used for motivation it also hinders them from seeking support.

"I agree with everything everyone has said about being a strong black woman. It can be good because, you know you're determined. It's your motivation... But it's a downfall because when there's help, you don't ask for help..." (Woods-Giscombe et al, 2016; pg 7)

One study reported women feeling they had to be strong to get through difficult situations because nothing in life is easy. Additionally the internalisation of how maternal figures in their lives pushed through difficult seasons and emotional pain became a contributing force in how they managed difficulties.

"...What doesn't kill you makes you stronger. And it reminds me like that in order to be great; you can't do the ordinary stuff... so that you can be stronger, you have to go through some stuff." (Woods-Giscombe et al, 2016; pg 11)

"... Big Momma went through a struggle, so she taught her daughter how to handle that struggle, so she wouldn't have to worry about it. And then so her daughter has a daughter, she teaches her daughter. It continues..." (Woods-Giscombe et al, 2016; pg 11-12)

As a result of society's message that Black people are supposed to be strong, women believed that they had to deny the existence of mental health difficulties and viewed them as a 'normal' way to live. This in turn creates unhealthy management of mental health difficulties, with Black women not receiving the appropriate care needed.

"Being African American, stubborn, 'I don't need that. Those things don't happen to our people. We don't have mental issues.' That's just a given thing. I guess because we have to be so strong in everything else, they figure that we're not inclined to have nervous breakdowns, and things like that, which we do. I mean a lot of people sitting at home having nervous breakdowns and don't even know what they had." (Ward et al, 2009; pg 9)

### Theme 2: Stigma and Bias

Ullman and Lorenz (2020) explored mental health help-seeking behaviours in African American women who had survived sexual assault and found cultural barriers to seeking support. The need to supress emotions due to perceived expectations from their communities and families as well as fears of not wanting to be labelled as 'crazy' emerged from the data.

"That's another reason why I don't tell people because they start to think you're going crazy!..." (Woods- Giscombe et al, 2018; pg 8)

"When they told me to go to psych, I was so embarrassed to, ... I was embarrassed to tell people outside of here and my peers in here that I had to go to the psychiatrist, I was extremely embarrassed." (Jones et al, 2015; pg 6)

The resistance to psychiatric labelling was directly linked to fear of stigmatisation from both society and the Black community.

"I think there's a stigma as well... about failure and not being able to cope. The whole word 'depression' ... it's got such negative connotations. So perhaps that actually keeps us from actually going to ask for help". (Edge & Mackian, 2010; pg 19)

Black women expressed beliefs that service providers viewed all black people as having the same problems.

"I think [doctors] have the tendency to generalize the black population. They just put us all into one lump, regardless to what the problem may be." (Jones et al, 2015; pg 5)

"[Service providers] look at the black people thinking we're all addicts, or think that we're mentally ill..." (Jones et al, 2015; pg 5)

"Being a black woman and an addict, being alienated and shamed not only because of my addiction but based on my race and gender... And what's their view of me? Black uneducated, lazy, just making babies. It's enough to put you back on the streets." (Jones et al, 2015; pg 6)

The stigma of seeking mental health services was still present as a barrier for these women, even when those around them encouraged them to do so. They found however that survivors were able to access mental health services through disclosing to informal support systems.

"I eventually ended up telling my mother a couple of months after, as by that time I was having a lot of mental issues and she ended up taking me to the hospital where they admitted me because I actually was trying to kill myself." (Ullman & Lorenz, 2020; pg 12)

Discouragement of involving professional support from a young age by parents was reported to be internalised by survivors and contributed to the barriers in seeking formal support.

#### Theme 3: Lack Of Trust

Mistrust of professionals was reported (Ullman & Lorenz, 2020) and women expressed not being able to open up to non-Black therapists as there was a lack of understanding of their lived experiences as Black Women.

"You could have 20 things on the list and you're like 'ok, I'm talk to you about these 5' but the other 15 you can't even get with me because you can't identify with me and there is no trust." (Jones et al, 2015; pg 7)

"...[people from other ethnic groups] don't have a clue sometimes. They really don't. They try to, and they don't even know they don't have a clue. That's it." (Woods- Giscombe et al, 2016; pg 9)

"I wouldn't wanna particularly unburden myself to some white woman [therapist], if I'm honest about it. It's [effective counselling] about having someone who you can chat to who understands what you're doing, where you're going, where you're coming from and all that kind of stuff". (Edge & Mackian, 2010; pg 21)

One participant expressed feeling like she was supporting the therapist when disclosing experiences she had been subjected to due to her race; consequentially she did not return to therapy.

"Well I wanted to seek help before. I thought I was depressed. And then when I went there, and the woman-like you- if anything, I was helping her... But it was like she couldn't help me. She'd say, 'Oh, my God' ". (Woods-Giscombe et al, 2016; pg 9)

Being seen by a Black therapist was referred to as a sense of comfort in a challenging environment.

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"There's a bond between Black women, you know what I'm saying... Just knowing that you're Black, to me, is like a sense of comfort sometimes especially in a place like this [substance abuse treatment programme]." Jones et al, 2015; pg 8)

One participant alluded to a term known as misogynoir (Bailey, 2013) which is a unique experience that Black women face. The term highlights the intersectionality of racism and sexism, otherwise known as anti-black misogyny.

"It's not a racial thing, but It's hard for someone to understand what it is to be a Black woman first of all in this society and to deal with a Black child that is male by yourself." (Copeland & Snyder, 2011; pg 14)

The lack of trust from the 'government systems' in place around mental health was reported. Fear of losing children, or being labelled as 'crazy' by the 'system' deterred Black women from expressing any concerns with their mental health.

"I am an African American woman and I have two children now that I have a problem with and if I go in there and explain to this counselor, this psychiatrist, or this therapist, you know, I'm depressed. I'm this, I'm that, you know in my mind I'm feeling they're going to take my kids away because they feel like I can't handle my kids." (Copeland & Snyder, 2011; pg 10)

"I thought I didn't want to go in therapy because I'm scared, that they are going to say that I'm really, really crazy." (Copeland & Snyder, 2011; pg 14)

Black women reported a lack of trust in clinicians as a result of overt dismissal of their psychological distress when they reached out for help. The invalidation of their feelings were memories that stuck with them and shaped the way in which they sought professional help in the future. Echoing the previous theme, the narrative that Black women cannot be depressed was perpetuated by those working in the healthcare system.

"He [GP] say's you're not depressed... ' He said you're doing too much, you're doing far too much'... He said, 'you're not depressed' He said, 'will you stop thinking you're depressed?'..." (Edge & Mackian, 2010; pg 21)

"I went to see the consultant a couple of weeks ago... and when I told him [about being diagnosed with postnatal depression] he said, 'you haven't got postnatal depression. You're too cheerful and bright and laughing'." (Edge & Mackian, 2010; pg 23)

Black women raised the issue of clinicians not wanting to acknowledge or actively avoiding talking about culturally sensitive issues related to race and gender. This contributed to the lack of trust in clinicians and the absence of a safe environment in which women would be able to explore how their experiences as a Black woman plays a role in their mental health.

"... most therapist can't relate to you either because culturally they don't know or they cannot understand what you went through or where you're coming from, so, they don't get into details..." (Jones et al, 2015; pg 7)

"People don't want to talk about race and substance abuse, people don't want to talk about that in treatment. Not Blacks, we can talk about it all day in amongst each other, but when we mix up in groups with White people- counselors too, no one wants to talk about that." (Jones et al, 2015; pg 8)

#### Theme 4: Lack of Education

Women expressed that to seek help they must first recognise feelings of depression as symptoms that need attention and external validation. Additionally, women reported that within the Black community there is not a clearly defined construct of mental 'illness' in the same way as it might be represented in wider society.

"I'm not saying it's [depression] totally a white person's thing. I think it is amongst Black people but it it's just that it's unheard of... Therefore they're not going out there to seek help, are they?... if they haven't recognised that there is a problem [they're] not going to seek help." (Edge & Mackian, 2010; pg 13)

"...Like for the longest time, I thought therapy, number one, was for [pause] white people. And number two was for weak people... like, why can't you conquer this yourself?" (Woods-Giscombe et al, 2010; pg 7)

There is the perception that more tangible and overtly presenting illnesses are discussed within society compared to the more 'taboo' mental health. The 'taboo' of mental health and the lack of awareness (including both education and knowledge of signs and symptoms) of mental 'illness' was suggested to be the reason why mental health in the Black community is not well recognised.

"We spend a lot more time talking about heart disease and diabetes and cancer and this kind of thing. In our society we don't spend a lot of time talking about mental illness." (Ward et al, 2009; pg 11)

### <u>Theme 5: Role Strain</u>

The women expressed having to balance multiple roles and feeling like others must come first before their own needs.

"I let myself have a breakdown twice a year, and I do that in privacy. I probably need therapy: I surely could use it. But it's just then, I don't know how my life would be if I wasn't like putting out fires all the time, that this just seems like that's just normal. That's just how it's going to be, and that's how it is. I just learned to deal with it" (Woods-Giscombe et al, 2016; pg 12)

Holding multiple social roles, whilst also struggling with their own mental health was shared across interviews. The women felt that they should be able to cope with the difficulties and not show that they are struggling.

"... If I could just act like everything's okay all the time, and I don't. I really let it get to me. I don't sleep, and I'm just depressed. I'm crying and everything, And he worries about that..." (Copeland & Snyder, 2011; pg 13)

### **Theme 6: Financial Strain**

Across studies, women expressed financial difficulties, as well as factors such as being a single parent, coming from a low income household, lack of resources in the neighbourhood they live in, as taking a toll on both their mental and physical health. Additionally women in the USA shared experiences of not having enough money for a health insurance plan that would cover the mental health needs for both their child and themselves.

"No benefits. Do you have health insurance? For the kids. They cut me off when I had my, when I did have one job.... So I'm back at agency. So know I'm waiting to see if I qualify [for health insurance] again for myself..." (Copeland et al, 2011; pg 12)

"...A lot of the systems that are set up in poor neighbourhoods are overstretched; they don't have adequate resources. And so people can't go to get support. And, even for a lot of working people, their insurance covers 'X' number of visits and if you have to go beyond that, you pay out of pocket. A lot of people simply don't have that ability to pay." (Ward et al, 2009; pg 11)

Ullman and Lorenz (2020) also found the presence of financial strain, including lack of money for therapy, posed a barrier to receiving continued mental health support.

"I saw her for 4 months and thought the hospital was taking care of that and then they started sending me a bill that I couldn't pay it at that time cuz I didn't have no money coming in... But I couldn't pay them, so I had to stop going to see her... I felt good talking to her." (Ullman & Lorenz, 2020; pg 14).

### Theme 7: Last Resort

Women felt they had to seek help from other areas such as church, friends and family due to professional help being seen as the last resort which was only to be sought when self-help and informal support failed. "... I think it's a culture barrier for us as black people. We always were told that we had to deal with it, and either go to your minister, or go to a family member, someone that you can trust and talk to." (Woods-Giscombe et al, 2016; pg 10)

"It's about where you get the strength from to cope, within your structure before you actually go to the GP. It's in the home... it's from your mates and your family circle and stuff like that". (Edge & Mackian, 2010; pg 15)

Lacey, Jiwatram-Negron and Sears (2021) investigated Black women in the US (African American and Caribbean Black women) exposed to severe physical intimate partner violence. They explored the barriers the women encountered when seeking mental health support. They found that 22.9% of participants did not seek help because they "wanted to resolve the problem on their own", and 19.2% "thought the problem would get better by itself". Of the women who took part in the study, 14.9% reported that they "did not think it would help" and 11.6% believed that "they did not need help or did not think they had a problem". When both African American and Caribbean women were compared, African American women had high rates of not seeking help due to thinking it would not help. On the other hand Caribbean women. Additionally Caribbean women were more likely to turn "to God" for help, suggesting they "did not seek help due to cultural/religious reasons". Lastly they found that more Caribbean Black compared to African American women reported that they "could not afford it, or had no insurance".

#### **DISCUSSION**

#### **Overview of Findings**

This review aimed to understand the different barriers that Black women face when seeking support for mental health difficulties. The studies highlighted a multitude of barriers that Black women encounter when seeking mental health support. Some of the main barriers found were: the "Strong Black Woman" narrative, "Lack of trust" in clinicians and clinical services and the fear of "stigma and bias" from both the Black community and clinical professionals. Additional barriers surrounded more practical barriers of accessing care, such as lack of understanding of mental health symptoms, 'juggling' multiple roles and lack of finances. Furthermore, participants expressed seeking clinical support as the last 'port of call' and favouring less formal support from family, friends, community groups as "self-help" being a preferred source.

Barriers experienced around maintaining the image of strength was closely linked to shame about seeking mental health support. The 'Strong Black Woman' schema is seen as a mixture of beliefs and cultural expectations that Black Womanhood is made up of strength, ceaseless dependence and independence (Abrams, Maxwell, Pope & Belgrave, 2014). As a result resilience is used to combat both physical and psychological hardships, thus a majority of Black woman have become highly skilled at portraying a picture of strength whilst concealing trauma they have endured. This art of balancing both acts is often held in high esteem amongst Black Women and is clearly evidenced in this review.

The analytical framework of Intersectionality (Crenshaw, 1989), helps to understand how different aspects of one's identity, such as, race, gender, class all overlap to create different types of discrimination and privilege. This was an important

factor within the review. Women not only expressed barriers that can be seen as "cerebral" for example, fear of stigma, fear of not being viewed as strong, but also practical barriers such as lack of money to access mental health services, lack of time due to holding various roles. Across the review there was a strong sense of intersectionality that contributed to the barriers in seeking mental health support. Intersectionality and its role in perpetuating barriers to help seeking needs to be addressed in future research.

Findings also suggested that Black women utilise other strategies to cope such as relying on family members and friends. Other research also illuminated both the pros and cons of support provided from the church with regards to mental health difficulties (*Woods-Giscombe et al, 2016*). This suggests that clinical services need a better outreach strategy and should take into consideration partnering with local community groups such as churches to start building trust within this client group as well as education regarding mental health symptoms. Furthermore the majority of Black women spoke about the whiteness within mental health services as being a factor that hindered them from engaging in therapy. The use of peer support workers to help facilitate and navigate the support offered by mental health services would be beneficial in order to help Black women feel welcomed within these services.

#### Limitations

Only a very limited amount of papers met the inclusion and exclusion criteria of exploring Black women's experiences of professional help-seeking and barriers they encounter whilst doing so. As a result this review synthesises a limited number of papers. However, despite this, the richness and depth of data within the qualitative studies meant that there was no negative impact on the depth of the review carried out.

With regards to the transferability of this review, it is important to highlight that all of the studies reviewed were based on Western populations of Black women; therefore the results may not be relevant to other non-western cultures. Additionally barriers regarding mental health help-seeking may have been more varied and further nuanced had research from other nations been included. Furthermore over two thirds of the studies reviewed were based in the US where healthcare is only provided for those who are able to afford it compared to the UK in which free healthcare is provided through the NHS. As a result the review in some ways fails to encapsulate other barriers that may arise in countries who offer universal health care. However, monetary barriers only made up a small part of barriers that Black Women expressed despite most papers being based in the US.

Due to the qualitative nature of the studies reviewed, all studies reported small sample sizes. As the studies were aimed at seeking a deeper understanding of Black women and mental health help-seeking, smaller sample sizes were appropriate (Dworkin, 2012). The data collected was rich therefore small sample size did not hinder the validity of the research. Furthermore the studies in the review cannot be generalised to all Black women due to the design of studies, however the results do provide insight into some of the barriers that Black women face when seeking mental health support.

Lastly studies that used retrospective data had limitations of possible memory bias. It is important to take this into consideration. However, participants' narratives of barriers are a result of their sense making of experiences and therefore are valid.

### **Implications for Research and Practice**

Despite the growing recognition over the last few years of Black women's mental health, literature around the experiences of Black women and the barriers they face accessing services has unfortunately failed to materialise. As Black women have one of the highest rates of mental health difficulties and one of the lowest rates of mental health service utilisation, services need to explore further the barriers and difficulties that arise during the help-seeking process in order to ensure that this client demographic is given the best possible care.

Across the majority of the studies reviewed, the most prominent theme that Black women are perceived as stronger than the average person and therefore do not need psychological support was highlighted. Although there is now more research that proves that this is not the case, service providers and clinicians unfortunately have not taken this on board. This has had detrimental effects on Black women who have sought support and in turn has hindered future help-seeking in this population.

This review foregrounds the importance of person-centred care within mental health services. This would help reduce the perception that Black women cannot access services due to race or due to fear that clinicians within the system will stigmatise them and not take into account how race intersects with the difficulties they are facing.

Lack of trust was seen as a multi-faceted theme within the review and Women discussed not only services as a whole being untrustworthy but also Whiteness within these spaces as being a barrier to both seeking and engaging in professional services.

It is important to highlight the lack of representation within these services and acknowledge that more Black mental health professionals be trained and hired in order for services to become accessible to this client group. Additionally anti-racism ally-ship initiatives should be carried out across services to ensure that not only Black women

experiences are treated with sensitivity but also to allow these spaces to be truly safe for everyone's well-being.

The review has provided insight into the barriers that are experienced by Black women when seeking mental health support and therefore it is imperative that preventative measures are considered to ensure that these barriers do not become permanent. Providing sufficient mental health access to Black youth groups within the community will allow for young girls to be reached. Having Black and well as White mental health professionals run workshops within youth groups regarding mental health and normalising the use of mental health support may help break down any cultural and societal barriers of stereotyping. The workshops may help young girls to understand and recognise mental health difficulties and where to seek support.

The acknowledgement of Black experiences, particularly Black women's experiences within services will be imperative to engaging with this potential client group. Within the review, women expressed a chosen denial of the Black women experience from clinicians and how this made them turn away from seeking professional support. It should be proposed that clinicians wanting to work with this client group are educated on the nuanced experiences that Black women face and how that might influence the therapeutic relationship in order for trust to begin to build and a healthy therapeutic alliance to be experienced.

#### Conclusion

This review integrates experiences reported by Black women who considered accessing mental health services and the barriers they encountered in the process.

Black women are faced with a multitude of barriers including, but not limited to, fear of stigmatisation from both white professionals and the black community, lack of resources such as time and money to access mental health support and mainly the pressure to maintain the image of being a 'Strong Black Woman' which is perpetuated by society expectations as well as expectations from within the Black community. This review provides a multitude of implications for clinical practice; by recognising the difficulties and barricades (both tangible and intangible experiences) that Black women face when trying to seek or thinking about seeking support from clinical services, services can create systems and structures in which these barriers can be alleviated which in turn will see Black women engage in services that are much needed more.

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## **PART TWO: Empirical Paper**

This paper is written to the format ready for submission to the journal: Psychology of Women Quarterly

Please see Appendix G for submission guidelines

Total word count: 9524 (including references, tables and figures)

## Exploring the experiences of miscarriage and help-seeking afterwards amongst Black women

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#### Abstract

#### Background:

It has been estimated that in the UK approximately 1 in 4 pregnancies end in miscarriage and 1 in 100 women experience recurrent miscarriages (three or more in a row). Research has shown that experiencing a miscarriage can have adverse effects on the mental health of women such as feelings of guilt, intense grief and depressive symptoms. Previous studies have explored the experiences of miscarriage in women and have assumed that the findings can be generalised to Black Women. However as Black Women are twice more likely to experience a miscarriage it is important to explore their experiences and their help-seeking after a miscarriage. No research to date has explored help-seeking in the context of Black Women in the UK after miscarriage.

*Method:* 12 volunteer participants aged 26-41 were recruited via online platforms and semi-structured interviews were conducted. The data gathered was analysed using thematic analysis.

**Results:** Results show both miscarriage and help-seeking afterwards is a multifaceted, multi-layered experience. Three key themes of: miscarrying as an experience, experiences of support and barriers were explored.

*Conclusion:* Further research into the barriers that Black women face when accessing maternal mental health care need to be conducted as well as further research into service provision tailored for Black women and families.

Keywords: Black women, miscarriage, help-seeking, barriers, maternal mental health

#### **INTRODUCTION**

#### Psychological Effects of Miscarriage on Women

Miscarriage is an extremely emotionally stressful experience and the loss of a pre or unplanned pregnancy can result in immediate and long-term stress reactions such as guilt, grief, and depression (Robinson, 2014). Women in the US experienced elevated levels of depressive symptoms for at least 6 months after miscarriage (Neugebauer, Kline, O'Connor, Shrout, Johnson, Skodol, Wicks & Susser, 1992). Jackman, McGee and Turner (2012) investigated the experience and psychological impact of a first trimester miscarriage on women. Women reported unsatisfactory medical care, little consultation around decisions about viewing or disposing of the remains of their baby and a range of negative emotions at the time of the miscarriage. Months after the event, 44% of the women reported clinical levels of psychological distress and attributed this to poor medical management and the inability to discuss miscarriage at their follow-up appointment. Additionally, Volgsten, Jansson, Skoog Svanberg, Darj and Stavreus-Evers (2018) found that women experienced elevated feelings of grief and depressive symptoms one week after miscarriage and reported the emotional aftermath such as isolation and baby loss persisted for longer than four months.

Freidman and Gath (1989) used the Present State Examination (PSE) and identified 32 out of 37 women who has experienced a recent loss to be "psychiatric" cases. This rate is four times higher than in the general female population and in each case women

presented with depression as well as typical features of grief. Depressive symptoms were significantly associated with a history of a previous miscarriage.

#### Support after Miscarriage

Within the UK women who have experienced a miscarriage are advised by NHS England to seek support through their GP who refer them onto counselling and bereavement support services (NHS, 2018). Additionally, women are signposted onto third sector organisations for support: The Miscarriage Association and Cruse Bereavement Care.

Past studies have focused on the psychological effects of miscarriage on women as well as on understanding women's experience of miscarriage. The experience of miscarriage can lead to damaging effects on later maternal mental health (Rowlands & Lee, 2010). Based on this research organisations have been informed of support needed such as better medical management and more information after miscarriage as well as empathy from medical staff (Rowlands & Lee, 2010) and services have emerged to support the growing need for psychological support (e.g. Miscarriage Association UK, Tommy's, Sands).

Black people access mental health services less than their white counterparts (McGuire & Miranda, 2008). Black Caribbean women were less likely to access mental health services for perinatal depression due to biases in how "help-givers" perceive them and their particular needs (Edge and MacKian, 2010). Research has also reported racial biases around pain perception of others with individuals believing that Black people experience less pain that white people (Trawalter & Hoffman, 2015). Taking into consideration the lack of access to mental health services as well as racial biases around pain it is important to explore Black Women's experiences of miscarriage and

"perceived" clinical support, as miscarriage impacts both mentally and physically. Black Women's experiences of miscarriage are under researched and investigations into black women's help-seeking after miscarriage remains unexplored.

#### Black Women and Miscarriage

Black Women are more likely to experience miscarriage compared to their White counterparts (Mukherjee, Velez Edwards, Baird, Savitz & Hartmann, 2013). Current research published on the effects of miscarriage on women assumes that Black Women have similar experiences and, based on the research that shows that Black Women are more susceptible to miscarriage, it would be naïve to generalize these findings. It is imperative to explore Black women's experiences to inform clinical services about necessary service changes to accommodate this client group. As miscarriage can lead to feelings of guilt, grief and depression it is important that Black Women feel able to come to services and access the support they may need. Miscarriage has been identified as a trauma (Lee & Slade, 1996) and as Black Women are more likely to experience a miscarriage, this may mean possibly going through multiple miscarriages, therefore multiple traumas, it is important that their experiences are explored to inform adequate and timely support. Further barriers for Black Caribbean Women accessing mental health services due to perinatal depression include a lack of care from Black psychological therapists who Black women believed would be able to understand and empathise with their lived experiences (Edge and MacKian, 2010).

The current study aims:

1. To explore Black women's experiences of miscarriage

- 2. To explore Black women's help-seeking after miscarriage
- 3. To explore barriers faced by Black women when seeking support

This is the first study to explore experiences of miscarriage and help seeking afterwards in Black women living in the UK. Understanding how Black women in the UK experience miscarriage and why access support services afterwards is low (Edge & MacKian, 2010) is extremely important.

The findings of this study have huge potential clinical relevance, as 1 in 4 women miscarry and Black Women are almost twice more likely to experience miscarriage compared to their White counterparts (Mukherjee, Velez Edwards, Baird, Savitz & Hartmann, 2013). Engaging Black women in psychosocial interventions aimed at reducing depressive symptoms, anxiety, isolation, guilt and chronic grief could be enhanced through an in-depth understanding of barriers to accessing clinical support. The findings of this research may also help to challenge some of the stigma, taboo and negativity surrounding miscarriage. Additionally the research could add significantly to the existing literature regarding miscarriage and clinical support which until now has focused heavily on the experiences of White Women.

#### **METHOD**

#### Design

This study explores the phenomenology (the meaning and the experience; Smith, 2006) of miscarriage in Black Women and their help-seeking behaviours afterwards. The use of semi-structured interviews and interview prompts generated qualitative data, which was analysed using thematic analysis (Braun & Clarke, 2006). Demographic data such as

age, nearest large city and time since miscarriage was collected to contextualise the qualitative data.

## Participants

14 volunteer participants were recruited from online platforms (Instagram, Twitter and Facebook) and through community and personal groups using the snowball sampling technique (Faugier & Sargeant, 1997). Of the 14 participants who expressed interest, 2 did not participate due to personal circumstances. Therefore the final sample was 12 Black women who met the following inclusion criteria:

- Identifies as a Black Woman;
- Aged 18-41; in order to explore how current healthcare support is sought and provided.
- Experienced one or more miscarriage within the last 10 years;
- Miscarriage occurred in first or second trimester (pre-24 week's gestation)
- Able to give informed consent.

Volunteers were not able to participate if they met the following exclusion criteria:

- Experience of miscarriage over 10 years ago
- Does not identify as a Black woman
- Unable to give informed consent
- Experienced an induced miscarriage also known as an abortion (Swanson, 2000)
- Is not living in the UK

Participants' ages ranged from 26 to 41 and all identified as Black women. The majority of participants were located within the South of the UK (n=8) with the remaining participants in the Midlands (n=4). Most Black women had experienced one miscarriage (n=10), with one participant experiencing two miscarriages and one participant experiencing 7 miscarriages. The time since miscarriage ranged from 3 months to 8 years (See Table 2).

Participant	Age	Nearest biggest	Time since	Number of
		city	miscarriage	miscarriages
Participant 1	29	London	Not answered	1
Participant 2	33	London	1 year 11	1
			months	
Participant 3	35	London	6 years	1
Participant 4	31	Leicester	5 years	1
Participant 5	41	Birmingham	8 years	1
Participant 6	41	London	4 years	1
Participant 7	31	Dartford	3 years & 2	2
			years	
Participant 8	Not answered	London	Not answered	1
Participant 9	26	London	1 year 2 months	1
Participant 10	Not answered	Leicester	4 years	1
Participant 11 *	35	London	3 years 6	1
			months	
Participant 12 *	40	London	3 months	7

**Table 2.** Participant demographic information

\*- participants whose transcripts were missing from the final data analysis

#### Procedure

Volunteer participants who had experienced miscarriage were recruited via social media platforms (Instagram, Twitter & Facebook) and through the snowballing technique (Faugier & Sargeant, 1997). Each participant was provided with a brief written overview of the study and information sheet (see Appendix H) with further details in which they were asked to provide a contact number. Each potential participant was contacted to arrange a time and date for the interview. Participants

were then asked to fill out the consent (see Appendix I) and demographic form (see Appendix J). Before the interview, the researcher explained the study again and gave participants the opportunity to ask questions or raise concerns.

Interviews were audio recorded on an NHS encrypted laptop. Semi-structured interviews lasted between 60-90 minutes. The interview schedule was guided by participant's responses (see Appendix K). At the end of each interview participants were sent information and contact details of support organisations (see Appendix L) by email (SANDS, Tommy's, Miscarriage Association, Samaritans). Additionally participants were given an extended debrief after the interview.

#### Data Analysis

Participant interviews were analysed using thematic analysis (Braun & Clark, 2006). Transcripts from each interview were analysed in detail following the six step protocol set out by Braun and Clarke: (1) familiarising with the data; (2) generating initial codes; (3) generating themes; (4) reviewing themes; (5) defining and naming themes; (6) producing the report. Transcripts that had been initially coded were reviewed by an independent researcher to ensure that all codes were accounted for. Any discrepancies in and between codes were discussed and a resolution agreed upon. A portion of a transcript evidencing initial codes can be found in Appendix M.

Two of the participant's transcripts were missing and therefore were not able to be analysed in the same way as the other interviews. However the audio files of the two interviews were used to quality check the data and the themes that were compiled.

The study was reviewed and approved by the University of Hull Ethics Committee (see Appendix N). All data collected was anonymised to ensure confidentiality.

## RESULTS

From the data analysis three key themes and 12 subthemes emerged; these are

summarised in Table 3.

<b>Table 3.</b> Summary of key themes and subthemes identified from data.

## **MISCARRYING AS AN EXPERIENCE**

This theme refers to the cognitive, emotional and behavioural processes of miscarriage that women expressed.

## Emotional responses to miscarriage

Across interviews women expressed feeling a multitude of negative emotions in response to realising that they were having a miscarriage.

"Um and then I would say about an hour later I went to the toilet and then I noticed I started to have bleeding and, and, yeah I think at that point I just completely freaked out"

(Participant 4)

Feelings of fear were present during the beginning stages of the miscarriage with one participant explaining that *"fear was the biggest" (Participant 4)* and others expressing fear of not only losing the child but also of the physical impact.

"Long story short, got home was in excruciating pain was absolutely a mess and then erm I said to my mum, "I'm gonna die" and she was like, 'what do you mean you're gonna die?', and I was like, "I'm just gonna die, this is it, I'm gonna die, I'm not gonna survive this" (Participant 3)

Women spoke about feeling blindsided by their miscarriage and one participant spoke about the shock of finding out she was pregnant and miscarrying at the same time.

"It was yeah it was a shock because I don't know if it was naivety or what what but for some reason I just didn't think that something like that would happen to me. Erm so I was really surprised when I found out when obviously I miscarried." (Participant 1)

"Um I found out that I had been pregnant after thinking that I was not pregnant and then also been told that what the blood test is looking like is the fact that I'm going to lose the baby." (Participant 10)

Feelings of sadness were discussed and one participant explained that even after seeking support she still felt *"a silent sadness" (Participant 7). "A sense of loss" (Participant 3)* was found to be closely linked with feelings of grief going through the miscarriage.

"Emotionally, it's just like, it just feels like your world is ended really um and it's really hard to describe. It's just basically like a overwhelming sense of grief and a overwhelming sense of loss cause obviously like pregnancy is such a, it's a beautiful thing." (Participant 7)

"I don't know what happened, I just, it was almost like instant, from feeling pregnant but being in a lot of pain to literally feeling nothing at all. It was like um it was like all the hormones, all the, everything disappeared like in, in that moment. It was a horrible, horrible, horrible weird empty, weird empty feeling." (Participant 5)

A participant spoke about feelings of hopelessness and dread after experiencing multiple miscarriages.

"I just remember waking up and I was again I felt like I was back to square one, and all the progress that I had made over that year had literally just come crashing down and yeah it was just horrible." (Participant 7)

Anger and embarrassment were also common.

"um, there was anger, I would say" (Participant 2) "yeah, yeah so, yeah I think I just felt a bit silly at that point" (Participant 4)

#### Managing the loss

The theme of wanting both physical and emotional distance from the loss of their baby was prevalent in the majority of interviews. "I remembered like obviously.... To get a sample um and looking down at that point and realising that was the um the sack, the uh, the yeah (R: oh gosh), yeah and like I remember I just wanted to get rid of it at that point (R: yeah) I think when I got back into the room I just like thrust it at the lady cause I just didn't want to look at it cause I'd already seen it, the whole thing." (Participant 4)

Women reported a process of emotional distancing. One participant explained that she *"felt almost numb... for a long time" (Participant 6)* and another reporting that she *"felt um, very, like hollow... very like empty" (Participant 5)* when describing feelings after the miscarriage. This numbness and hollowness was echoed throughout interviews and represented a way in which women initially managed the loss of their baby.

"For me that was quite a numbing experience cause I think even now when I explain it it's kinda like um it wasn't happening to me, I was watching it sort of happen to someone else." (Participant 9)

"I wasn't taking anything in it was just almost like I have no emotions like everything had left me, I was just saying ok ok ok ok ok but erm I wasn't there like I was just, nothing was

*there." (Participant 1)* 

Being confronted with their loss was mentioned across interviews. Women spoke about the difficulty of being around other pregnant women and healthy babies.

"A few weeks later on, a month or so later I went back to church and I saw a friend was pregnant and she confirmed that she was pregnant...I remember when I came home after that happened, I did cry, I did cry after that sort of the grief hit. And I actually did grieve for the child really." (Participant 6) "The ward I was on there was still sort of normal birth mothers on that ward, so you could see their babies you know alive and being taken to their side It was quite hard, I didn't cry or anything but I noticed it." (Participant 9)

Women expressed seeking self-isolation after their miscarriage. One participant explained *"I wanted to be by myself" (Participant 1)* and another said *"I would spend a lot of time like crying or just not wanting to be around anyone" (Participant 9).* 

"I just yeah I just like very much withdrew into myself" (Participant 4)

## "I didn't want to hear anybody else's um opinions of why it happened I just wanted to be kind of left alone" (Participant 2)

Women also expressed the difficulty of feeling like people did not understand how they felt as they had not gone through it themselves and also a longing to be understood as they tried to make sense of what had happened.

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"well my husband he was quite, my husband he was um, he he did try but I felt he sort of
didn't understand either" (Participant 1)
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" I think even more so at that point I just yeah I didn't think anyone would, would really get, would really get me and um understand it." (Participant 4)

One participant expressed wanting to be understood however not wanting that to come at a cost of unhealthy bonds with others who had also experienced baby loss.

"I didn't want to trauma bond with people I didn't want people to then be like oh I went through it too so let's be besties, no, I just didn't want to do that" (Participant 2) Distraction was also used a coping mechanism by some women following miscarriage. Women spoke about "going back to work" (*Participant 1*), "getting back into fitness" (*Participant 7*) and "getting back into [a] normal routine" (*Participant 9*).

One woman highlighted how others managed the loss of her baby. She experienced avoidance due to people not knowing how to console her during this time.

"I think when I went to church I could sense that people were like making a bee line so they didn't see, cross my path if that makes sense and I know obviously it's not like they were being malicious but it's like, I guess they didn't know what to say to me." (Participant 7)

#### Pressure to move on

Pressure to move on from the miscarriage and return back to "normal" life was expressed by women. This pressure often came from family members, friends and even themselves to move forward and not dwell on the loss if their baby.

"A bit like I said, it's almost a, oh don't worry, you know? It's not forever it's just now, it will get better and that's it , we don't discuss it again because discussing it is almost like dwelling on it. You know, you just need to move forward" (Participant 1)

"being a business owner as well and being a teacher there was a point where I just thought well I need to get back to teaching, I need to get back to like running the studio and just keeping things moving" (Participant 2)

One participant spoke about not wanting to be a burden on those around her as the fighting force that made her feel like she needed to move on.

"basically I wanted to speak about what had happened but then I didn't want it to be a case of oh I'm still going on about the miscarriage" (Participant 7)

### Questioning why

Women expressed feeling a sense of injustice with regards to their miscarriage. Participants spoke about doing all the 'right' things to ensure that they had a healthy pregnancy and not understanding why they lost their child.

"I thought it was people who smoke or drink and that's the reason they say don't do these things. Folic acid which is what you usually take when you are trying to get pregnant. I was on folic acid and on vitamins and don't smoke or drink I didn't have no symptoms" (Participant 1)

"So I already had that feeling of why me, like why does my pregnancy have to be like this? All my friends have got pregnant you know, why? A lot of it was why?" (Participant 3)

Women spoke about seeking understanding as to why they were miscarrying and trying to find concrete answers to explain what might have 'triggered' the miscarriage.

"Um because I think, because the inkling if you like I – because of the thoughts that had crossed my mind earlier like oh my gosh... perhaps I was wondering what, what had gone into my body type thing" (Participant 4) Various forms of self-blame were present across the majority of interviews with women expressing feeling like a *"failure" (Participant 8)* and that their *"body had failed the baby" (Participant 1).* An added layer of a previous abortion brought forth further feelings of guilt and shame in one participant and feelings of 'tempting fate' was expressed. Additionally women mentioned guilt for exercising during their pregnancy and an *"internal blame" (Participant 2)* was described by another participant.

"cause obviously I had an abortion before that it was very, is it my fault?" (Participant 8)

"I would do exercise, I tried to do gentle exercise... So it was that case of oh I probably could have contributed to the miscarriage in that way" (Participant 6)

"I just felt so guilty, like I was just like this is your fault" (Participant 7)

"Yeah because I was you know going to yoga, hot yoga and things um during that first trimester (R: yeah) and then looking up after what-what poses causes miscarriages and things like that. You do some really you know messed up things to yourself, the amount of blame you hold within yourself. Um, um and it feels, you feel really" (Participant 2)

#### Lack of Control

Due to the spontaneous nature of miscarriage women expressed feeling the event was out of their control.

"And what can I do to change my situation when really and truly there was nothing that I could do" (Participant 3)

"And I think for me at that point it was just the knowing what was happening and I couldn't stop it." (Participant 4) Women spoke about re-traumatisation due to different reasons. One participant spoke about her past experience of having an incomplete abortion being the same process physically as her miscarriage. Another explained that she had two miscarriages which happened on the same day a year apart. Additionally a third participant discussed complications following her miscarriage meaning that she had to relive the event again.

"I believe I was traumatised because it was reliving the whole experience where it was the incomplete abortion because the same process happens" (Participant 8)

"I was just in tears and remember I was screaming, not again, I can't do this again, I was like not again...So then again, It was like the same day, the same room, and even some of the same, the nurses that I remembered from the day before and they remembered me, so it was just nuts, literally crazy" (Participant 7)

"I couldn't even believe it that this was happening not only losing a baby but I then the procedure that was meant to be a simple procedure got messed up and now I was then having to miscarry again basically so it was almost like I was reliving it over and over again." (Participant 1)

### Repercussions of Miscarriage

The miscarriage experience was described as having *"many layers"* (*Participant 3*) and a lasting psychological effect afterwards. Women spoke about being *"resolute on having another baby"* (*Participant 8*) even if it meant their health may be in danger.

## "um they could have told me, you know if you got pregnant now you would die and I'd probably choose to die as the option" (Participant 3)

"all I wanted was to have another baby cause I wanted to get back what I had lost. So hence why I got, so I had the miscarriage in April and I was pregnant by June."

(Participant 8)

The majority of women who continued to have future pregnancies all expressed their miscarriage as having a negative impact on their future pregnancy journey.

"through the whole second pregnancy I was panicking everything she didn't move or I didn't feel like I was pregnant or um I was always worried that I would miscarry again, it would be later or obviously like I said when I went to have her, I didn't even have labour I just had the emergency caesarean. So you're thinking is she going to die, am I going to have a still birth this time" (Participant 8)

"So then when I did discover I was pregnant, probably a few weeks after that um I panicked the entire way through \*laughs\* probably until I got to about 20 weeks I panicked...I think I went for an early scan and I went for another early scan" (Participant

5)

"so what was happening at the beginning of my pregnancy was focusing on getting past that day that I lost the baby (R: yeah), when I got past that it was like phew ok, alright, I made it, now let's get to the 3 months, ok so just a couple more days and I'll be 3 months pregnant, I was very over cautious" (Participant 3)

Participants discussed being cautious about telling people about their pregnancy following baby loss as there was a fear that *"something might go wrong" (Participant 5)*. Some women spoke about how their miscarriage has negatively affected their perception of labour.

"I have my child now, she's 2 now I didn't have any labour with her, I had a straight um emergency caesarean, so I've never experienced labour ever. The only labour I've experienced is expelling the unviable foetus, I've never had labour pains replace the pain of miscarrying" (Participant 8)

"I still remember that and then obviously like both times there was just silence and I think that was very eerie, It was a very eerie thing, cause obviously when you give birth the baby's crying isn't but then it was just like an eerie silence and then it was just like me crying that all, like you couldn't hear any baby crying. So yeah, I can still remember that, so it's like it doesn't really leave you, um yeah, yeah it doesn't really leave you" (Participant

7)

#### **EXPERIENCES OF SUPPORT**

This theme refers to the varying degrees and quality of support that women received following their miscarriage. Women highlighted both the positive and the negative support received.

### Being seen, being heard

Some participants spoke about 'coming as you are', that those around them provided a space in which they felt permitted to grieve in any way they wanted to.

"Some people would come to my house and not say anything at all, you know and not say any, they won't open their mouth, and they'd just be there. That's good for me because you're not trying to make me accept something that I hadn't yet accepted" (Participant 3)

"I think one of my friends, the day I was discharged from hospital, she just came round and she just sat with me in silence and she cried, we just cried together and she just allowed me to like um yeah just say what's on my heart or if I didn't even want, want to say anything we just sat in silence and that really helped." (Participant 7)

Hearing other women's baby loss stories was reported to be beneficial. Having others close to them come forward and share stories fostered an environment of reassurance that they were not to blame and would one day hopefully go on to have healthy pregnancies.

"there was even women in my church who opened up and said yeah I've had a miscarriage and they were like, but if I didn't have that miscarriage I wouldn't have my daughter now. So they were just encouraging me like there is hope, you will have a child one day"

### (Participant 7)

"I think it was nice having an older person who had had then successful pregnancies afterwards and things and knowing she's a, she was a very housey woman anyway. And knowing that it wouldn't have been anything that she'd done, it was quite... having someone like that share their experience "(Participant 5) Additionally connecting with other women online who had experienced baby loss was seen as positive and provided a *"sense of community" (Participant 7)*. Some women expressed that speaking out publicly about their miscarriage provided them with a space to be heard.

"I also started a blog, just to express my feelings about it ... so I found that to be really therapeutic to work through everything" (Participant 9)

"it was just important for me to speak about it and I made a podcast episode (R: oh wow) about it as well" (Participant 2)

Those who were offered support by family members considered this helpful; it gave women confidence that they could get through the aftermath of their miscarriage. In some cases, support from family members encouraged women to seek further professional support.

"Um, I think just having like supportive family um yeah cause when I was recommended to get the counselling um yeah I just discussed with my mum and my husband and they were just like yeah go for it. Like if I didn't have that support I probably wouldn't have gone for it so yeah family support was massive" (Participant 7)

"my family were massive, a massive help, um and I think yeah essentially really grateful for the um my cultural values and being able to sort of to share my pain if you like and to um yeah I just had that sort of sense of openness and support no matter what time of day it is, no matter sort of I dunno if I was grumpy when they last saw me." (Participant 4)

Some participants stated that their faith in God played a big role in feeling supported. One participant explained that due to her faith she found solace in the belief that her child *"has gone straight to heaven" (Participant 6)* and that one day she will see them there.

"My faith in God, God just really, yeah held me hand really. So I just had to really dig deep within myself and exhaust every resource that I knew within myself, in order to get out of the, the dark pit that I was in. So, yeah that's how I got through it" (Participant 7)

"I believe my emotional support came a lot from my faith and those around me who are of the same faith...it was my faith that got me through, so if I was feeling heavy or low or anything like that, I either sing a worship song or read something that will encourage me or speak to someone and they'll pray for me or you know that kind of thing." (Participant

6)

Three women expressed that they had positive encounters with professional psychological support which they found helpful. Being able to acknowledge and speak through the difficult emotions that were being held in was seen as a *"turning point" (Participant 7)* and a catalyst for learning how to channel the *"grief and pain in a more healthy way" (Participant 2)* 

"Yeah I found it really helpful, so those sessions were just me with the therapist uh one on one and sort of she would talk through my symptoms, how I'm feeling um we would have sort of 2 weekly sessions um so I found that really helpful just to work through everything"

(Participant 9)

"I had a session with her and I think that was one of the main things that helped me through the process"(Participant 2)

#### Seeking and not finding support

Seeking and not finding support was mentioned throughout most interviews; women expressed dissatisfaction about which type of professional support was offered to them, and how, following their miscarriage. Women discussed that some clinicians offered support in the form of leaflets which was described as *"generic"* (*Participant 10*) and not meeting their needs. Despite counselling being presented as an option, one participant had an experience in which she felt pressured to decline support due to the high demand.

"the most they do is say that you need counselling if you don't feel like you need it then say so because obviously our counselling service is very stretched at the moment, they only had one counsellor in my clinic" (Participant 10)

Women spoke about the difficulty to reach out for professional help and consequently alluded to feelings of abandonment when no follow up regarding emotional support was received.

## "they kind of forgot about me" (Participant 8)

"it was like it was just yeah because some people say it's easy to follow up, it wasn't like they got in touch with me and asked oh have you spoken, or the bereavement officer, she

# wasn't like she didn't like message me and say no erm if ever you need blah blah blah so yeah"(Participant 1)

One woman shared her experience of seeking support from a therapy group that she was already a part of and found that her miscarriage experience was minimised as she was told that it is common and her feelings dismissed.

"Um but yeah, that's the whole, I don't really know about mental health because they was nothing, there was no support, there was nothing, it was just that's it, it was forgotten. You've done that, that's happened, you're only 25% of people that suffer from it get over it sort of thing, that's the whole attitude" (Participant 8)

When women were able to gather the courage to speak out and ask for support, some were met with disappointment due to the lack of support they received whilst meeting with clinicians.

"Um went to the appointment, when I got to the appointment I sat there, the woman was like 'you look so fabulous', she just couldn't get her head around how gorgeous I looked and how you know she just was like 'you look so great' and she was praising me...Well I was just a bit confused, I thought, well ok, well maybe I do look fabulous, maybe I am ok then. So I just went with her flow and she really encouraged me in terms of you look amazing, you look like you know, you've managed the situation kind of thing. So under that I just thought, oh right so I'm ok then, and I left. And that was the last time I heard from her" (Participant 3)

"I just didn't think she was very helpful, I don't know, I don't know what I wanted her to help me with but I just, yeah she was, I don't, she felt quite disconnected um uh yeah" (Participant 4)

#### BARRIERS

Barriers to help-seeking were highlighted across interviews with the following subthemes emerging.

#### **Cultural barriers**

Across interviews, cultural barriers were brought to the forefront both when being explicitly asked about barriers as well as when women shared their experiences. Women spoke about barriers faced within the Black community regarding miscarriage. Although the Black community has started to engage in conversations regarding baby loss, women expressed that there is still a taboo.

"There's still sort of this taboo around miscarriage in the African culture you know it's not spoken about its either that child wasn't really a child or just a thing of ... I still think its ignorant to say that your child could have had a disability you never know...and even if my child um had a disability that doesn't mean I wouldn't want that child" (Participant 9)

"miscarriage in itself, it's kinda, it's like a taboo isn't it, it's all happy and nice when someone says oh I'm pregnant and it's like a sign that your fertile you know, it's like God's blessing but when it's like the opposite, when there's a death, although people offer their condolences, there's not so much noise, it's more of a silence" (Participant 7)

Professional support was seen as the last resort; some women spoke about counselling not being a form of support that the Black community acknowledge as being for them. "Within our community we tend to kind of wait um and try and deal with things ourselves um and it's only until kinda the worst case scenario that we kinda call out for that help"

#### (Participant 3)

"yeah even counselling I don't really hear black people saying yeah I'm going for counselling (R: yeah) as well and even myself when I, when I was um recommend to get counselling, even myself I was thinking oh how is that going to help me?" (Participant 7)

Stigma was also discussed as a barrier to seeking support; the stigma around mental health within society compounded with the stigma experienced within the Black community is experienced as a heavy load which deters Black women from seeking professional support.

"yeah, I think within our community and also, I mean there's stigma in general when it comes to mental health issues but within our community in feel like its double double really, you know don't tell people" (Participant 6)

The additional fear that if you do reach out for professional help you may be labelled as having severe mental health difficulties, be sectioned or placed on medication was also shared during interviews.

"you don't want to be suddenly...what's the word... carted off to a mental facility when actual fact all you needed was a bit of support." (Participant 5)

"I was quite low so what you're thinking, at my lowest point was the last thing I want is for someone to say to me that I've got depression or anxiety now I'm going to have to start talking antidepressants" (Participant 10)

#### Societal barriers

Not belonging was a consistent theme across interviews. Despite finding other women's stories regarding child loss helpful, women also stated that there was a lack of representation.

"there's not a lot of representation um you know when you hear of these stories when you see people on um big media platforms, I don't think you see a lot of black women , I don't think you hear a lot of stories from black women" (Participant 9)

"So even was I was like looking for hashtags on Instagram all the accounts that I came across were like white ladies (R: yeah) and obviously that's good but I wanted to see someone like me" (Participant 7)

"there's a website called Tommy's charity, which um talks about like bereavements and you know things you go through, troubles that you go through, pregnancy. And they had like quite a few ladies that came out, that had actually suffered a miscarriage. And I remember there's only, with all the people they interviewed, I think there was only one black couple... it was just like oh ok does this not happen to us then or like do we just not talk about it? I don't, I just didn't understand why there was only one couple I didn't feel like I could relate to it as much if you know what I mean?" (Participant 1)

Furthermore women expressed a lack of community for Black women who have experienced baby loss.

"uh, yeah, yeah, I think there are. I think there are barriers to help-seeking um in society and I think it's just because if we look at it from a societal point of view the word that comes to be is belonging. And there isn't really a space where you belong to air out the issues that you're facing and therefore where that doesn't exist you're quite far removed from people understanding what your needs are to be able to ensure that

there is something out there that serves" (Participant 10)

The Strong Black Woman was a narrative rejected by participants, however it was acknowledged that this construct not only affects how women seek help but also whether others deem Black women to need help. The fact that *"Black women are seen as quite strong"* (*Participant 3*) meant that women felt they had to live up to this image and *"just get on with it"* (*Participant 1*).

"this is the why the strong black woman troupe is so dangerous because to them... means we don't we aren't vulnerable and actually vulnerability is the major key to strength but we're not allowed not be vulnerable in the same way that we see our white counterparts being able to. So seeking help, why what do you, you're a strong African woman, you're fine, you'll be ok" (Participant 2)

A subconscious internalisation of the Strong Black Woman schema played a role in the lack of help-seeking behaviour.

"I'll speak for myself, I definitely think there is something in us, just getting on with it, getting on with it. I don't know where it comes from, I think it's deeper than that and I can't go there cause I don't have the answers but I do feel like that is a thing. There is a, that's what you call the invisible barriers. I can't fathom how they come about or where they've come from but there's definitely a barrier in our behaviours that don't allow us to, to get the help that we need, um yeah" (Participant 10)

Encountering long waiting lists for support after miscarriage was a barrier for some.

"When I left the hospital and the bereavement nurse, she gave me leaflets and was like here contact this person, and this organisation. I think I did try to call one of them but like there's like a waiting list you know you can't really get through but I guess that was my experience anyway" (Participant 7)

"Around June is when I signed up for um a new therapist you know I um and I did that private because I've had um is through the NHS before and I was just not prepared to be waiting 8 weeks." (Participant 2)

"So yeah there are barriers there are financial barriers you as well (R: yeah) cause not everybody can afford to have, to go private to get a therapist" (Participant 2)

#### **Being Silenced**

Women discussed not being able to talk about their miscarriage.

"And I look back to the whole thing uh (R: yeah) it sort of, it's not spoken about" (Participant 4)

"it wasn't something that was discussed it was just oh no I'm sorry that you went through this , don't worry you can try again next month or whatever." (Participant 1)

"I just learnt to accept that I must be what they say I am, I shouldn't be angry at anything, I shouldn't feel sad, I shouldn't feel, they made me feel that all my feelings were abnormal. So um, yeah, it didn't help anything; it didn't help whatsoever because according to them you can't grieve for miscarriage there's nothing to grieve about. Um so yeah that was it really, it was, it weren't good" (Participant 8)

Some women spoke about both dismissal of their physical pain before the miscarriage as well as dismissal of their emotional responses from clinicians. The invalidation of their concerns and feelings contributed to the lack of support sought from healthcare professionals in the future.

"yeah I had the twinges and I was a bit concerned about that. I did mention it to the GP when I actually first went to say that I was pregnant because I did a home pregnancy test and then it was, there was, maybe I didn't emphasise it or maybe I didn't, he just brushed it aside, it wasn't, sort of oh that could be something or that could be something"

#### (Participant 6)

"yeah it's funny because it says in here [reads a list of different emotions]. So like I just said, they were all the things that I felt but MBT\* told me they were all wrong. You know I shouldn't feel angry, I shouldn't feel guilty, I shouldn't feel a sense of loss." (Participant 8)

\*Mentalization-Based Treatment- long term psychotherapy group.

One woman, when speaking about looking for support following her miscarriage, showed internalised invalidation of her grief which stopped her from attending a support group. "but I did look online and try and see erm because they had meetings for people who had like gone through grief with their kids and things but I think it's a bit different to having a miscarriage and a bereavement for your child" (Participant 1)

#### Lack of trust

A lack of trust in the healthcare system was expressed; women spoke about historical abuse perpetrated by clinical staff and the medical field as being a hindrance to trusting that the healthcare system is safe for them and will therefore support them. The dehumanisation of Black women and their bodies was highlighted, and the disproportionate number of maternal deaths seen amongst Black women compared to their white counterparts also added to the mistrust in healthcare.

"there are barriers; yeah yeah there are definitely barriers because I think that historically um black women's bodies were just seen as sights of experimentation within the medical field. So when it comes to seeing black women as feeling human beings um that deserve empathy that deserve to be heard, and um you know listened to and the things that they say happened. I think that the medical field is still struggling with that greatly and even with my most recent pregnancy when I had my son you know I was there arguing with really with midwives as to whether I was you know in labour or not and that or whether my waters had broken or not." (Participant 2)

"a lack of listening to uh black women means that there's a distrust between black women and the healthcare industry, the medical field and then professionals and um that distrust is, why we have a disproportionate number of maternal deaths for black mothers in comparison to white mothers" (Participant 2)

#### DISCUSSION

#### **Overview** of findings

The study primarily aimed to explore the experiences of miscarriage and help seeking afterwards amongst Black women. From the analysis of the data three key themes were generated: miscarrying as an experience, experiences of support and barriers.

A variety of emotions were first reported when women described their experience of miscarriage. In line with previous research regarding miscarriage experiences (Moulder, 2001), feelings of anger, sadness and loss were reported by women.

Women spoke about the dismissal of their pain being linked to mistrust in the healthcare system; a notion that has been reported in literature around racial pain biases (Trawalter & Hoffman, 2015).

Despite research showing that, better medical management and more information after miscarriage as well as empathy from medical staff (Rowlands & Lee, 2010) is needed, Black women expressed poor medical management, minimal to no information after their miscarriage and at times a lack of empathy from medical staff.

Both positive and negative support from healthcare staff was a consistent finding which further emphases prior research findings of inconsistent miscarriage care (Bellhouse, Temple-Smith, Waston & Bilardi, 2019).

It is important to highlight the helpful support that some Black women received from clinicians, family members and friends. The client centred approach which led to them feeling "seen" and "heard" is one that should be adopted across clinical health settings when interacting with this client group.

#### Strengths and Limitations

This is the first study to explore the experiences of miscarriage and help seeking afterwards amongst Black women. Using a qualitative design and employing thematic analysis allowed for a deeper exploration of Black women's experiences. The use of semi-structured interviews created a space for women to speak their truth and all of the women commented that the research had provided them with a platform for both their voices and their stories to be heard. For one participant, this research was the first time that she had told her story.

Due to unforeseeable circumstances, the transcripts for two participants (marked with \* in the demographic table) were lost and unable to be retrieved before data analysis started. Therefore themes that may have emerged from their transcripts cannot be accounted for.

Additionally it is important to note that the sample inclusion criteria excluded 'older' participants from taking part in the research meaning that the experiences of 'older' women who had experienced a miscarriage were not included. This meant that the results do not include data from historical miscarriages when healthcare and mental health services were set up in a different way. However as the current research aimed to focus on the current access to mental health and healthcare services, this did not have a negative impact on the overall findings.

Furthermore women were aware that the researcher was a Black British female which although was beneficial in allowing women to share their experiences freely it also occasionally proved to be a limitation in the study. At times nuanced experiences of being a Black woman were not further explained as there was a presumed unspoken acknowledgement of mutual understanding, meaning that topics discussed around race, culture and barriers could have been further explored and added to the richness of the data collected. Additionally when conducting, analysing and writing up, the researcher is not able to detach from her race therefore any information pertaining to race or culture also encapsulated the researcher's lived experiences (Boylorn, 2008).

Additionally, as the researcher had personal experiences of miscarriage, it was important that any biases were regularly reflected upon during research supervision in order to minimise any possible impact on the researcher's process (Dietrich, 2010).

#### Implications

Although the literature and societal awareness of the effects of miscarriage is growing, the experiences of Black women have unfortunately been underrepresented. This study has highlighted a variety of ways in which service provision for this client group can be improved.

One of the central subthemes reported on the underrepresentation of Black women's experiences of miscarriage on social media and charity websites as a barrier to reaching out and accessing professional support. It is therefore important for charities and healthcare services to ensure that Black women are represented on their platforms as this is a client group that is often marginalised and cannot easily access support.

With regards to cultural barriers, continued education within the Black community is key. Spoken awareness and open dialogue regarding baby loss needs to continue and events run by members of the community, in the community may provide further education and understanding on baby loss and its effects.

The study revealed that support following baby loss is wanted by Black women however the lack of knowing where to seek support prevents them from accessing the support they need. The utilisation of social media platforms such as Instagram, twitter, clubhouse, Facebook as well as third party charity websites to inform Black women what services are available to them would be beneficial.

The interviews with the women brought up wider implications of systematic racism that must be addressed. With the climbing rates of Black maternal deaths, Black miscarriages, (MBRRACE-UK; 2019) and the disappointing denial of institutional racism within the UK (Commission on Race and Ethnic Disparities: The Report, 2021), this is an implication of the upmost importance. As women throughout the interviews expressed not being believed when in pain and having their emotional experiences invalidated by clinical professionals it is understandable why there is a lack of trust within this client group. It is imperative that clinicians wanting to work with this client group are well versed in anti-racism and allyship in order to create a safe space in which Black women can come for support following a miscarriage.

As women spoke about a lack of a supportive community, there is a vital need for support groups led by Black clinicians for Black women who have experienced a miscarriage. Having a space in which women can meet with other women they identify with to discuss their lived experience is a source of support that women stated is

needed. An increase of Black professionals working within the maternal mental health field will also be vital in reaching this client group.

For too long Black women's voices have been silenced; being seen and being heard is an important factor and needs to be priority in making sure this client group can access the support they need. The current initiative of "birth reflection" sessions being run in some UK NHS trusts could be adapted to accommodate "miscarriage reflections". As women expressed that non-patient centred care was provided, this would allow women the space to speak with a clinician regarding their experience and a tailored signposting onto relevant support services to be carried out should a women want further support. Collaboration with Black maternal mental health organisations should be sought out by any organisation wanting to work with this client group to ensure that culturally sensitive support can be access during baby loss.

Future research into Black maternal mental health in the UK needs to be conducted as research into this client group is very limited. Further research looking solely at the number of Black women accessing maternal mental health services and the barriers in doing so should be conducted. A pilot study on the efficacy and validity of black led support groups for Black women who have experienced a miscarriage may help inform what service provision needs to look like. Additionally research into race disparities in maternal care should be conducted. Research into what type of support is needed for Black women after miscarriage will be beneficial in starting to create tailored service provision for this client group. Research into Black men's and Black families' experiences of miscarriage may also be important in understand what support is needed for Black families' during a time of loss.

#### Conclusions

Despite the cultural and societal taboos around miscarriage, each of the women interviewed were able to speak up about their experiences, whether that be on podcasts, social media platforms, personal blogs or through the research conducted. This highlights that despite the barriers Black women face regarding baby loss, they still want to be heard and will continue to fight to be heard within the Black community and most importantly within the UK white majority society. The research has highlighted Black women's experiences of miscarriage and the barriers they encounter when seeking support. Further research into Black led clinical interventions, systematic barriers that Black women encounter when seeking maternal care and the effects of miscarriage on Black families need to be conducted.

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MBRRACE-UK (2019)- <u>https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202019%20-%20WEB%20VERSION.pdf</u>

Miscarriage, NHS (2018)- https://www.nhs.uk/conditions/miscarriage/afterwards/

Menopause, NHS (2018)-https://www.nhs.uk/conditions/menopause/

Part Three: Appendices

#### Appendix A: Reflective Statement

#### Designing the research

Being a Black woman who had witnessed multiple baby losses within my own family was the sole driving force to choosing my research topic. The research area being a topic that was close to my heart meant that I was both passionate but also intimidated by what felt like was a heavy responsibility in making sure that the voices of Black women were finally heard in research. Research was an area that I did not feel completely confident in and often times throughout the process felt out of depth. However, my passion and reassurance in knowing that God had placed me here for a reason kept me going in times when I was unsure of what the next step might look like.

#### **Ethics Application**

The ethical approval process was new to me and seemed quite daunting to begin with. However, the process of obtaining ethical approval for my study was one that went surprisingly smoothly. Being granted ethical approval not only meant that my study was ready to go ahead but also in a way gave me a sense of being approved as a researcher. This was the boost of confidence I needed to start what I didn't know would be a lengthy and challenging process.

#### **Recruitment Process**

Having braced myself for a difficult recruitment process based on the client group I was reaching out to, I was overjoyed when I had a multitude of Black women come forward and express interest in my research. The fact that I was able to exceed my desired sample size was validating and emphasised even more to me that miscarriage is a topic that needs to be spoken about. Being another Black woman who was familiar with baby loss within the Black community created a space of familiarity amongst the women who took part in the study. I recall conversations that I had with women after the research interview was over, reflecting on the importance of the research and what it was like to be Back women within society today.

Carrying out interviews during the 1st COVID-19 lockdown and the racial injustice experienced by Black people brought to the forefront due to the merciless murder of George Floyd was extremely challenging. I recall going through twitter and witnessing yet another video of police brutality in not only the US but also the UK and hearing the racial injustice that some of the participants had endured during their miscarriage. Despite this being a reality that I had lived, the overt and constant racial abuse being shown daily was hard for me to tolerate.

Additionally, stumbling across the MBRRACE-UK report which reported that Black women in the UK were 4 times more likely to die from childbirth compared to their white counterparts was beyond shocking to me and at the time was the straw that 'almost' broke the camel's back. The highlighting of racial injustice within society and the medical field further fuelled my determination to have Black women's voices heard.

At one point being surrounded by stories of Black deaths both in my research and within the news outlets took a toll on me and resulted in many nights of weeping and prayer. With the help of God and those closest to me, I was able to move forward and find the strength to continue pushing through my research.

#### Data Analysis

Analysing the data that I had collected was without a shadow of a doubt the hardest part of the research process for me. Listening, transcribing, reading and re-reading women's story of their miscarriage was honestly at times challenging and overwhelming. Despite not ever having experienced a miscarriage myself, the nuanced cultural and societal barriers that Black women face regarding support seeking was one that I resonated with heavily. Being able to have my supervisor and a fellow peer look over my analysis was imperative in making sure the data extracted was as un-biased as it could be.

The process of data analysis was a laborious one; going over transcripts multiple times, trying to pull out information from each interview and what felt like, the mammoth task of trying to group the codes together to create key themes and subthemes. The perfectionist in me, once again made an appearance in wanting to make sure that I had captured all that the women had spoken about.

Due to delays in data collection, I was still carrying out data analysis whilst starting a full time post in the NHS following the 'end' of the course. Trying to juggle full time work with data analysis and the write up was something that I was unprepared for. However, despite this, I was able to keep moving forward and eventually finish writing up.

#### The Write-Up

The write up process was a blur of late nights, bottomless caffeine, a few tears and a lot of faith. In wanting to make sure that each participant's voice was heard I attempted to include nearly every quote relating to each theme... as you can imagine, my word count very quickly soared over 10,000 words and my supervisor kindly advised me to reconsider the lengths of the quotes.

My write up highlighted negative processes within me; I often found myself worrying about not 'sounding smart' or not explaining my themes well enough. This was a process that led to a lot of self-doubt in my abilities and avoiding writing as I wanted my

work to be 'perfect'. A reminder from a close peer, that perfection is subjective and unattainable helped me to move past this process and start a healthier way of engaging with my research write-up.

SLR

Choosing my area of topic came extremely easily to me as it linked with my empirical paper and also highlighted the experiences of Black women. To begin with I was enthusiastic and rearing to start researching. However, as time went the engagement levels with my SLR were very low; reflecting on this time, I believe it was due to my sheer lack of understanding, knowledge and an immense fear of failure that drove my disengagement. However, with the support of my clinical supervisor and research team at the university, I was able to find my feet again and continue on the journey. I recall a frantic video call with member of the research team adamant that I should start my SLR process from the beginning again as I was unsure whether my research question was no longer relevant. The encouragement and reassurance that I was on the right track and was in fact researching an area that was so important, especially in a time such as this, was the assurance that I needed to keep going. Looking back at the whole process of the SLR I note my pathological avoidance produced by my fear of failure was paramount in how I approached this part of the portfolio.

#### Summary

As a whole I reflect on the process of research as one that has truly stretched me beyond what I thought I could achieve. The process I am glad to say has not only helped mould me as researcher but has also helped me grow as an individual. I feel privileged to have been entrusted with the sacred stories of each Black women's experience of their miscarriage and even more privileged to be able to share their stories with the research community. The entire research process has solidified my personal passion in women's wellbeing as a whole. It has been a true blessing and a testimony to the God that I love and serve that I can say I have been able to produce two pieces of research highlighting the voices of Black women.

#### Appendix B: Epistemological statement

Due to the steer towards qualitative analysis, it is important to reflect on the lens in which research has been undertaken. The way in which the researcher understands reality to be known is the foundation of epistemology and how knowledge is studied (Carson, Gilmore, Perry & Gronhaug, 2001). The epistemological stance is an important theory to reflect upon when carrying out research; this is more imperative when conducting qualitative research due to its use of interpretation (Willig, 2001).

With regards to qualitative research there are two main epistemological perspectives that are often taken; positivist or interpretivist. As the research carried out, sought to report on the experiences of help-seeking amongst Black women as well as their lived experiences of miscarriage, the research can be viewed through the lens of interpretivism. Interpretivism takes into account differences such as culture, circumstances and social realities. In comparison to positivism, this stance aims to gather the richness that is produced from individual stories rather than attempting to establish concrete truths that can be generalised to the general population (Myers, 2008; Saunders, Lewis and Thornhill, 2012).

My ontological stance means that as a researcher I assume that there are multiple realities and each is subjective (Al-Ababneh, 2020). This can be seen through how I chose to conduct my systematic literature review and empirical paper; by seeking to hear the individual stories of Black women and taking each experience as truth. My ontological positon influenced my epistemological stance of interpretivism. I believe that as the researcher I interact with the research topic and therefore assume that research will be influenced by values and biases (Al-Ababneh, 2020). As a result of my ontological and epistemological stance, qualitative methodology and analysis was the most appropriate to be used for both the systematic literature review and the empirical paper.

As stated above, the importance of considering one's personal lens is one in which I have found beneficial and imperative throughout the research process. The influence that my own personal lens would have had on the follow up questions asked, the content of the interviews and the way in which they were conducted was a process in which I was able to reflect upon. Being a Black woman interviewing other Black women I was aware of the potential biases that I could bring to the interviews and the analysis process. I aimed to minimise this by allowing women to speak for themselves and explain further that the meant. However, it has to be noted at times this was difficult as mutual understanding of the second generation Black women experience was assumed by both me and participants. During this process I made sure to be self-reflective both throughout the interviews and across the whole research process to ensure that results shared told the exact stories of each participant.

In conclusion the researcher's epistemological stance is interpretivism. However, despite the research conducted aligning with that of an interpretivist perspective; it is important the note that a variation of interpretivism known as hermeneutics (Littlejohn & Foss, 2009) may have also influenced research. As a self-identifying Christian, biblical sources and wisdom literature play a role in both my outlook on life and the lens in which this research was approached.

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## Appendix C: Submission guidelines for: Clinical Psychology Review



#### **Peer review**

This journal operates a single anonymized review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. Editors are not involved in decisions about papers which they have written themselves or have been written by family members or colleagues or which relate to products or services in which the editor has an interest. Any such submission is subject to all of the journal's usual procedures, with peer review handled independently of the relevant editor and their research groups. More information on types of peer review.

#### Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

## Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing

material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least to 3 months within date of submission) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (http://www.prisma-statement.org/) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

## Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

## Essential title page information

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.** 

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.** 

*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

## Highlights

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that

capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

## Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

## Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Authors can make use of Elsevier's **Illustration Services** to ensure the best presentation of their images and in accordance with all technical requirements.

## Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

## Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

#### **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

## Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

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• Ensure that color images are accessible to all, including those with impaired color vision.

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• Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;

- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

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Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

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## Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

## References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the most recent publication manual of the American Psychological Association. Information can be found at https://apastyle.apa.org/

## Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

#### Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

## Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

#### References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

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When preparing your manuscript, you will then be able to select this style using the Mendeley plug-ins for Microsoft Word or LibreOffice.

## **Reference style**

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of

publication. References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).

*Examples:* Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59.

Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. http://dx.doi.org/10.17632/xwj98nb39r.1

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#### Data linking

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For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect.

In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

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To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the

research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

## Appendix D: Data extraction form

# Title of Study:

## <u>General</u>

Author(s)	
Year of publication	
Country	
Research aims	

## **Participants**

Sample size	
Demographics of	
sample	

## <u>Methodology</u>

Method of data collection	
Type of research method	
Type of analysis	
Methodological quality checklist score	

# Findings and Conclusion

Main findings	
Limitations	
Generalisability	
Conclusions	

# Appendix E: Quality Assessment Checklist (Qualitative)

# Checklist

<b>Study identification:</b> Include author, title, reference, year of publication			
Guidance topic:	Key research que	stion/aim:	
Checklist completed by:			
Theoretical approach			
1. Is a qualitative approach appropriate?	Appropriate	Comments:	
For example:	Inappropriate		
• Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?	Not sure		
• Could a quantitative approach better have addressed the research question?			
2. Is the study clear in what it seeks to do?	Clear	Comments:	
For example:	Unclear		
• Is the purpose of the study discussed – aims/objectives/research question/s?	Mixed		
• Is there adequate/appropriate reference to the literature?			
• Are underpinning values/assumptions/theory discussed?			

# Study design 3. How defensible/rigorous is the research Defensible Comments: design/methodology? Indefensible For example: Not sure Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? Are there clear accounts of the • rationale/justification for the sampling, data collection and data analysis techniques used? Is the selection of cases/sampling strategy • theoretically justified? **Data collection** 4. How well was the data collection carried out? Appropriately Comments: For example: Inappropriately Are the data collection methods clearly described? Not • sure/inadequately Were the appropriate data collected to address the • reported research question? Was the data collection and record keeping • systematic? **Trustworthiness** 5. Is the role of the researcher clearly described? Clearly described Comments: Unclear For example: Has the relationship between the researcher and the •

participants been adequately considered?	Not described	
• Does the paper describe how the research was		
explained and presented to the participants?		
6. Is the context clearly described?	Clear	Comments:
For example:	Unclear	
• Are the characteristics of the participants and settings clearly defined?	Not sure	
• Were observations made in a sufficient variety of circumstances		
• Was context bias considered		
7. Were the methods reliable?	Reliable	Comments:
For example:	Unreliable	
• Was data collected by more than 1 method?	Not sure	
• Is there justification for triangulation, or for not triangulating?		
• Do the methods investigate what they claim to?		
Analysis		
8. Is the data analysis sufficiently rigorous?	Rigorous	Comments:
For example:	Not rigorous	
• Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?	Not sure/not reported	
• How systematic is the analysis, is the procedure reliable/dependable?		
• Is it clear how the themes and concepts were		

derived from the data?		
9. Is the data 'rich'?	Rich	Comments:
For example:	Poor	
• How well are the contexts of the data described?	Not sure/not reported	
• Has the diversity of perspective and content been explored?		
• How well has the detail and depth been demonstrated?		
• Are responses compared and contrasted across groups/sites?		
10. Is the analysis reliable?	Reliable	Comments:
For example:	Unreliable	
• Did more than 1 researcher theme and code transcripts/data?	Not sure/not reported	
• If so, how were differences resolved?		
• Did participants feed back on the transcripts/data if possible and relevant?		
• Were negative/discrepant results addressed or ignored?		
11. Are the findings convincing?	Convincing	Comments:
For example:	Not convincing	
• Are the findings clearly presented?	Not sure	
• Are the findings internally coherent?		
• Are extracts from the original data included?		
• Are the data appropriately referenced?		

• Is the reporting clear and coherent?		
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments
13. Conclusions	Adequate	Comments
For example:	Inadequate	
• How clear are the links between data, interpretation and conclusions?	Not sure	
• Are the conclusions plausible and coherent?		
• Have alternative explanations been explored and discounted?		
• Does this enhance understanding of the research topic?		
• Are the implications of the research clearly defined?		
Is there adequate discussion of any limitations encountered?		
Ethics		1
14. How clear and coherent is the reporting of ethics?	Appropriate Inappropriate	Comments
For example:	Not sure/not reported	
• Have ethical issues been taken into consideration?		
• Are they adequately discussed e.g. do they address consent and anonymity?		
• Have the consequences of the research been		

<ul><li>considered i.e. raising expectations, changing behaviour?</li><li>Was the study approved by an ethics committee?</li></ul>		
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ +	Comments:
	-	

# Appendix F: Quality Assessment Checklist (Quantiative)

# Checklist

Study identification: Include full citation details		
Study design:		
• Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design		
Guidance topic:		
Assessed by:		
Section 1: Population		
1.1 Is the source population or source area well described?	++	Comments:
• Was the country (e.g. developed or non-developed, type of health	+	
care system), setting (primary schools, community centres etc),	_	
location (urban, rural), population demographics etc adequately described?	NR	
	NA	
1.2 Is the eligible population or area representative of the source	++	Comments:
population or area?	+	
• Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)?	_	
• Was the eligible population representative of the source? Were important groups underrepresented?	NR NA	

<b>1.3 Do the selected participants or areas represent the eligible population or area?</b>	++	Comments
• Was the method of selection of participants from the eligible population well described?	_	
• What % of selected individuals or clusters agreed to participate? Were there any sources of bias?	NR NA	
• Were the inclusion or exclusion criteria explicit and appropriate?		
Section 2: Method of selection of exposure (or comparison) group		1
2.1 Selection of exposure (and comparison) group. How was selection bias minimised?	++	Comments
	+	
• How was selection bias minimised?	-	
	NR	
	NA	
2.2 Was the selection of explanatory variables based on a sound theoretical basis?	++	Comments
	+	
• How sound was the theoretical basis for selecting the explanatory variables?	-	
	NR	
	NA	
2.3 Was the contamination acceptably low?	++	Comments
• Did any in the comparison group receive the exposure?	+	
• If so, was it sufficient to cause important bias?	_	
	NR	

2.4 How well were likely confounding factors identified and controlled?	++	Comments:
• Were there likely to be other confounding factors not considered or appropriately adjusted for?	– NR	
• Was this sufficient to cause important bias?	NA	
2.5 Is the setting applicable to the UK?	++	Comments:
• Did the setting differ significantly from the UK?	+	
	-	
	NR	
	NA	
Section 3: Outcomes		I
3.1 Were the outcome measures and procedures reliable?	++	Comments
• Were outcome measures subjective or objective (e.g. biochemically	+	
validated nicotine levels ++ vs self-reported smoking -)?	_	
• How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)?	NR	
• Was there any indication that measures had been validated (e.g.	NA	
validated against a gold standard measure or assessed for content validity)?		
	++	Comments
<b>3.2</b> Were the outcome measurements complete?		
<ul> <li>3.2 Were the outcome measurements complete?</li> <li>Were all or most of the study participants who met the defined study outcome definitions likely to have been identified?</li> </ul>	+	

	NA	
3.3 Were all the important outcomes assessed?	++	Comments
• Were all the important benefits and harms assessed?	+	
• Was it possible to determine the overall balance of benefits and	_	
harms of the intervention versus comparison?	NR	
	NA	
3.4 Was there a similar follow-up time in exposure and comparison	++	Comments
groups?	+	
• If groups are followed for different lengths of time, then more events	_	
are likely to occur in the group followed-up for longer distorting the comparison.	NR	
• Analyses can be adjusted to allow for differences in length of follow- up (e.g. using person-years).	NA	
3.5 Was follow-up time meaningful?	++	Comments
• Was follow-up long enough to assess long-term benefits and harms?	+	
• Was it too long, e.g. participants lost to follow-up?	_	
	NR	
	NA	
Section 4: Analyses	1	I
4.1 Was the study sufficiently powered to detect an intervention	++	Comments
effect (if one exists)?	+	
	1	

• Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?	NR NA	
4.2 Were multiple explanatory variables considered in the analyses?	++	Comments:
• Were there sufficient explanatory variables considered in the	+	
analysis?		
	-	
	NR	
	NA	
4.3 Were the analytical methods appropriate?	++	Comments:
• Were important differences in follow-up time and likely confounders	+	
adjusted for?	_	
	NR	
	NA	
4.6 Was the precision of association given or calculable? Is	++	Comments:
association meaningful?	+	
• Were confidence intervals or p values for effect estimates given or possible to calculate?	_	
• Were CIs wide or were they sufficiently precise to aid decision-	NR	
making? If precision is lacking, is this because the study is under- powered?	NA	
Section 5: Summary		
5.1 Are the study results internally valid (i.e. unbiased)?	++	Comments:
• How well did the study minimise sources of bias (i.e. adjusting for	+	

• Were there significant flaws in the study design?	_	
5.2 Are the findings generalisable to the source population (i.e. externally valid)?	++	Comments:
• Are there sufficient details given about the study to determine if the findings are generalisable to the source population?	_	
• Consider: participants, interventions and comparisons, outcomes, resource and policy implications.		

# Appendix G: Submission guidelines for Psychology Women Quarterly

Manuscript Submission Guidelines:

Manuscript Submissions

*Psychology of Women Quarterly* accepts submission of original articles only through its online web system at http://mc.manuscriptcentral.com/pwq.

Please follow the instructions through the site. It will be helpful to have a separate title page and fully masked, electronic main document prepared in advance. The main document must include the Abstract and all Tables, Figures, and appended materials and must mask unpublished Author Citations throughout the manuscript.

If you have any questions or problems, please contact Dawn Szymanski (Editor) or Cora Powers (Assistant Editor) at pwq@utk.edu.

Manuscripts should be submitted as an electronic file in Microsoft Word. An accompanying letter should request review and include the following information: that the manuscript (a) is not currently under review elsewhere, (b) has not been previously published in whole or in part, and (c) conforms to APA standards on ethical treatment of participants. If you are using the data from this study in any other study (either completed or planned), explain this in detail in the cover letter to the Editor and indicate in the manuscript that the study is based on a larger dataset.

# Manuscript Review Policy

Standard masked peer review procedures are used for all submissions. APA policy prohibits an author from submitting the same manuscript for concurrent consideration by more than one journal. Prior or duplicate publication constitutes unethical behavior. Authors have an obligation to consult the Editor if there is any question about an article's suitability for PWQ or if there are questions concerning piecemeal publication (see pp. 13-15 of the *Publication Manual of the American Psychological Association Publication Assocation*). Student reviewers may provide independent reviews under the supervision of a Consulting or Associate Editor.

Manuscript Preparation, Length, and Style

All manuscripts should be prepared according to the Publication Manual of the American Psychological Association (7th edition). The entire manuscript - including abstract, quotations, notes, and references- must be typed double-spaced, with margins of at least 1 inch on all sides and use of Times New Roman 12 point font. Manuscript pages must be numbered consecutively. The use of sexist or ethnically biased language is unacceptable. As a general guideline full-length manuscripts reporting results of a single quantitative study should not exceed 35 pages total (including title page, abstract, text, references, tables, and figures). Reports of qualitative studies generally should not exceed 45 pages. For manuscripts that exceed these page limits, authors should provide a rationale to justify the extended length in their cover letter (e.g., multiple studies are reported).

Title and Acknowledgements (page 1). To facilitate masked review, all indication of authorship must be limited to this page (other pages must show the short title plus page number at the top right). Include on the title page (a) full article title, (b) names and affiliations of all authors, (c) acknowledgments, and (d) mailing and email addresses and telephone and fax numbers of the individual serving as the point of contact.

Abstract and Keywords (page 2). Abstract should not exceed 200 words. After the abstract, list appropriate keywords for the manuscript, preferably using terms from the Thesaurus of Psychological Terms.

Text (page 3). Use a five-character paragraph indent. Do not use desktop publishing features, such as right margin justification or underline. Only bold and italics may be used. Use a 12-point typeface.

References. References cited in text must appear in the reference list, and entries in the reference list must be cited in the text. References should conform to the 7th edition of the *Publication Manual of the American Psychological Association*.

Notes. Footnotes are not permitted in the text. If necessary, endnotes may be used. Number consecutively throughout text and list on a separate page preceding the following section. Tables. Tables must appear as a unit following the reference section. Each table should be typed double-spaced on a separate sheet, be numbered consecutively, and include a caption. All tables must be cited in the text.

Figures. Figures and artwork should be submitted in the following digital file formats and with minimum resolution of 300 DPI (600 DPI for line art): TIFF, EPS, PDF, JPEG, or Microsoft Word. Prepare figures according to the guidelines provided in the 6th edition of the APA manual.

# **Teaching Briefs**

*Psychology of Women Quarterly* accepts submission of non-empirical contributions to the scholarship of teaching and learning in the psychology of women only through its online web system at http://mc.manuscriptcentral.com/pwq. Limited to about 10 pages, these essays should follow the general guidelines of APA's Publication Manual, except without an Abstract or title page and confining headings to a single level (Level 1). A 1-2 sentence bio will be requested during the submission process for each contributing author.

Please follow the instructions through the site. It will be helpful to have a separate title page and fully masked, electronic main document prepared in advance.

If you have any questions or problems, please contact Dawn Szymanski (Editor) or Cora Powers (Assistant Editor) at pwq@utk.edu.

Teaching essays should be submitted as an electronic file in Microsoft Word. An accompanying letter should request review and include the following information: that the manuscript (a) is not currently under review elsewhere, (b) has not been previously published in whole or in part, and (c) conforms to the 6th edition of APA's Publication Manual.

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# Supplemental Information

The option of including online information supplemental to a paper is available to authors. Examples include the list of noncited articles included in a meta analysis

and materials that might be useful to teachers implementing ideas presented in the teaching section. The APA manual lists other suggestions for online supplements.

# <u>Title of study:</u> Exploring the experience of miscarriage and help seeking afterwards amongst Black Women.

I would like to invite you to participate in a research project which forms part of my Clinical Psychology Doctorate research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

# What is the purpose of the study?

We know very little about the experiences of Black Women who have experienced miscarriage in the UK and what it was like for them seeking help afterwards. This study is looking to understand the experiences of miscarriage in Black Women. We are also looking to understand more about Black Women's opinions and beliefs about help-seeking after miscarriage. We hope that this study will help us understand more about miscarriage in Black Women and how help afterwards is sought which may hopefully help improve support in services.

# Why have I been invited to take part?

You are being invited to participate in this study because you identify as a Black Woman who has experienced miscarriage and have expressed interest in taking part in the study.

# What will happen if I take part?

If you agree to take part then I will contact you to arrange a meeting at a convenient place and time. I will ask you to answer some short questions about you, for example your age and details of your miscarriage. Then you will have a conversation with me which will last around 60- 90 minutes. I will ask you about your experience(s) of miscarriage such as what was it like, what help did you seek, what barriers where there, what did you find helpful? I will audio record the discussion. There is no right or wrong answers and I am only interested in your opinions, your beliefs and your experience of miscarriage and help-seeking.

# Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part I will ask you to sign a consent form and you will be given a copy of this consent form to keep.

#### What are the possible risks of taking part?

Participating in the study will require 60 - 90 minutes of your time and this may be inconvenient for you. Some people may find it upsetting to talk about their experience of miscarriage because it may bring to mind difficult issues about the miscarriage and pregnancy. If this happens to you the researcher will offer support and help you to gain access to further help from non-NHS organisations or your GP, if needed.

# What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about Black Women's experiences of miscarriage and how help is sought afterwards. It may also help to highlight how services can better support Black Women who have experienced miscarriage. Sometimes people find it useful to have the opportunity to talk about their experiences.

#### Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

All of the personal information that you provide will be kept strictly confidential. Any information that could be used to identify you will not be used in the research. Direct quotes from the discussion may be used in research publications and presentations but you will not be identified in these. To protect your anonymity you will be assigned a code or pseudonym. This will ensure it will not be possible to identify you from the information you provide. To protect the security of the audio recordings an encrypted recording device will be used. After the research is completed, all of the audio recordings will be destroyed. Anonymised transcripts of the recordings will be stored securely in an on-line storage repository at the University of Hull for a period of ten years. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

Your contact details will be held securely for the duration of the research but will be destroyed when the research is complete.

#### **Data Protection Statement**

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found in the Research Privacy notice which will be given to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Information Compliance Manager, Mr Luke Thompson (I.thompson3@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

#### What if I change my mind about taking part?

You are free to withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until data analysis has commenced, after which withdrawal of your data will no longer be possible as the data will have been anonymised and/or committed to the final report. If you choose to withdraw from the study before this point the data collected will be destroyed.

#### What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk/. The research may also be published in academic journals or presented at conferences.

#### Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

#### **Elizabeth Adekeye**

Clinical Psychology Aire Building The University of Hull Cottingham Road Hull HU6 7RX Tel:07775674216 E-mail: blackwomenresearch@gmail.com



# What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

# Dr Annette Schlösser

Clinical Psychology Aire Building The University of Hull Cottingham Road Hull HU6 7RX Tel: +44 (0) 1482 464094 Email address: a.schlosser@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

# Appendix I: Participant consent form



Version number and date: V1-06/09/19

# **CONSENT FORM**

Title of study: Exploring the experience of miscarriage and help seeking afterwards amongst Black Women.

Name of Researcher: Elizabeth Adekeye

		Please initial box	
1.	I confirm I have read the information sheet about the above research project and would like to participate in the study.		
2.	I understand what the project is for and what it involves.		$\square$
3.	I understand that participation in the project is voluntary and that I can withdraw at any time for no reason without it affecting my legal rights.		
4.	I understand that my participation, information about me and contact details will be kept confidentially.		
5.	I have had the opportunity to ask any questions I had and confirm I have had satisfactory replies to these.		
6.	I have agreed to be audio recorded and for any quotes to be anonymized when being used in the current research.	I	

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix J: Participant demographic form



# **DEMOGRAPHIC FORM**

# Title of study: Exploring the experience of miscarriage and help seeking afterwards amongst Black Women.

Name of Researcher: Elizabeth Adekeye

Age:

Nearest big city to you:

Time since miscarriage:

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

# Appendix K: Interview Schedule

# **Interview Schedule**

The questions below provide a framework of general themes that will be explored. More informal questions will be asked in order to make the individual feel more comfortable before the interview officially begins. **Theme 1: What was it like?** 

- Can you please tell me about your miscarriage?
  - Medically what was it like?
  - Emotionally what was it like?
  - Socially what was it like?

# Theme 2: Did you seek help?

- How did you first know something was wrong? What did you do? Did you seek help? From who? What happened? Who did you involve/ did you want to involve?
- What type of help were you seeking? (medical, social, emotional support)
   What was that like, who helped you and what helped you.
- $\circ$  Was there someone who stood out to you during this time?
  - What did they do that was helpful?
  - How did that help you?
- Do you feel your culture had a role to play in how you sought help?
- How do you think your culture impacted how you seek help? Was that helpful?

# Theme 3: Where there any barriers when seeking help?

- As a black woman what do you think are the barriers to seeking help? Medically or psychologically? Follow up: and how about socially? Or the people around you?
- Do you think there are any barriers to seeking help?
  - Personally, professionally, health service and socially (family, friends) and social groups (church) and then widely from society.

# Theme 4: Was there anything positive?

• What was helpful? Is there something you did, health service, family, friends or community groups or culture that was helpful?

 Is there any standout positive interaction that you had that you found really helpful?

# SOURCES OF SUPPORT AND INFORMATION ON ACCESSING HELP THAT ARE AVAILABLE TO YOU

**Sands** (stillbirth and neonatal death society) is a charity that provides information on baby loss and bereavement support services. These include the Sands Freephone helpline, mobile app, online community, family support packs, memory boxes and over 100 regional support groups run by trained befrienders.

#### Website: https://www.sands.org.uk

Email: helpline@sands.org

#### Confidential helpline: 0808 164 3332

**Tommy's** is a charity that provides information on pregnancy and baby loss. They provide support for women who have experienced baby loss on their Facebook support group.

#### Website: https://www.tommys.org/baby-loss-information-and-support

**Miscarriage Association** is a charity that offers information and support around miscarriages. These include the miscarriage association telephone helpline, live chat, online support via Facebook and forums, support groups and a helpline email.

Website: https://www.miscarriageassociation.org.uk/how-we-help/

#### **Confidential helpline: 01924 200 799** (Mon-Fri: 9am-4pm) **Helpline email: info@miscarriageassociation.org.uk**

**Samaritans** is a charity that operates a free confidential helpline for support around relationships and family problems, bereavement, financial worries, loneliness and isolation, depression and thoughts of suicide.

Website: https://www.samaritans.org

#### Confidential helpline: 116 123

Search engine to find a suitable counsellor or therapist:

You can also seek help from your GP or someone you feel will provide you with the support you need (such as a family member or friend).

Transcript	Initial comments
R:what was that like for you in terms of erm you know going through this miscarriage and sort of going through a procedure and thinking that almost that door was shut but then it not quite being done right, what was that like for you emotionally? P: oh god it was distressing, upsetting, it put me in a low low place, very low place. Erm I was angry, I was in pain I was upset that I couldn't even believe it that this was happening not only losing a baby but I then the procedure that was meant to be a simple procedure got messed up and now I was then having to miscarry again basically so it was almost like I was reliving it over and over again. And so	Multitude of emotions Re-traumatisation due to clinical negligence
R: yeah so that sounds really difficult. So can I just ask you about erm sort of seeing help after wards, I know you said that you were giving an e-mail for a bereavement counsellor, I'm just wondering um if you if you wanted to seek help and what type of help you wanted to seek P: in the beginning no, erm I didn't really, It wasn't something that even crossed my mind. And erm because I have another child erm she kind of took the was a distraction so that wasn't really on my mind I didn't really think that I needed to see somebody, I thought that I could deal with it myself but after I realised that you know what it would be nice to be able to speak to someone because I didn't have, at the time I didn't have any friends who had gone through it (R: right). So I had no one to talk to no one to understand what I was going through. Like I said before, It was almost like you know, we're sorry this happened, don't worry these things happened and don't worry you'll bounce back. No one felt what I felt or understood you	<mark>Self –reliance</mark> Needing an expert Wanting to be understood Feeling alone
know. When it got to that point I did want to erm speak to someone. Erm but I didn't I don't know if I lost the paper for the woman's email or what (R:yeah) but I did look online and try and see erm because they had meetings for people who had like gone through grief with their kids and things but I think it's a bit different to having a miscarriage and a bereavement for your child (R:yeah). I didn't bother, but id do really much, it wasn't like there was loads of you know loads of erm when I was researching it wasn't like I found loads of places sorry it was like it was just yeah because some people say it's easy to follow up, it wasn't like they got	Miscarriage grief seen as different Internalised invalidation of miscarriage grief It's hard to reach out Feeling abandoned

in touch with me and asked oh have you spoken, or the bereavement officer, she wasn't like she didn't like message me and say no erm if ever you need blah blah blah so yeah.	
R: yeah and did you, did you um, seek any sort of emotional from your social circles, friends, family?	
P: Again I tried to but the response I got was, it was almost like because because they didn't understand they couldn't give me that emotional support (R:mmm) but like I said none of my friend's had gone through it so it wasn't like, it was almost like they didn't understand and they didn't understand what I needed	Wanting to be understood
R: mmm, that's ok yeah. So I'm just wondering about how you coped with your, your miscarriage and who would you say was around you to support you um, who did you involve or who did you want involve at the time? P: Um how I coped was I will honestly say time. Time is what helped me cope, time is a healer and um it was literally only over time more things happened in my life and I (*baby cries*), sorry	
R: that's ok P: um like I said, I've got another child as well so you know distractions, like family distractions, normality, going back to work cause you know you have to go back to work. You don't get maternity after having a miscarriage. (R: yeah)	Having other life demands Lack of financial support if time taken- off
<ul><li>Yeah it was just busyness basically. Um in terms of support, it was my husband and my mum, my siblings, that was around um, that helped.</li><li>R: yeah, what is that helped about having them around?</li><li>P: Um I guess just taking my mind off things, um, that helps a lot really, yeah taking my mind off things really helped</li></ul>	Distraction as a coping mechanism
R: and, and was there someone who stood out to you during this time? In terms of someone who was helpful? P: Nope R: No P: no well my husband he was quite, my husband he was um, he he did try but I felt he sort of didn't understand either (R: yeah). So it was like the blind leading the blind it wasn't like he you know, it was the first time , we didn't know this, we didn't know anyone who had experienced this, all what we've been through so (R: yeah), we both just didn't know how to deal with it. It was like, its ok he would just say it's alright (R: yeah), don't worry, you need to	Feeling alone Wanting to be understood Feeling helpless Pressure to move on
accept what, he used to say things thing: like accept the things you cannot change (R: mm). Um but I didn't want to accept obviously so yeah (R:yeah). I did not, I couldn't understand his yeah (R: yeah). I guess because also sorry, apart from just losing, it was also the going through the um,	

not surgery, I think it was the extraction, the um (*P mouths sorry* R: that's ok), the procedure obviously to remove the foetus failed (R: yeah) and I ended up being in pain. So apart from the emotional, the physical side which obviously no one else could understand apart from me, so it was just yeah. So there wasn't anyone that really (R: yeah), but I'm guessing because no one really understood or knew me.	Emotional and physical pain Feeling alone Wanting to be understood
<ul> <li>R: Yeah. And, I'm just wondering whether you feel like um your culture had a role to play in how you sought help? Or didn't seek help I guess?</li> <li>P: probably, yes, I would say it did. So us black people, we don't really discuss things, things are almost just brushed under the carpet. A bit like I said, it's almost a, oh don't worry, you know? It's not forever it's just now, it will get better and that's it , we don't discuss it again because discussing it is almost like dwelling on it. You know, you just need to move forward. So really, so yes I would say, it played a big part on what made me go straight back into a routine, trying to just put myself somewhere, not dwell on it and not speak about it or try and seek even more help for you know, carry on and then you know later, sooner or later you can try again.</li> <li>R: mm, yeah.</li> <li>P: oh it's happened, you just have to you know *baby cries* sorry (R: its ok)</li> </ul>	Cultural influences on speaking up Feeling silenced Feeling pushed to move on Feeling silenced
R: okay and so do you think um, I know you said you think that your culture had a role to play in how you um sought help um I'm just wondering if you thought that was helpful, if you felt like it was unhelpful? P: I felt like it was unhelpful It's almost like a taboo, you just don't talk about it, you don't talk about these things (R: yeah), you know. Um so, its, its definitely not helpful. We should be able to talk about it, and share, experiences, and meet other people who have gone through it. Cause at the end of the day your family can only support you to a certain point, but if they've never been through it theres only so much support, there's only so much sorry's and so much oh I um you know things will get better and all the emotive thoughts but and the end of the day I need to talk to someone who had experienced the exact same what I had gone through, who understood it so that we could like just be that shoulder for each other sort of thing. R: yeah, yeah and as a black woman do you think there are	Wanting more, wanting change Perceived lack of understanding from others Wanting to be understood. Wanting an emotional companion
barriers to seeking help? Sort of medically or psychologically?	

P: um, I don't know if there is or not to be honest because I don't really know anyone who has and I don't really see that much information about that if I'm being honest. Yeah I can't it's just more Caucasian people that I see really. R: yeah, And as a black woman yourself, do you think there are barriers sort of erm societally I guess, society has put in place that un doesn't allow your or permit you to seek help? P: um, I guess yeah because we, there's no community, there's no um, like there isn't. I don't know if it's because of the colour, I'm not too sure but there I, I don't know like there's just no community where you can go to and people be like and and um they tell you that oh this is the place you can go to um give you information things like that um there isn't such a thing really. You just have your doctors and um I mean I don't think there is to be honest no.	No community for Black women No space where Black women gather and share experiences
R: yeah P: even when I was like looking up um things about people who had experienced what I had gone through I was looking on social media and you know, all I could see was Caucasian people, I couldn't really see, there was no black women (R: yeah). It didn't really, even like there's a website called Tommy's charity R:mm), which um talks about like bereavements and you know things you go through, troubles that you go through, pregnancy. And they had like quite a few ladies that came out, that had actually suffered a miscarriage. And I remember there's only, with all the people they interviewed, I think there was only one black couple. (R: ok) so. R: yeah what was that like for you erm you know P: well it just shows that we're just misrepresented, it was just like oh ok does this not happen to us then or? (R: yeah) like do we just not talk about it I don't, I just didn't understand why there was only one couple (R:mm) I didn't feel like I could relate to it as much if you know what I mean?	Looking for support on social media, however lack of representation as a barrier to engage. Lack of representation-I can't see myself-where am I? Lack of representation leads to lack of knowledge Lack of representation leads to being silenced
R: yeah, yeah and do you think there are any, as a black woman sort of barriers to seeking help um professionally like at work or um socially with friends and family or social groups at church? S: um yeah there are barriers because like I said before, it's not talked about you just don't as a black woman you don't talk about the issues going through, your just meant to be this great strong black woman and you just get on with it	Internalisation of strong black woman Perceived and internalised Strength as a barrier
R: Yeah yeah, so I'm just wondering, we're just coming up to the end, um thank you so much for sharing so far. But we're just coming up until our last um sort of section of the questions um and I just want to know if there was anything	

helpful, anything positive um at during the time of your miscarriage that you did or that the health service did or your family did or your friends did or community groups did or culture that was helpful? S: Um, I can't say the healthcare did, with everything that I experienced with them was a negative, from the minute I had my miscarriage I, it was a negative experience. I, there was no follow up, there was no nothing like that, they just gave a leaflet and a piece of paper with someone's e-mail. Um but in terms of, I think having family around um is good, like it helps you take your minds off things, which helps for a little bit. Um but I wouldn't say, there was no, there wasn't a community, there isn't a community, I don't know if there is now, but at the time when I was going through it there was no community, there's load of women, I don't know, who explain their experience talk about their experience. And how they overcame it, how they you know, things they do to um like reduce the pain, I don't know, things like that (R:mm) but there was nothing so I don't have any positives experience (R: yeah)	Healthcare unhelpful and negligent. Support offered was generic, not patient- centred Distraction as a band aid Lack of community, isolation in grief/ miscarriage experience Looking for a place of understanding Looking for a place where voice will be heard/ looking for tribe/ safe space
<ul> <li>R: yeah, yeah, is there anything um was there any sort of standout um positive interaction that you had um during this time that you can think of?</li> <li>P: um, I'd say maybe going church. (R: yeah) Going to church that lifted up my spirit and</li> <li>R: what was it about going to church that helped?</li> <li>P: Um it was just um finding that peace, it felt like I could just lay my problems in front of God and you know um just help me get through this, like you're the only one that I can turn to right now (R: yeah) it helped me. You're the only one who understands why I've gone through this, so just help me get through.</li> <li>R: yeah, yeah that's great thank you so much for um taking time to do this</li> <li>P: that's ok</li> <li>R: Um this interview, I'm just going to pause, well stop the recording now.</li> <li>P: ok</li> </ul>	Faith in God being a place where vulnerability could be shown. Faith in God being a place where support was sought Faith facilitating acceptance and peace

#### Appendix N: Ethical approval letter



University of Mult Nucl, NUE 785 United Kingdom T, H44 (0)(1462-460306 || El e waiters(ihultacus T, H44 NULLacus

PRIVATE AND CONFIDENTIAL Elizabeth Adekeye Faculty of Health Sciences University of Hull Via email

22<sup>nd</sup> January 2020

Dear Elizabeth

REF FHS204 - Exploring the experience of miscarriage and help seeking afterwards in Black Women.

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the <u>Research Ethics Committee</u> web page for reporting requirements in the event of any amendments to your study.

I wish you every success with your study.

Yours sincerely

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Professor Liz Walker Chair, FHS Research Ethics Committee



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