Recovery and resilience: African, African-Caribbean and South Asian women’s narratives of recovering from mental distress
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Foreword by Veronica Dewan

“Oh baby, I’m just human. Don’t you know I have faults like anyone?”

Nina Simone, whose voice soars and breaks, fills my heart. I am thankful for her life, her music and her politics. I dance then focus on the words I need to write.

Words are so powerful. Lyrics, poems, novels, memoir. The words of black women like bell hooks, India Arie, Audre Lorde and Maya Angelou shed light on our lives, give voice to our struggles.

We can write our own words, but as service users/survivors we are written about. Our lives are recorded, reinterpreted, they stagnate in official documents. Major decisions are made that may have coercive elements couched in seemingly benign language. When we feel unsafe, we don't show ourselves easily, and are often misunderstood.

In this report black women service users/survivors share their wisdom, tell their unique stories, and consider how they relate to the concepts of recovery and resilience. These women have put their trust in the research team to share their struggles, confusions, successes and perspectives. In acknowledging the depth and interconnectedness of their lives, the interviews have been conducted by black women with their own direct experience of mental distress. It is an extraordinary relief to read this report which is written in a language that resonates so powerfully with me. I read about women whose lives intertwine with mine, of mixed heritage, who have been homeless, who have attempted suicide.

These are resourceful, creative women who have fought injustice, have resisted coercion, and have overcome internalised negative stereotypes. They take many different paths towards healing. Some see it as a continuous journey.

This is something I relate to. My experience, one of transracial adoption and reunion, highlighted the difficulties of sustaining a relationship with my birth mother. It’s painful to live with the constant push and pull, of acceptance and rejection. It follows me through my life and affects all my relationships in my search for community, for a sense of belonging.

I remember as an in-patient being told by a nurse that she and her colleagues would not speak to me as I was too complicated. I remember an old friend telling me that I wouldn't have any problems on a psychiatric ward because I was compliant. I became more alert to the gravity of the situation I found myself in.

In subjecting to scrutiny the terms recovery and resilience, this report provides a penetrating critique of the motivation of psychiatry in claiming these models and approaches. I am mindful of the words Truth and Reconciliation; these words were not chosen lightly. In the words of one interviewee: ‘Be watchful’.

This report is a guide towards spreading understanding, among black women service users/survivors, and among people willing to resist injustice.

“But I'm just a soul whose intentions are good; Oh Lord, please don’t let me be misunderstood.”

Respect to Nina Simone and to all the brilliant women who have contributed to this report.
Recovery and Resilience project team

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We would like to acknowledge:

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- Beth Collier and Dr Dan Robotham for editorial input into the report.

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- Workers at various voluntary, community and user groups and other organisations who disseminated information about this study and helped us set up interviews.

- Magie Relph, quilter and passionate fair trader of African textile arts and fabrics, for donating the main image for this report.
Recovery and Resilience: African, African-Caribbean and South Asian women’s narratives of recovering from mental distress is the report of a research project exploring the concept and settings of recovery from mental and emotional distress. The project sought to collect positive stories of recovery and resilience and highlight what helped women from these communities in their healing process.

Background and scope

Recovery is often defined as a process of curing or managing the symptoms that are associated with psychiatric diagnoses. It has been argued that medical definitions of recovery overlook the creation of new debilitating conditions as a result of long-term medication, dependency on mental health services, and social exclusion. Some people who have experienced mental distress argue that recovery is a process of moving forward from symptoms, side effects, negative attitudes, devaluing and disempowering services, prejudice in society and social exclusion. Others talk about recovery as a process rather than a goal or end point and that people need to have the chance to talk about their lives - the bad as well as the good aspects - and to reflect on their life journey.

While people from black and minority ethnic communities may share some of these viewpoints, there have been few studies that focus on their specific experiences. Research over the years has shown that people from many of these communities experience compulsory and coercive treatment within mental health services. Evidence also shows that many people had experienced racism and discrimination within and outside services. Much of this evidence has focused on men from these communities as they have faced consistent disadvantages. The issues facing women from minority ethnic communities have been less well researched, yet available data shows that women from these communities are equally disadvantaged.

This research project endeavoured to address this gap in the knowledge base around recovery by focusing on women from African, African Caribbean and South Asian backgrounds.

The main aims were to:

1. Explore distress and recovery based on the experience and understandings of African, African Caribbean and South Asian women.

2. Formulate an approach to recovery that will consider people's identities as black people and/or as members of black communities, and experiences that have been effective in their own recovery.

3. Contribute to knowledge on recovery and resilience in order to enable the development of programmes of work to support people.

4. Rethink the term ‘recovery’ itself and explore whether it resonates with people’s experiences.

How the study was conducted

The study involved one-to-one interviews with 27 women. It used a reflexive methodology in developing, conducting the research and analysing findings. Researchers themselves also took part in the study as interviewees. A steering group of seven members, who brought in a range of experiences and knowledge of working with women, gender, ‘race’ and culture issues, mental health and recovery and research, and/or lived experience of mental distress, provided direction and advice for the project team.
The audience

This report is aimed at all those who are involved in the planning, development and delivery of mental health and recovery services to black women and minority ethnic communities in general. This includes central government, policy makers, professional bodies, the NHS, social services, voluntary, community, service user and carer organisations, and academicians. We hope that black women and people who experience mental and emotional distress will find the stories in this report inspirational.

Main findings

The most important message from this study is that interviewees’ understandings of their recovery are intrinsically linked to the ways in which they made sense of their mental distress. Interviewees understood the causes and nature of their mental distress in a variety of interconnected settings, including socio-cultural, familial and personal, and bio-medical. They identified important elements of their recovery within these contexts.

Socio-cultural contexts of recovery

Many of the participants in this study made sense of their distress as arising from the adverse effects of socio-cultural experiences, including racism, sexism and other forms of discrimination in society. Their racial/cultural, gender, sexual and spiritual identities, a sense of worth in self and community, and a sense of belonging had a direct relationship with their views on mental and emotional wellness and recovery. This was predicated on being able to find ways and locations to rebuild a positive sense of identity and belonging. Many participants felt that mental health services and recovery frameworks did not account for their experiences of racism and other discrimination, essentially failing to address a significant part of their distress.

Personal and familial contexts of recovery

Oppressive practices and traumatic experiences, such as sexual and physical abuse, domestic violence, bereavement and loss, and stress from the obligations of fulfilling family roles were significant in how women in this study made sense of mental distress. Meanings of recovery and resilience, for these women, depended on how they had managed to overcome these situations and regain a sense of control over their lives. Attitudes of the family and immediate social circles towards mental distress had a key effect on recovery; negative and stigmatising attitudes hindered recovery whereas family support enabled it.

Spirituality and faith were important to some participants’ identity. The meaning given for mental distress was sometimes a part of a personal spiritual crisis or religious experience. Faith and/or personal spiritual grounding were important in their recovery.

Bio-medical contexts of recovery

Making meaning of mental distress within bio-medical frameworks involved some acceptance of psychiatric diagnoses and treatments. However, this acceptance was a complicated process based on whether a given explanation and/or diagnosis made sense of their experiences and whether the bio-medical explanation and accompanying treatment involved some kind of “therapeutic alliance”, i.e. a shared decision making approach to treatment and medication.
The requirement of compliance in bio-medical settings created tensions between the acceptance and the level of satisfaction with the solutions on offer. Medication emerges as a key factor. The majority of the participants who accepted a bio-medical explanation of their distress nevertheless made a clear distinction between medication as a necessity for symptom control and ‘real’ recovery. Their idea of recovery involved being free of medication.

Views about definitions and practice of recovery within mental health services

Only a minority of the interviewees felt that ‘recovery’ within mental health services resonated with their own definitions and meanings. Some wanted to distance themselves from the term because they saw it as professional-led, pressurising and meaningless. Part of the reservation was that recovery approaches and models did not start from a point where a person was supported in addressing the causes and contexts of distress, but from a point after the distress was seen as an ‘illness’ with psychiatric diagnoses and treatment.

For some, there was a conceptual inconsistency between the idea of recovery and the way mental health services worked. They felt that coercion as part of mental health care, for example through the Mental Health Act, contradicted with ‘recovery’ as something driven by a person’s specific needs. Overall, recovery models and approaches worked against the concept of recovery itself and that the way in which they are used in services today continues to put professionals in charge.

Views about the concept of resilience

People spoke of watching the resilience of parents as they adjusted to lives as migrants in a new country, bringing up children within racist and discriminatory environments. They spoke of mothers and sisters who survived domestic violence or other abusive relationships and of their own children growing up dealing with their mothers’ distress. They also spoke of collective resilience in terms of their communities, surviving colonisation, slavery and the continuing legacy of oppression and the resilience of black women.

The term had a positive connotation for many as they saw themselves as having demonstrated resilience. These positive connotations were based on the acknowledgement of inner strength and purpose that they had drawn on in their long journeys.

Others found it to be a disabling concept and felt that it generated the stereotype of a ‘strong black woman’ that worked against emotional and mental development, allowing no space to feel vulnerable without feeling guilty. Some felt that being unable to demonstrate resilience in their life increased their sense of self-doubt and failure.
Lessons for the future

This report should be read in the current political climate. The focus on recovery in the new mental health strategy, No Health Without Mental Health (Department of Health 2011), promotes recovery as a measure of a person’s overall quality of life. There is also a focus on personalised services and improving people’s access to psychological therapies.

However, there is a dilution of focus on the needs of specific groups of people, especially in terms of race equality and an increase in compulsion within mental health services. The substantial changes in the way health, social care and welfare services are to be delivered, combined with the effect of spending cuts, are being felt more keenly by minority ethnic groups. The study findings should be considered within this context; how these issues affect black women and people from minority ethnic communities in general.

Lessons for the future include:

- Any approach to recovery should account for the context of an individual’s distress, acknowledging that a person needs to recover not only from mental distress but from the underlying causes of it.
- The focus on the individual in recovery approaches needs to be broadened to include ways of overcoming socio-political oppression, acknowledging the limits that these factors may pose on people’s quality of life.
- Transcultural approaches to recovery should be developed to understand distress as a legitimate response to life events, spiritual crises, trauma and stress.
- Further work should be done to explore the actual effect of the continued use of medication and its role within recovery.
- A need for increased access to talking therapies, counselling and forms of therapeutic alliances in order to explore the causes of distress and the contexts for recovery.
- A need for more investment to create further opportunities for black women to tell their stories about distress and recovery, which have important personal and political functions.
This report is based on twenty seven rich and complex narratives. The sense of a complete narrative can be lost in a report like this. We have made every effort to capture the richness and complexity of the narratives in this report.

Part 1 of this report sets out the context and background of our work. In the first chapter, we present the aims of this work, briefly discuss the current conceptualisations of recovery and resilience and explain the rationale for this work, including why we chose to focus on women from African, African Caribbean and South Asian communities. The second chapter discusses the methodology in detail.

Part 2 re-locates recovery within the contexts of mental distress. The chapters in this section explore how people made meaning of their mental/emotional distress in different settings: the socio-cultural, personal and familial, and bio-medical contexts. Each chapter then goes on to discuss how people saw their recovery and what worked and did not work in each situation.

The final chapter in this part takes a closer look at the concepts of recovery and resilience. We turn to whether or how these terms resonate with people’s own definitions and meaning of recovery, healing or keeping well. We also look at people’s opinions about the recovery approach and recovery models currently used within mental health services and the alternative terms that people find useful.

Part 3 brings the main learning from this work together and highlights areas for future work on enabling black women to come to terms with their distress, work towards and maintain wellbeing, and to move on with their lives.

The main image

The main image used for this report is an image of a wall hanging, The Frog, The Lizard and The Turtle, machine pieced and quilted by Magie Relph. The quilt uses a traditional pattern called the log cabin.

“Log cabin was a favourite of African slave quilters and often referred to as ‘house tops’. I wanted to create a piece that reflected the improvisational style of these quilters using whatever fabrics came to hand, mostly African wax prints from my stash, and ‘old fashioned’ techniques. The frog, the lizard and the turtle just made themselves at home!” (Magie Relph, www.africanfabric.co.uk)
Part 1
Setting the scene
Introduction

This report presents the findings from a research project that aimed to explore the concept of recovery from mental or emotional distress\(^1\) from the perspectives of African, Caribbean and South Asian women. The study aimed to collect positive stories of recovery and resilience using in-depth interviews, focusing on the context of recovery and what helped people in their healing process.

Aims of the project

The main aims of the project were:

1. To explore formulations of mental distress and recovery based on the experiential understandings of African, Caribbean and South Asian women.

2. To formulate approaches to recovery that will take into consideration people’s identities as black\(^2\) people and/or as members of black communities and experiences that have been effective in their own recovery.

3. To contribute to the knowledge base on recovery and resilience in order to enable the development of programmes of work to support people.

4. To rethink the term ‘recovery’ itself and explore whether it resonates with people’s experiences.

Exploring the concept of recovery

Although recovery gained prominence in debates around mental health care in the latter part of the 20th century, the concept has a much longer history. Some scholars date it back to the late 18th century, to the collaborative work between Jean-Baptiste Pussin, a former patient of the asylum of Bicêtre in Paris who later became its governor, and Philippe Pinel, the man who is credited with developing traitement moral, a humanistic approach that removed compulsion and coercion in the treatment of the people in asylums (Davidson, Rakfeldt and Strauss 2010).

Since then, the term has come to mean many things to many people: a medical concept that defines illness and wellness; a personal journey of wellbeing; an aspiration; a state of being; a quantifiable and measurable entity with models and outcome measures; an ideology that defines a social movement; a meaningless and overused term; a political agenda to cut public spending in care and push people back to work; even an impossibility. Its usage in medical understandings of mental distress or psychiatric illnesses has depended on accepting psychiatric diagnoses and descriptions of ‘illness’ and the role of the ‘patient.’

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1. The term ‘mental distress’ or ‘emotional distress’ is used in this report to refer to a range of mental health and emotional crises including conditions that are normally defined as mild, moderate or acute. In our view, the term ‘mental distress’, one of the widely used terms within service user/survivor communities, straddles diagnostic, managerial and social categorisations of mental and emotional crises, and allows people to define them according to their specific contexts and experiences. In quotations from the narratives, we have retained the terms the narrators have used to describe their experiences.

2. The term ‘black’ is used in this document to refer to people of African, Caribbean and Asian origin. It acknowledges the political use of the term to refer to people who have been historically discriminated against on the basis of their skin colour. However, this usage does not deny the vast diversity and difference within and between these communities, and the fact that there are people who do not sign up to the identity position of being ‘black’. While the term is used in the general discussions in the report, it will retain the terms used by interviewees in referring to their identities while quoting directly from their narratives.
The Department of Health, in its 2001 publication The Journey to Recovery, acknowledged the potential of all people to recover and proposed that the mental health system must support people in settings of their own choosing and enable access to community resources or whatever they think is critical to their own recovery. Recovery is a key focus in the recently launched mental health strategy, No Health without Mental Health (Department of Health 2011a). This policy focus, some would argue, has not always been a blessing, as ‘the recovery approach’ has become more standardised, quantified and professional-led, and puts too much pressure on people experiencing mental distress (Social Perspectives Network 2007b, Trivedi 2010).

In the last few decades, the concept of recovery has been recovered and re-articulated from a service user/survivor point of view to give it new meanings beyond definitions of illness and cure, including a journey of resilience, discovery and hope, self-determination, agency and empowerment (Deegan 1988, Coleman 1999, Repper and Perkins 2003, May 2005). These are remarkable in the diversity of their positions and understandings of recovery. However, the perspectives of those from minority ethnic communities are not well represented within this work, with the exception of a few studies like those by the Scottish Recovery Network (Outside the Box 2008, SRN 2008), the Southside Partnership (2008), and the Mental Health Foundation (Wright & Hutnik, 2003).

Exploring the concept of ‘resilience’

Despite its centrality in developmental psychology, the term ‘resilience’ is not one that is commonly used in mental health contexts. It has a much more extensive history in critical thinking around women’s experiences in the context of violence, rape, abuse and adversity, in understanding health contexts like cancer and HIV/AIDS, and in individual and community contexts of poverty, racism, disadvantage, disaster and so on. In popular media articulations of recent times, resilience has featured heavily in talking about communities after the 9/11 and 7/7 bombings in the US and the UK respectively, the Asian Tsunami of 2004, and more recently in the context of economic recession. In everyday terms, resilience is often understood as the innate ability of people and communities to overcome adversities, move on with life, ‘recover’.

In the mental health context, the term gained credibility following the work of Norman Garmezy (1973) who studied adults living with schizophrenia and children at risk of developing the condition. The development psychologist Emmy Werner’s work moved on from a focus on risk to a focus on positive factors that enabled resilience – “self-righting” capacities (Werner and Smith 1982). However, within psychology, ‘resiliency’ became a character or personality trait, one that could be trained, developed and measured. It was not long before research went after empirical evidence and guidelines for resilience – the American Psychological Association has, for example, a ten-step map to develop resilience4.

Critics have pointed out that studies on resilience in black communities have tended to focus more on risks than personal, social and cultural factors that enable resilience, “particularly their ability to seek and receive both formal and informal assistance” (Miller 2003). Work by black feminists and educationists have sought to address this problem by focusing on the roles of critical

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3. Throughout this paper, we use the term “service user/survivor” to refer to people who have lived experience of mental distress and of using psychiatric services. We acknowledge that there are many terms that people use to self-define, directly reflecting their personal experiences. It also needs to be highlighted that not all participants in this study subscribed to a service user/survivor identity.

social theory, communities, families, spirituality, and shared resources rather than only on the individual (Evans-Winters 2005, Hill Collins 2000). We wanted to explore this larger context of coping power within personal perspectives to see whether the concept of resilience provided a broader, social counterpoint to recovery, which in recent times has come to mean something more individualised.

Recovery and minority ethnic communities

Research over the years has shown that people from many minority ethnic communities are likely to experience compulsory and coercive treatment within mental health services. The latest Mental Health Bulletin (NHS Information Centre 2011) shows that, while there has been a fall in the overall number of inpatients in mental health services, the number of people detained in hospitals has risen, for a consecutive third time, for people from Mixed, Asian or Asian British and Black or Black British groups, with proportions of people from Black or Black British groups rising from 53.9% in 2008-09 to 66.3% in 2009-105. Both the Mental Health Bulletin and the Care Quality Commission (CQC 2010) agree that a larger proportion of people from some minority ethnic communities, than might be expected from the detained population, are liable to be issued a community treatment order, a fact confirmed by the study carried out by the Mental Health Alliance (Lawton-Smith 2010).

Evidence shows that many people have experienced racism and discrimination within mental health services and that these incidents need to be addressed before productive and healing relationships between services and service users can be formed (Keating et. al. 2002, Blakey 2005, Kalathil 2009). Moreover, discussions within black and minority ethnic (BME) user/survivor groups showed that the ideas of recovery that mental health services worked with, and those held by service users and survivors from these communities, were often in conflict. There needed to be more space for discussing or working with the service user’s or survivor’s own sense of what recovery meant and what might be helpful in his/her recovery.

To explore this further, a working group was set up with members of Catch-A-Fiya, a national BME mental health service user network hosted by the Afiya Trust, and independent researchers and activists. The group produced a study paper on recovery (Kalathil, 2007) and the ensuing discussions resulted in conceptualising the current project.

5. The demographic categories used here and later in the report while referring to research literature are those used in the reports referred to.
Focus on black women

The decision to focus on black women in this project was influenced by practical as well as conceptual factors. The funding available for this project restricted the study to London and required us to define our target group more clearly. Conceptually, we believed in the need to resist a ‘one-size-fits-all’ cultural awareness approach that bundles all minority ethnic groups into a homogenous category, thus denying social contexts and self-definitions of identities in recovery (Trivedi 2004, Kalathil 2006).

There is a growing body of literature on how some minority ethnic communities are disadvantaged in the mental health system. Much of the research in this area is focused on men from these communities, especially from African and Caribbean communities, because they have faced consistent disadvantage within the system. Specific disadvantages have been identified in terms of over-representation within the mental health system, diagnosis and medication, side effects of medication, issues with compliance and control, support for moving on, addressing family and socio-cultural needs. (CQC 2009; Sainsbury Centre for Mental Health (SCMH) 2006; National Institute of Mental Health in England (NIMHE) 2003; Keating et. al. 2002; Bhui 2002; Warner 2000).

The issues facing women from minority ethnic communities have not figured highly in research agendas in recent times. But the available data shows that women from these communities are equally at a disadvantage. The 2008 Count Me in census showed that rates of admission for women from African, Caribbean and South Asian groups (except Indian) were three to six times higher than average. Experimental statistics from the Mental Health Bulletin showed that the proportion of women spending time in hospitals was higher for Black/Black British and Asian/Asian British groups when compared to White groups.

A recent study that looked at ethnic variations in pathways to acute care found that 42.3% of Black Caribbean, 48.8% of Black African and 44.8% of ‘Black Other’ women were under compulsory admission (detained under the Mental Health Act) compared to 13.2% of white British women (Lawlor 2010). The study also found that rates of schizophrenia related diagnosis were lowest among women from white groups and highest among those from Black African backgrounds, and that ‘Black Other’ and Black African women were also more likely to reach services via the police or the criminal justice system.

Another study (Howard et al 2008) found that, compared to white women, non-white women were significantly less likely to have been admitted to a women’s crisis house and more likely to be admitted to a hospital ward. This was significant because crisis houses do not admit those who are under compulsory detention under the Mental Health Act. Of those under detention in this study, 61% were from non-white communities compared to 39% from white backgrounds.

Women from Asian and black backgrounds were less likely to be referred to Improving Access to Psychological Therapies (IAPT) services. Emerging evidence also shows that women from Indian, Pakistani, Bangladeshi and Black African backgrounds are less likely to enter treatment once referred, although the reasons for this are not yet known (Glover and Evison 2009).

The inequalities faced by women from these communities within mental health services are compounded by other socio-cultural and political factors including their asylum/immigration status, family circumstances, employment, education, social inclusion and so on. Gender and ‘race’/culture based discrimination, both within communities and outside in the society at large, form a significant part of their experience of mental distress. Hearing the stories of women belonging to three specific groups (while being fully aware of the diversities within these groups) would give us an opportunity to examine these factors more closely.

6. This data was not available in Count Me In 2009.
7. For Mental Health Bulletins and Mental Health Minimum Data Set annual reports, go to www.ic.nhs.uk.
8. ‘Black Other’ or ‘Other Black’ is a census category used by the Office of National Statistics. Just under 100,000 people used this category to describe their ethnicity in the 2001 census. http://www.statistics.gov.uk/cci/nugget.asp?id=455.
Recovery narratives and black women

Recovery within a medical model is often defined as a process of curing or managing the symptoms that are associated with psychiatric diagnoses. Service users/survivors have argued that the medical definition often overlooks the creation of new debilitating conditions as a result of long-term medication, dependency on mental health services, and social exclusion. Some service users/survivors have argued that recovery is a process of moving forward from symptoms, side effects, negative attitudes, disempowering services, prejudice in society and social exclusion (Repper, 2005). Others talk about recovery as a process rather than a goal or end point, and that, in this journey, people need to have the chance to talk about their lives – the bad as well as the good aspects – and to reflect on their life journey (Wallcraft, 2002).

As discussed above, while people from black communities may share some of these views about recovery, there have been few studies that have focused on their specific experiences and understandings. The various discussions among the Catch-A-Fiya membership and other service user/survivor forums showed that, for a considerable number of black people, the language of recovery is a problematic one as they saw it as a term that posits an illness as a pre-given category. A focus group with women from minority ethnic communities, conducted by the Social Perspectives Network (SPN), found that:

“...defining what exactly recovery is proved to be one of the major talking points in the discussion, with several women saying the concept of recovery was not one they would use for their own journey, as recovery relied on the idea of having an illness one needed to recover from, or as a linear process towards a single goal” (SPN 2007a).

This view was echoed in a study day on diversity issues in recovery (SPN 2007b). Current recovery models, used within mental health services claiming to work within a ‘recovery approach’ and originating within mainstream understandings of mental distress and getting well, had universal elements that made sense to everyone; hope, sense of meaning in self, control over one’s destiny and so forth. But they did not consider some of the key issues that service users from minority ethnic communities have identified as barriers to their recovery – specific oppressions in the form of racism or sexism, and denial of cultural and spiritual needs.

Personal writings by some service users have found that an approach that takes their sense of identity and experience as black people into consideration has been effective in recovery.

“I now have a psychotherapist who is a Black woman of African Caribbean and English heritage. She works in a way that takes account of the whole of me. She understands the damage caused by racism, and how the process of assimilation has profoundly and painfully distorted my identity and truth. She gives me hope that my identity can have its own meaning” (Dewan, 2001).
Trivedi (2010) argues that it is not always clear if or how ‘difficult’ issues like racism, internalised oppression and questions of identity are raised when using recovery models with people from minority ethnic communities:

“In my experience, black users often discuss recovery in broad contexts which invariably include a lifetime of personal and institutionalised racism and the limitations and disadvantage that this has imposed on them in terms of education, work, access to economic and other resources and forced them to spirals of oppression from which it can be almost impossible to escape. Recovery for BME service users often therefore involves finding a way of overcoming social and political factors as well as personal mental health related issues...”

There is also discomfort among some black service users/survivors and writers about the focus on the ‘personal’ in recovery approaches. Fernando (2008) warns that the danger of seeing recovery as a very personal journey is that:

“... it mimics the psychiatric model of recovering from a (personal) ‘illness’, usually through some intervention or therapy, rather than as a social model of finding a way through complicated and difficult life situations that involve social systems, relationships and so on. A limited personal recovery is wide open for a takeover by the psychiatric system as being equal to ‘getting better’ from illness.”

The argument is that for many people from minority ethnic backgrounds whose experiences of both the society and the mental health system are defined by racism, sexism and other forms of oppression, recovery, while being a personal journey, would also entail a social and political journey (Fernando 2010a).

Discussions within black service user/survivor forums showed that this perspective was a common one. We wanted to explore this in some detail: how do we focus on the personal within a context of communality rather than that of individuality?

There already exists, within black communities, several definitions and models of recovery. From the perspective of providing inspiration and hope to others, it is important to systematically collate and disseminate stories of recovery. More significantly, it is important to analyse these various viewpoints in order to develop an understanding of recovery that is based on people’s lived experiences and realities of survival, resilience and moving on. It is against this background that the project was conceived.
Telling our stories

“...at the early stages of my recovery when I was at home, I said, one day I hope I get the opportunity to share what I know.”

“I won’t get Jeffrey Archer or Mills and Boone to write my story. Or an overworked nurse or an alcoholic parent... Write it myself...”

“...sometimes you can’t make sense of what has happened in your life unless you are actually telling somebody the story, you know, so re-living the story for me is always a healing experience for me. Even though I might feel that I am completely healed, you heal a bit more every time you tell the story. So yes, amen to that.”
Methodology

One of the abiding messages from service user/survivor perspectives of recovery from mental/emotional distress is the fact that it is a journey that is in a constant state of flux. Providing a context for a person to tell her own story is the best way to capture the complexities of that journey. As Brown and Kandirikirira say, “the use of narrative is compatible with the ideas of recovery” (2007: 11), allowing for recollections, choosing and emphasising experiences and sliding back and forth through time.

Ethics and data protection

The project underwent ethical scrutiny by the Social Care Research Ethics Committee. After gaining ethics approval, a seven-member steering group was set up to provide direction and advice to the project team. Five of the seven members had lived experience of using mental health services. The steering group members brought in a range of experiences and knowledge of working with women, gender, ‘race’ and culture issues, mental health and recovery and research. Additional project supervision was available from the Mental Health Foundation’s research department.

An information sheet explaining the purpose of the research and the ways in which it will be conducted was prepared and sent to each participant. This document also explained how the stories collected will be transcribed, stored and analysed. Participants were asked to give signed consent before the interviews. The processes of ensuring anonymity were explained. In addition, each participant had the option to choose a pseudonym if they so wished (see Appendix 1 for the information sheet).

Although the focus of the study was on the positive aspects of healing and moving on, it was acknowledged that the telling of one’s story would potentially bring up distressing memories. The interviewers were primed to ask the participant how they felt after the interview and how they felt about the interview. All participants were given the contact details of the interviewer, the project lead and the Head of Research at the Mental Health Foundation. A document containing information about support organisations and helplines was also given in case they did not want to contact the research team post-interview.

Recruitment

The research focused on women from African, Caribbean and South Asian backgrounds who defined themselves as recovering or having recovered from mental distress or mental health problems. Both ‘mental distress’ and ‘recovery’ were left undefined as these were subjective and open to personal and cultural interpretations.

The recruitment leaflet was distributed and information given out through user/survivor networks, statutory, voluntary and community mental health organisations, organisations working with women and minority ethnic groups, faith groups, newsletters and message boards of various groups, online forums and through word of mouth.

The initial aim was to recruit 24 women, 8 from each of the communities under study. Over 60 expressions of interest were received either by mail or by telephone. Those from outside London were ineligible as the study was London-based. The lead researcher had telephone and/or email conversations with the remaining people, explaining in detail the purpose of the study and what it would entail.
The final selection was made purposively to reflect a range of experiences, settings, cultural backgrounds, and practical considerations, such as availability to be interviewed. Each final participant had an opportunity to clarify any questions they had about the research. The participants were then put in touch with the interviewers to select date, time and venue for the interview.

Research process

The narratives were facilitated using a semi-structured interview schedule (see Appendix 2). The questions in the schedule provided focus for the participant to tell her story, allowed the interviewer to support that process, and provided a framework for later analysis.

In line with the conceptual framework for this project (see section following), the questions were developed in a half-day workshop with the researchers, in which they explored their thoughts about recovery and getting well and what would help someone tell their story, drawing on their own experiences as black women, of mental distress and of doing research. The workshop explored methodological questions, and set up support structures for both the researchers and the participants, including de-briefing protocols and signposts to support organisations.

After obtaining feedback on the interview schedule from the steering group, a pilot interview was conducted. The schedule went through considerable re-write and re-arrangement after the pilot interview because it failed to capture aspects of the person’s recovery journey, focusing instead on the experiences of distress itself. Given that one of the main aims of this project was to collect positive stories of recovery and learn what worked in helping people get better, it was imperative that the questions enabled the telling of this part of the story. The revised interview schedule was finalised with input from the researchers and the steering group.

Conceptual framework: reflexivity

This study used a reflexive narrative methodology. To summarise a large and nuanced body of literature and theory, feminist research methodologies pay attention to how knowledge is constructed by the active interpretation of everyday experiences by both the ‘researched’ and the researchers. They pay analytical attention to the role of the researcher in the process of research (Lentin 1994). Drawing on the work of feminist sociologists like Anne Oakley (1981) and Caroline Ramazanoglu (1992), a reflexive methodology challenges the assumption of a knowledge-based hierarchy and ‘objectivity’ in research. The principle of reflexivity first of all accepts that the very act of ‘doing research’ shapes its outcomes, and that the presence and subjectivity of the researcher shapes the stories collected and its interpretation. It is especially relevant in situations where the ‘provider of data’ is acknowledged to be a peer of the ‘collector of data.’

All the interviewers were women belonging to the communities explored, who self-defined as having recovered or being on the road to recovery. The methodology allowed them to break away from the rigid, and often artificial, constraints of interviewer/interviewee relationship and make contextual judgements about sharing their own experiences with the interviewees. As researchers, they drew on their intellectual, conceptual, personal and collective experiences of being women, belonging to the communities under study and having experienced mental/emotional distress. It is important to specify that, like the
women interviewed for this study, the researchers brought different interpretations of ‘community’, gender identity, mental/emotional distress and the idea of being well or of recovery.

As the research questions explored aspects of the researchers’ own life, and as befitting a reflexive process of enquiry, five of the six researchers chose to be interviewed for the study and narrated their own stories. These are analysed along with the rest of the stories.

From the beginning, the research team was interested in both the formal and subjective processes of the research itself. Reflections on the research process were facilitated in the following ways:

– De-briefing sessions were set up with the lead researcher after each interview to reflect on the process and its effect, think about emerging themes from each interview and how that contributes to the overall research.
– The last section of the interview schedule provided an opportunity for the interviewee to reflect on how the process went, including the perceived differences and commonalities between the interviewer and the interviewee.
– The interviewers had the option to keep field diaries in which to reflect their thoughts about the interview process and their participation in this study as researchers.

Data analysis

After the interviews were completed, another workshop brought the researchers together, where they identified and discussed the key themes emerging from the interviews. These themes formed the framework for analysis. The framework and emerging themes were presented to the steering group, which helped to finalise the structure for thematic analysis of the data.

The participants

The initial aim was to recruit 24 interviewees, eight from each community. Twenty two of these 24 interviews were conducted. With the addition of the five researcher interviews, a total of 27 interviews were conducted for this study.

We did not collect specific demographic data beyond the broad identification of backgrounds for recruitment purposes, as there was no intention to compare and quantify experiences according to demographic groupings. The participants revealed information as and when relevant in their stories. This gives a broad descriptive picture of the diversity of participants who ultimately took part in the study.

– National/cultural identities were expressed as Black, Black British, African (Liberian, Nigerian, Ethiopian, Angolan, South African), African Caribbean, Asian (Pakistani, Bangladeshi, Indian, South Indian, Gujarati, East African Indian), mixed heritage and migrant. Most people identified as members of black communities, but for some the accent was on ‘being black’ rather than ‘belonging to a black community’.
– Eight of the 27 women were born outside the UK and came here as children of migrant parents, refugees or migrant adults. Migrant or refugee status was part of the identity of some women.
– Participants’ age ranged from mid-20s to mid-60s.
– Three participants spoke about their identities as lesbian or bisexual women.
– Religious/faith identities expressed included Hindu, Christian, Muslim, Buddhist and atheist. Some people spoke of a personal spirituality that was not linked to religion or faith.
– Family and relationship configurations included married, divorced, single and in partnerships; some had children and grandchildren; some were single mothers.
– Three women lived in supported housing; some lived alone and
others with families. One person was homeless and living with relatives at the time of the interview. Two others had experienced homelessness in the past.
- Most women had been in touch with mental health services over a long period of time, had accessed in-patient services, and had been given a range of diagnoses and medication. A few had additional physical ailments.
- Many women expressed a ‘service user’ or ‘survivor’ identity and considered themselves part of a larger ‘community’ of service users/survivors. For others, it was important that they avoided being seen as service users and actively resisted these identities.
- Some had no contact with mental health services any more while others continued accessing services as and when required. At least one person spoke of consciously avoiding mental health services.
- Women were engaged in paid or voluntary work; some claimed benefits and some were in the process of accessing benefits.

**Limitations of the methodology and research**

One of the criticisms about qualitative methodologies using narrative analysis is that it is difficult to ‘validate’ the findings. Traditional notions of validation may be pertinent when projecting or generalising research findings across a population or specific group. We have not attempted to do this; instead we have focused on the uniqueness of each story and pulled together common or comparable elements to showcase what works in getting well and moving on after experiencing mental distress.

While the interviews focused on supporting people to tell their stories of recovery, the stories they told in the space of an interview lasting between 40 and 90 minutes provide only a very limited view of their life. In some cases, it was apparent that this process left some people a little dissatisfied as they felt that there was much more they wanted to share as part of their recovery narrative. We would have liked to explore these further but were restricted by time and resources.

Resource restrictions also prevented us from going through a process of the interviewees reading and amending the transcripts. However, the participants were asked whether they would like to have a copy of their transcripts. We thought this was important because, for many people, this was the first opportunity they had to tell their stories. Also, the transcripts would give them a framework from which to develop their life stories if they so wished. 18 participants said they would like to have a copy of the transcript.
“[Taking part in the interview] has been very comfortable for me. I have been allowed to be where I am... I think this is part of my healing process as well for me, a part of sharing who I am because I don’t often get the opportunity to say what makes me tick, what is important to me.

I’m really passionate about BME issues and as far as I can, whatever platform I get, I would like to promote to practitioners, to professionals, the importance of working in a holistic way for our people.”
Part 2
Re-locating recovery
03 Re-locating recovery within subjective meanings and contexts of mental distress

Narrative explorations of recovery in the UK context have to some extent emphasised the ‘personal’ nature of recovery and the link between identity and recovery. The Scottish Recovery Network’s work, for example, reported: “Re-finding and re-defining a sense of identity and self-confidence that has potentially been eroded by institutionalisation or ill-health was often the first step on a recovery journey” (Brown and Kandirikirira 2007).

Other recent studies have also made this connection between identity and recovery, pointing to the importance of understanding the illness and developing social roles in supporting personal growth (Ajayi et al 2009). But the exploration of this connection between identity and recovery remains limited by the fact that the focus is on an ‘illness’ identity rather than on questions and configurations of identity in a broader socio-cultural context in which an ‘illness’ identity is one of the factors.

The reason for this limitation, perhaps, is that the effort has been to focus specifically on the ‘post-illness’ narrative in order to capture elements of recovery. This was a key focus of our work as well. However, we also wanted to ask a crucial question: “What would you say you were recovering from?” This question gave people a chance to frame their understanding of mental distress and the follow-up questions explored how they made sense of their experience in relation to the ‘official’ or medical narrative. The section that followed was designed to pick up specific socio-cultural aspects including experiences and identities of being women, being members of a racialised group, cultural and community identification and sense of belonging, and comfort in their own sense of self, if they featured in their framing of their experience (see Appendix 2 for the interview schedule).

The process of making meaning of mental distress is, we believe, central to the idea of recovery – a belief that was borne out by the findings of this study. Making sense of one’s mental health crisis has an important impact on how they understand and define recovery and helps individuals to place it in a larger social context (Davidson et al 2005, Mueser et al 2002, Schon 2009). For example, a Swedish study that explored how men and women in recovery gave meaning to severe mental illness (Schon 2009) found that the subjective reasons that people attributed to their illness influenced how they coped with it as well as the process of their recovery.

Our questions about how people understood what they were recovering from and how they defined their distress unearthed a range of ways in which people made sense of their experiences.
The most important message from this study is that the interviewees’ understandings and definitions of their recovery are intrinsically linked to the ways in which they made sense of their mental distress. Women who took part in this study understood the causes and nature of their mental distress in a variety of settings, including socio-cultural, bio-medical, familial and personal, and in the interconnectedness of these situations. What they identified as the important elements of their recovery were also placed within these contexts.

Socio-cultural contexts

As far back as 1981, in her seminal book Ain't I a Woman, bell hooks wrote:

“Widespread efforts to continue devaluation of black womanhood make it extremely difficult and oftentimes impossible for the black female to develop a positive self-concept. For we are daily bombarded by negative images. Indeed, one strong oppressive force has been this negative stereotype and our acceptance of it as a viable role model upon which we can pattern our lives.”

Exploring the psychological impact of this devaluation on black women and offering ways of coping with it, hooks argues that “life-threatening stress has become the normal psychological state for many black women” and that this stress is directly linked to “the way in which systems of domination – racism, sexism, and capitalism, in particular – disrupt our capacities to fully exercise self-determination” (2005: 40).

Writers like Trivedi (2010) and Fernando (2008, 2010a) have made references to black people’s experiences of oppression, born at the intersections of marginalised positions, and its links to recovery. However, research based on service user/survivor narratives has not explored this issue in any detail.

For many participants in this study, their racial/cultural, gender, sexual and spiritual identities, a sense of worth in self and community, and a sense of belonging had a direct relationship with their views on mental/emotional wellness and recovery. Many of them attributed their mental health difficulties to their experiences as black women in the broader society. Mental wellness, in these narratives, was linked to a sense of belonging and personal pride in who you are. Resolving – or at least making sense of – these issues had a major part to play in what people saw as recovery.

The causes and nature of mental distress in the socio-cultural context included discussions of:

- Personal experiences of racism and discrimination; perceptions of how communities and families were treated in the larger society, including the continuing legacy of the historical oppression of black people through slavery and colonialism.
- Cultural clashes, crises and confusions arising from contexts of mixed heritage, migration and/or growing up as children of migrant parents, or trans-racial adoption.
- Experiences of gendered oppression and sexism in society and within communities.
- Social and cultural norms of gendered behaviour, assumptions about women’s roles and their impact on emotional growth.
- Socio-cultural attitudes towards sexuality and sexual identity.
- Experiences within mental health services.

For those who made sense of their mental distress in these socio-cultural contexts, a significant part of recovery involved overcoming – or at least coming to terms with – oppressive experiences through re-gaining a positive sense of self and belonging, a sense of pride in one’s communal/cultural identity, having control over their lives, participating in political activism and community activities, and gaining a sense of social justice. Personal healing was predicated on achieving or moving towards a renewed and empowered sense of self and identity.
Personal and familial contexts

Highlighting how psychiatric practices medicalised women’s experiences and reactions to negative personal, familial and social situations has been a major part of feminist readings and critique of psychiatry and mental distress. Elaine Showalter, for example, has demonstrated how assumptions about proper feminine behaviour influenced the classification and treatment of female insanity from the Victorian times to the present day (1987). Phyllis Chesler’s seminal book on women and madness analysed the role of stigmatising diagnostic labels in creating whole ‘careers as psychiatric patients’ for women (2005). Analyses of women’s writing unearthed how patriarchal attitudes towards women’s roles and behaviours affected definitions of madness and confinement of women, and how women used their writing as ‘protest’ (Kalathil 2001, Hubert 2002).

Attention has also been paid to the need to address gender based inequalities within communities and families and the effect of personal trauma in working with women’s mental health (Williams and Miller 2008, Kohen 2010). A WHO enquiry pointed out that there has been an over-emphasis of the impact of biological factors on women’s mental health and an under-emphasis of their social and emotional lives (Astbury 2001).

Personal experiences of these broader inequalities and oppressive practices, within the contexts of the family and relationships, emerged as extremely significant in how women in this study made sense of their mental distress. Meanings of recovery and resilience and the perception of having recovered, for these women, depended on how they had managed to overcome these situations or make peace with them and move on.

Bio-medical contexts

The treatment of “the mentally ill” has historically centred on the individual and, as histories of psychiatry have shown, there has been an element of blame attached to the individual seen as insane or mad, including a lack of will or self-control or a sense of morality (Foucault 1965, Mack 1975, Wirth-Cauchon 2001). A bio-medical explanation, based on genetics or chemical imbalance, externalises the responsibility for distress and to a certain extent allows people to free themselves of the blame. Groups as diverse as the National Alliance of the Mentally Ill (NAMI) in the US to NGOs and user/carer groups in India10 have used the bio-medical model.

Attitudes of the family and immediate social circles towards mental distress had a key effect on recovery – negative and stigmatising attitudes hindered recovery and family support enabled it.

The following key themes emerged in discussions of mental distress in personal and familial contexts:

- Oppressive experiences like sexual and physical abuse, domestic violence, bullying and the trauma arising from these experiences.
- Bereavement and loss.
- Tensions between the individual’s and their family’s expectations and aspirations.
- Accumulated stress in relationships, bringing up children and fulfilling other familial roles.
- Stress from the workplace and other personal circumstances.
- Mental distress as a personal, spiritual or religious experience.

Recovery in these contexts was intrinsically tied to moving away from or overcoming oppressive and stressful situations, making sense of the abuse/trauma experienced, learning ways of coping with stress and loss, making peace with the family and significant others through communication and re-evaluating relationships, and acknowledging the role of spirituality, faith and religion in recovery.

10. See, for example, the user/carer group Schizophrenia Awareness Association (www.schizophrenia.org.in) and the non-governmental organisation SCARF (www.scarfindia.org).
as a weapon to fight against stigma and discrimination of mental health issues in society, for example, through arguing that it was “an illness like any other” (Sayce 2000).

However, it has been suggested that bio-medical models create their own stigmas based on assumptions about difference, disorder and dangerousness, both within their own communities and families and in the wider society (Prins et al. 1993, Taha and Cherti 2005, Fitzgibbon 2007, Corrigan 2007). Psychiatry has a history of pathologising both black communities and women (along with other “non-normative” groups like homosexuals) based on definitions of deviance and disorder in opposition to the definitions of ‘normalcy’ and ‘reason’ of Europeans (Metzl 2010, Wirth-Cauchon 2001, Showalter 1987). For example, Dr Samuel Cartwright, a Louisiana physician, diagnosed African slaves with ‘drapetomania’ (illness of repeated running away) and ‘dysaesthesia aethiopis’ (work-refusal and insensitivity to punishment), and claimed that both could be cured with care, kindness and hard work (Cartwright 1851). More recently, Metzl has examined how blackness and schizophrenia came to be connected in parallel to the national political events in the 1960s and 1970s, especially the civil rights movement, in the US (2010). The legacy of this history, some have argued, is evident in practice today (Fernando 2010b, Sashidharan 2001).

Making meaning of mental distress within a bio-medical framework involved some acceptance of psychiatric diagnoses, treatments, and, in some cases, a ‘doctor knows best’ attitude. However, this acceptance was a complicated process based on whether a given explanation and/or diagnosis made sense of their experiences, the level of self-blame, isolation and other stigmatising factors that a person experienced, and whether the bio-medical explanation and the accompanying treatment involved some kind of “therapeutic alliance” - a shared decision making approach to treatment and medication (Brown and Kandirikirira 2007).

A bio-medical model also requires compliance and an abdication of control to professionals which, as we shall see, creates a tension between the acceptance of the model and the level of satisfaction with the solutions that are on offer within this framework. Medication emerges as a key factor in this. Majority of the participants in this study who accepted a bio-medical explanation of their distress nevertheless made a clear distinction between medication as a necessity for symptom control and stability and their idea and definition of recovery and getting on with ‘normal’ life.

The discussions of mental distress in bio-medical contexts included:

- An understanding of mental distress as an ‘illness’, attributing the causes to genetics, chemical imbalances, damage to brain and other medical explanations.
- Acceptance of an illness model, sometimes in conjunction with other explanations.
- Discussions of physical illnesses, side effects and the bodily experience of mental/emotional distress.
- The impact of bio-medical interventions, including medication and its efficacy.

Recovery in these contexts was predicated on accepting psychiatric diagnoses and the role of medication and other interventions. This, however, did not mean that people were always satisfied with these explanations and interventions. Some people made a clear distinction between medication-based recovery – symptom control and management – and ‘real’ recovery, which they saw as a life free from medication and its effect on the body and self. In all narratives where a bio-medical understanding of distress experience and recovery was central, there was a tension between self-perceptions of ‘life as a patient’ and ‘normal life’.
“If I narrowed it down it would be one thing – God. I felt powerful, I felt protected, I felt loved. I felt important, whole, I didn’t feel like I was alone... I’ve met a lot of people as well and I’ve had family support... I’ve met other service users with this diagnosis... Some people are really positive, which just makes you feel ten times younger, it makes you feel good inside, so mental illness is not just the negative side, it’s the positive side as well.”
Making sense of mental distress and recovery in socio-cultural contexts

Socio-cultural causes and contexts of mental distress

Through the narratives, it is evident that several socio-cultural factors contributed to causing mental and emotional distress. These included experiences of racism, attitudes towards women and their sexuality, issues arising from contexts of migration and mixed heritage, tensions with negotiating cultures, and attitudes towards race and culture within mental health services.

Experience and effect of racism

Asked what she thought she was recovering from, one participant answered:

“Basically what I think I was recovering from was self-hate, feeling of self-hate, feeling of being alien... but I can understand why I felt that way from what had gone before and it’s not seeing it as actually me being demonically possessed or me being mentally ill... it’s an appropriate human response to a situation; it’s an extreme response, yeah....”

This narrator attributes this sense of self-hate that led to her mental distress to negative social situations in which racism had a significant part to play:

“Well, basically when I was a child we lived on an all-white road. Nobody was friendly to us and, as luck would have it, our next door neighbour was a member of the National Front and he kept throwing abuse over the garden wall at us... It was really horrible, horrible stuff. And when you were growing up as a child, you think that’s how the outside world sees you. You are not going to have pride in yourself and you actually fear the world around you. I can see where that has had a knock-on effect on my experience or paranoia...”

Internalising racism

Loss of self-worth and sense of pride in oneself as a direct result of experiencing racism while growing up was a key theme that ran through other narratives as well. The experience of not being valued had resulted in internalising negative self-images, as shown in the following excerpt from a participant who was born in the UK to migrant parents.

“...being brought up in [a South London community] that really didn't want you around, having that made very clear to you ... They don't know anything about me and my family apart from our appearance and if it’s that that they hate so much that they'll kick you in the street or they'll be really nasty to you or kids will chase you down the road... If that’s what I know about me then there must be something inherently wrong with the colour of my skin. So I think I did a bit of, well more than a bit, of internalising that so I think that had quite a big impact. It’s probably only in the last 10 years that I’ve felt comfortable in my skin.”
Internalising a negative image of oneself and one’s community results in being silenced, creating a sense of not belonging and in losing confidence in one's own abilities, as the following narrative, also from someone born in the UK to migrant parents, shows:

“I think racism has had a big part to play in not feeling like I belong, not feeling accepted, not feeling like a valued person and that then contributed to having very low [self] esteem, little confidence, devalued, disempowered and if you have not got any of those then you are not going to get on in life and I suppose I did not get on in life... one job after the next, I just did not get on with them. I had lot of negative experiences from trying to go out and trying so, so hard, thinking why can't I get anywhere. It is because of those messages I was given when I was little, and growing up with those messages. Racism, you know, it is I find in our society in the UK covertly oppressive and it is a very subtle message that you get that you cannot talk to anybody about – it keeps you silenced.”

Damage to self and identity

Societal attitudes and prejudice based on ‘race,’ and skin colour and the resulting confusion, isolation and a damaged sense of self were key causal factors for those participants who were from a mixed heritage background. One participant, a daughter of an English mother and Jamaican father, described herself as having no sense of home because all through her childhood and growing up years she and her family had to keep moving houses because of racial prejudice.

“In those days, it was no Irish, no blacks, no dogs. So what my mum used to do was go along and find a flat and then sneak her children in and then sneak her husband in and when they found out that she has got black children and a black husband, she would get kicked out... we lived in lot of different homes. And although my parents stuck together... they were also fighting among themselves... and had to fight the world as well so that had an impact on us children so it was very hard... All that took its toll on me over the years. So I can see why I had a breakdown in the end.”

These narratives show the cumulative effect of negative messages about ‘race’ and community on a person’s mental wellbeing. The impact of racism in society also has a continuing effect on some people’s wellness and has the potential to undermine the sense of self and identity that people have built up over the years. One participant, who migrated to the UK in her 30s, said that the racialisation of people seen as Asian and/or Muslims as potential ‘terrorists’ had made her own identity – “your motivations, your capabilities, the ‘who you are thing’.”

“In terms of causing distress, racism has been a huge issue especially post July 7th 2005. I had some experiences of being racially abused on the street for being a Taliban *****, being asked to go home and all that kind of stuff... I'm also quite politically minded so when watching something on TV which is, you know, the programmes that are relentlessly islamophobic or whatever, that has a very strong impact on my mental state. So what I do now is I don't watch them any more than is absolutely necessary to keep track of what is going on in the world.”

Cultural clashes, crises and confusions

Caught between cultures

One participant, the daughter of an African father and English mother, and adopted and brought up by white English parents, spoke of her specific experience of being brought up by trans-racial adoptive parents in an all-white community in rural England. Isolation was two-fold for her. On the one hand, the immediate all-white society saw her as the ‘other’:

“I'd take myself on [bike rides] and I would get racial abuse hurled at me by people passing by in a car, which is really intimidating when you are in the middle of nowhere. You can't hide and there's a real feeling of not being able to hide. Or older women who sort of class themselves on their manners... but with you they don't display those manners, sort of making you feel very
much second best... You're isolated, you're the only one that's experiencing it, there's no one to share that experience with and if you do, you're told you're ridiculous or you're making it up or you're being over-sensitive.”

Yet on the other hand, the idea of ‘being black’ did not sit well with her own sense of self:

“I mean, when I went to school I was the only black child. But then the word black – not feeling like it fitted me... I didn't know any other people of colour. I didn't know the idea of being mixed-race. I'm not sure when the concept of being mixed race first came to me but I must have been at least 15 or 16. Even then I still felt the pressure to wear this badge of black which just didn't work for me.”

This sense of the world being divided into two and not belonging on either side is one of the defining factors of what she terms her ‘emotional distress.’ She saw a very clear distinction between her ‘race’ as the biological daughter of a black father and white mother and her ‘culture’ which she saw as the white middle class background of her adoptive parents.

Negotiating cultures

For some of the second generation migrant women in the study, negotiating cultures had a significant impact on their sense of self and belonging, and they see this as one of the causes of mental distress. For one participant, the last and only ‘British’ child of migrant parents, the community’s perceptions of whether or not she fulfilled their cultural expectations had an impact on her sense of self.

“In the first year of university, there was a group of Asian men who were students and they really hated me because I was quite ‘anglicised’ in the way I behaved and that caused me a lot of confusion and distress and I think things like that contributed to my feeling of ‘who the hell am I’.”

Another participant who grew up in Africa as the daughter of Indian parents talks about moving from a multicultural city in Africa to a “cultural desert” in the east of England.

“I came here at the age of fourteen, so I think in some way that did not help me really, changing and moving countries. I think also it is to do with growing up in one culture and coming to another – all that stuff that goes with that. I had to negotiate and find my way through these cultural agendas...”

She feels that her identity and sense of self is very much based on these various cultural trajectories and how she negotiated them. But this identity is constantly under question from the outside.

“...I think it was brought to me recently when I was talking about Black History Month and someone made a comment that Black History Month is about black African and Caribbean people... I really felt as if I was being excluded. Because part of me is African by birth and I always will be even though I don’t look African, I feel it and that is my heritage and that is my identity and I will be the first one to jump up when I see the flag of Kenya – perhaps not so much for the flag of India... When people here refer to me as Indian, I refer to myself as Kenyan. So it is all about identity...”

Gendered norms of behaviour

Many women in this study felt that being perceived as not fulfilling social, cultural and familial norms of being women had a direct impact on their mental health. Every culture prescribed certain gendered norms of behaviour, and sometimes there was not much difference between cultures in what these norms were. For some, going against these norms created conflicts which resulted in mental and emotional distress.
The ‘submissive’ woman

As with racial discrimination, gender-based discrimination had a negative impact on people’s sense of identity, confidence and self-worth, to the extent that it became internalised. One participant, for example, spoke of ‘being depressed’ as a suitable and accepted state to be in as that is what was expected of women in her situation – young, Asian, divorced and pregnant.

“I thought that being sad and not having confidence is feminine... I thought it was a good thing to be... to be submissive... I should just be very submissive and feeling depressed inside is actually good. I mean I wanted to be happy but if I feel happy after my divorce and after leaving your husband that is really bad. A woman in Asian [culture] when husband has left you or you have left him because of domestic violence or whatever, divorce, you have to be sad and that’s it, you know? So sometimes we act because women should act like this and it’s right.”

Sometimes these feelings of inadequacy were not as a direct result of personal experience of discrimination, but of internalising the perceived devaluing of women and girls in the environment around, as this narrator from an Asian background and brought up in three different cultures testifies:

“I must have been six when my four year old brother died and I think I took it upon myself to replace him mentally. I did not make a big announcement of it but the little girl at that time decided she was going to fill that gap for her parents because that is what society wanted – boys... I did wish it had been me that had died... As I was growing up I saw... that girls weren’t wanted and boys were.”

The ‘difficult’ woman

For many women in their 40s and above, not adhering to norms of behaviours within their societies and cultures meant that they were seen as ‘difficult’. This idea of ‘difficult’ women was not specific to any culture, but a reflection of a patriarchal attitude that is part of many cultures. The following excerpt is an example of the perception of a ‘difficult woman’:

“For a really long time, it was all about me just being difficult. There were reasons why I would have been thought of as difficult because as a child, I was naughty and not that nice for a girl... I grew up and became a feminist, I was going on campaigns and demonstrations, I married the wrong person without my family’s consent and I was not doing anything that a normal good girl was supposed to be doing...”

The impact of this perception had direct consequences to this narrator’s mental status. Asked what this narrator thought she was recovering from, she said that she was recovering from the distress caused by society’s attitudes towards a certain kind of woman, one that did not fit well within the prescribed norms.

The ‘strong’ woman

The image of women as ‘strong’ emotional beings cuts across cultures. In some cultures, this image seems to sit, seemingly with no contradiction, alongside the requirement for women to be submissive as we discussed earlier. While this could be interpreted positively as resilience (see discussion in chapter 7), many narrators in this study felt that the image of strength in the face of mental and emotional distress has stopped many women from seeking or receiving help at the time of their need. The following excerpts from two participants, both women of Caribbean heritage, show how the stereotype of ‘strength in the face of all adversities’ affects black women:
“I was unwell after the first three months of university and I actually didn't end up in hospital until two years later... I think one of the things I learnt from my mother was that we, as black women, you keep going and you are strong, and no matter how difficult, you know, you keep going and I think that had an impact. I think that had I not had this ideal in my head of the strong black woman, I would have perhaps, I don't know, I would have sought help earlier or they would have taken me more seriously or whatever, but I went on, I kept going for a lot longer than could have really.”

“Oh yeah, women of colour, African Caribbean, African, whoever they are, there is a stigma attached. They are not supposed to have breakdowns. We are supposed to be strong black women. Put up an appearance and take care of the house and so on. How are you going to do those things?”

One participant felt that the image of the strong yet subservient black woman in society is a legacy of the historical oppression they have had to face both due to their gender and race. This legacy, combined with contemporary attitudes towards women in society today, results in a negative self-image which a lot of black women are fighting against.

“Well what I see is that a lot of black women go through a hell of a lot of mental distress... I am talking about our extended family, what our mothers have gone through and the whole thing about even slavery, the impact that slavery has had on black women... How we must dress and how we must talk and how we must be submissive and dominated and subservient and be abused and not love ourselves and all those different things. All of that has an impact on how we betray ourselves as women... I think the whole slave mentality, it has taken us, we are still living it. I strongly believe that there is a whole correlation between the slave mentality and how black women were treated then to how black women are ignored in regards to their mental health issues that are going on within the community today, you know.”

Attitudes towards black women in mental health services

These attitudes about black women are reflected within mental health services as well. One participant felt that the professionals who worked with her after she was sectioned seemed reluctant to believe that she was highly educated and held down a senior level job, as this conflicted with their pre-conceived notions of black women as under-achievers.

“...being an educated black woman means being judged by mental health practitioners, which resulted, in my case, in over-medication. And I was given this medication without even being asked about allergies or told about any potential side-effects. They didn't check my records, key history or background.”

Another participant spoke eloquently about experiencing sexual abuse as a child, which generated extreme feelings of anxiety when she herself became a mother. She started feeling that her child might be in danger from (imagined) abusers and that she would not be able to protect him. She did not feel that anyone took her anxiety seriously, telling her to get on with the task of being a mother.

“I had all this stuff from my past catching up with me and I need to deal with it, but they still expect you to deal with it and it is wrong. It is wrong to leave a young child with someone who is feeling like I was at the time; maybe I was not the best person to be with a child on its own because I was getting so paranoid that nobody could touch my child. ... So I think that it is wrong in society to give so much responsibility to women especially the parenting part and the emotional loading... I think it is wrong to have this image of women like they're mothers, they are meant to be strong.”
Attitudes about sexuality and sexual identities

Socio-cultural attitudes about sexuality and sexual behaviours are as significant as attitudes about ‘race’ and gender in gaining and retaining a positive sense of self and belonging. The impact of negative attitudes towards non-heterosexual identities within communities and within the mental health services on continuing to maintain a wholesome self are not considered within recovery approaches, as some participants in this study pointed out.

Homophobia within communities

Talking about feeling part of a community, one participant said:

“My colour’s not the problem at the moment, it’s my sexuality. For example, I’m looking to move, to find somewhere to rent and if I want somewhere to live I can’t disclose my mental health issues and I can’t disclose – unless I purposely go into the gay parts of town – I can’t disclose that because I don’t know what the response will be. So it does actually affect me on a day to day level.”

Social participation through normal community networks was sometimes made difficult by negative attitudes towards gay people, or a perception of negative attitudes. Participants talked about avoiding community groupings like church or black projects because of fear of homophobia.

“I’m still wary of black projects in terms of homophobia... Just even being at work here, sharing an office with a black project... One of the staff was saying that ‘as black men we are naturally homophobic’ and stuff like that. I am not out, and so I am privy to people’s personal opinions and I find... that there is quite a lot of homophobia.”

Homophobia within psychiatric services

Homophobia and other fixed views on ‘correct’ sexual behaviours were not restricted to the wider community outside. One participant believed that one of the diagnoses she was given, borderline personality disorder, was based on how the psychiatrist perceived her behaviour within the framework of accepted cultural norms of gendered behaviour and sexuality.11

“I think some of my diagnoses were definitely given to me because I was a woman and it would not have been given to me if I was a man. I was openly bisexual and ‘promiscuous’. I think both these were factors in being given a diagnosis of borderline personality disorder.”

Her sexuality was seen by some psychiatrists as ‘wrong’ and as a part of her mental ‘illness’ and resulted in them trying to ‘cure’ her of it as part of her mental illness.

“... a huge issue for my psychiatrists as well, the fact that I went with both men and women and a lot of them tried to, kind of cure me of it, you know sort of make me normal, so sexuality has always been a very big issue.”

In terms of preserving a positive sense of self that accepts one’s sexuality and sexual behaviours, these narrators had no solutions to offer, apart from learning to be selective about how and who they disclose their identities to. There was, however, an ideal recovery space in mind.

“...there would be a space that I could go to where I felt safe, if I became unwell, definitely. Knowing I had that would also help me keep well, knowing there was somewhere for me to go if I wasn’t coping, somewhere appropriate, female only, you know, for black women and accepting of my sexuality, I would like that.”

11. The link between diagnoses of personality disorder, especially borderline personality disorder, and perceived notions of gendered behaviours across cultures, is well-evidenced. See, for example, Wirth-Cauchon 2001 and Becker 1997.
Placing recovery within socio-cultural contexts

The social and cultural contexts and causes of mental distress, including experiences of inequality, discrimination and expectations of behaviour, are not always taken into account in recovery approaches. Often, the effects of these experiences are pathologised as symptoms of mental ‘illness’. However, for many people, as the narratives above have shown, these have to be taken on board and made sense of in a socio-cultural rather than medical/pathological context in order to start the journey of recovery.

Acceptance of socio-cultural meanings in mental health services

Addressing the damaging effects of inequality and discrimination, including racism, sexism, cultural oppressions, or a combination of these, was a key element in their sense of recovery for many women. Clearly, these inequalities have not been eradicated; they have a continued impact, and developing a positive sense of self and identity meant that these experiences needed to be addressed, first and foremost, within mental health services. Many of them felt that mental health services did not take on board experiences of racism and other discrimination, and indeed were not capable of doing this, essentially failing to address a significant part of their distress.

“I think I understand now actually I have had years and years of being suppressed and oppressed and not being valued and not being nurtured in the way that I needed nurturing. And being told that, actually there is racism here, and you are battling against that, so no wonder you feel like this. Even that would have helped. Even to say you have not been listened to very well. I think those key messages would have helped just to make sense of the world.”

“I think it would have been good if I had someone to talk to, maybe like a counsellor but also a counsellor who kind of understood my culture. I think it might have prevented me from becoming ill... The reason people have been nasty towards me was because of my race... So I think I would have needed a counsellor who would have understood that. Even if that person was white, if they would have understood that...”

When people did meet services and staff who were able to understand the locations of distress, there was a positive effect. In some cases, it helped that the staff understood the specific cultural locations of distress and anxieties.

“My care co-ordinator was an African woman. [This] made a big difference because suddenly my job of trying to explain where I was coming from, I did not have to explain that part of it to her, you know... about being a black woman, about being a black mother, about black culture... And because she was a black woman, she recognised certain things as well, about what I need, you know, what my anxieties might be as well. I did not have to spell them out.”

Building a positive sense of self and cultural identity

A major part of what women described as recovery is regaining a positive sense of self, re-negotiating personal and cultural expectations and having a sense of control over who you are.

“I can say in one sentence what [recovery] means to me... It’s to be who I am meant to be actually and not what family or society or culture or mental health services say I should be. It’s me being me. That’s as simple as that really.”
We saw earlier how the experience of being from a mixed heritage background and being brought up in a trans-racial situation had generated conflicts in identity and sense of self for one of the narrators. A key aspect of it was the perceived conflict between what she saw as her ‘race’ and what she saw as her culture. Being able to work towards attaining a balance in her sense of self and gaining a positive perception of the black part of her identity that she had denied while growing up was a key moment in her journey to recovery.

“Gaining a sense of pride in the black part and realising how much I’d distanced myself from it growing up because black people were criticised, they were second best. So I wanted to disassociate from that side. But then actually reclaiming it as a positive thing but doing it in a way where I didn’t have to be fully black, I could still keep my white side, finding a balance for both of them. And having a very brief reunion with my birth father... and actually really acknowledging that, wow, I do have an African aspect to me... And that’s made a huge difference to me in my identity, I feel much more integrated whereas before I was very split.”

**Attaining a shared identity through collective action**

Another key factor in moving towards recovery included addressing these conflicts within a collective setting in the context of shared understanding with other women in similar situations.

“In my early 20s, I left home and moved to another part [of the country] and what was there for me was a very active, vibrant feminist community. There was a lot of questioning of psychiatrists and the psych-disciplines, seeing what this is doing to women, those kinds of things. So I think that was the route that helped me, looking at psychiatry, or more broadly what medicine was doing to women.”

For some, recovery involved a political process, exploring rights, questioning power structures and becoming part of movements like the survivor movement, anti-racism campaigns or women’s rights movements. Trying to get psychiatry and mental health services to take on board the effects of racism was a political process.

“It’s funny, isn’t it, for probably 25 years, yes, probably for that long, [experiences of racism] wasn’t an issue either for them [mental health services] or for me because it was ignored... but that in itself made it a problem really and I didn’t realise that until I had my awareness raised a bit more really, again coming into contact with people who were into the whole social black rights philosophy.”

Access to ‘recovery spaces’ where there was an opportunity to discuss and share experiences of distress from specific socio-cultural locations was a significant element in some people’s recovery.

“If I had not gone to the women’s recovery group I would have been back in hospital by now... Maybe before [being a black woman] was not taken into account, lots of things weren’t. I don’t know if it was a gender thing or a race thing. I don’t even think it was deliberate. People just did not take it into account; they did not think it mattered you see... But race and gender really matter when it comes to recovery, you know, you have got to take them into account, you know, you can’t cut them out... So yes, it was basically starting from the women’s recovery group and working outwards from there. It covered all sorts of areas in your life, relationships and spirituality, sexuality, gender, covered everything from being a woman anyway and being a black woman with all these different issues. So a lot of things need to be addressed before you can even move on and kind of look outwards...”
Summary

- Many people make sense of distress as arising from the adverse effects of socio-cultural experiences, including racism, sexism and other forms of discrimination in society.

- Negative societal experiences can lead to an erosion of the sense of identity and self.

- Recovery is predicated on being able to find ways and locations to regain and rebuild a positive sense of socio-cultural identity and belonging.

- Recovery approaches based within mental health services will need to take into account the impact of socio-cultural contexts and causes of distress and offer ways to cope with them.

- Elements of recovery in socio-cultural contexts include:
  - Addressing and overcoming the impact of negative social experiences.
  - Rebuilding a positive sense of self and communal identity.
  - Developing mechanisms to cope with societal oppression.
  - Attaining a shared sense of identity and social justice through collective action.
  - Access to ‘recovery spaces’ where the specific socio-cultural aspects of distress can be addressed.
A story of spiritual connection with the legacy of black oppression

The following narrative brings together several elements discussed in this section – mental distress and recovery as a spiritual journey, the continuing impact of the historical legacy of oppression of black people on the sense of self and identity, and the inability of a western system of psychiatry in addressing these key elements in some people’s mental wellbeing. The narrator is an African Caribbean mother of two children, a campaigner of black people’s right to mental health and a scholar of African Studies.

“...I think the spiritual aspects of [our experience] are never taken into account in terms of western psychiatry. I don’t think they have got there yet. They understand that spirituality is important in terms of recovery but they don’t take it into account in terms of diagnosis and I think that is really difficult...

...Because I worked in African and Caribbean culture, the transatlantic slave trade was a big part of my remit in my cultural teaching and also in terms of what I was studying as well and I went into it a little bit too deeply... And then all of sudden something unlocked in me... I started hearing my ancestors... I could hear them crying and I could feel their pain. All my female ancestors, I could feel them and I could feel all their children... and I could hear them on their voyage and I could feel all these people coming to me through all my reading and it started to affect me and that was a problem. That was one half of the experience that I could not even talk about to my psychiatrist or to anybody.

And even to my care co-ordinator – I cannot speak about it too much to her because she is an African woman you see... (M)ainland Africans... they do not understand about the transatlantic slave trade... It is only now that they have started to understand it, the pain aspect of it and the trauma that their African and Caribbean brothers and sisters are suffering still...

Still suffering. Because some of us have got too close or our ancestors are very close to us. And it is because we are now touching, because we are now linked up with our ancestors, we are being traumatized by this experience. Now you see, I talk about the slave trade and tears come. Do you understand me?

...My sister and I went to Ghana. We went to Elmina Castle, we went to Cape Coast Castle and we had these experiences and I brought my ancestors back with me. We went in 2005 and because I brought my ancestors back with me it all added to what was happening in 2006 [when she had a breakdown]. So now I have this open channel... another element of our spirituality opened, it opened up another dimension inside us. It was like there was a door in the mind... all the time I could hear people knocking and screaming, it was like I was haunted... because coming from this closed door it was warped and I was not hearing properly, I could not get it, I felt constantly tearful, angry and upset and rage... When we went to Ghana and we went to the Castle, suddenly in my mind, that door opened.

It felt like I had left Africa, gone to the Caribbean, gone down to Europe and gone back to Africa and ended up back at the gate, that doorway again. So my ancestor had gone through a door like this, I could feel her, when I stood at the door I could feel my ancestor when she was at that door. I felt her.

...You know this spirituality aspect... the fact that in terms of diagnosis that has never been addressed. I never disclosed it because for me, in terms of what I know already and what I know from my training, it is not taken into account and they can’t take it into account, they just don’t know how to deal with it... I think now there are a few things that have been written about it and I think I need to read a little bit more about Post Traumatic Slave Syndrome.”
Personal and familial causes and contexts of mental distress

Experiences of violence and abuse, bereavement, loss and other traumas, tensions within families and relationships, all contributed to mental and emotional distress for the participants of this study. For some, distress was a spiritual or religious experience.

Experience of violence and abuse

Four participants in this study connected their distress to having experienced domestic violence in the form of physical and mental abuse over an extended period of time. Five other participants had experienced sexual abuse. A total of 15 people spoke of first-hand experience of physical, mental and/or sexual abuse or of having grown up witnessing or being caught up in abusive and violent situations.

In addition to the pain and trauma of physical and mental abuse, the experience of domestic violence eroded any sense of positive identity and self-confidence.

“... [My husband] really made me feel that women are no good... that women, if they don't listen to their husbands, they have no life... My family will think bad of me and all the society will think bad of me and of course nobody is going to marry me and all those things and he kept saying all that, all that. And I thought if he hadn't said all those things, I may not have felt this bad you know. So I think men sometimes in their selfishness and insecurities, they really make women feel much lower than they have to. But when you are already feeling sad and you are pregnant and you are going through abuse and you think that the person you trusted to know the best for you is saying all these things to you, then you tend to believe all that and that is when things make you... I had no self-respect, and also courage...”

Erosion of self due to abuse

Two of the participants had been living in a situation of daily violence when, in the outside world, they were seen as socially and politically active and productive. This situation created significant crises in their sense of self and self-worth. One woman spoke of being in a relationship with steadily escalating violence which eventually saw her admitted in a hospital. She was also a political activist, a councillor who worked with women experiencing domestic violence, campaigning for better policies for

“...just that twitch inside says I need to recover... What made me want to recover was when I was in hospital my two children were 7 and 9 and they brought me... a painting of a mother platypus and a baby platypus and that is what made me say my children need me.”
protecting women and counselling women trying to escape situations of violence. It would be easy to think that a woman in her position – politically aware and with access to outside help – would be able to walk away from that situation quite easily. But overcoming family and cultural pressures and leaving such a situation is not as easy as it seems. She spoke of the effect of the conflicting roles of being a political activist and of being in a situation at home where she was caught up in the daily violence of her own marriage.

“…sometimes you don’t realise you were socialised in a particular way until when you are in a bad place and then you seek help and then your cultural norms suddenly act as a barrier… As a councillor for a very long time I did a lot of domestic violence case work and it used to be traumatic for me… I was doing all this sensitive counselling, when I was also submerging – is that the word – suppressing the pain I was in and I was being strong for other people but I was thinking who is going to be strong for me? Because in my culture – this is the African and western world colliding… and both cultures, strangely enough, believe that if your husband beats you... it must be something you did. So the fault is all in the woman and just no responsibility on the man. Behave as you want, it’s her fault, totally it’s a no win situation. And then we’re Catholic!”

Some women made clear connections between abuse and trauma and their mental distress experience, while others talked more about the indirect effects of abuse in terms of creating patterns of behaviours and self-images that were detrimental to their wellbeing.

“…I would say I was recovering from abuse and trauma and I had quite a lot of abuse through childhood and through my teens until I was 19, that’s physical and sexual abuse. I think that’s the basis of my mental distress or mental illness.”

Creating negative self-images

Another participant who had started accessing mental health services in her twenties talked about growing up witnessing violence as a result of her father’s alcoholism:

“My childhood was quite marked with a lot of violence. My dad had an alcohol problem. On the one hand he was this wonderful, loving, giving person and he was always finding new things for us to do, educating us in the best way possible. But it was almost a complete turnover come weekend and he started drinking and there was lots of violence. He used to beat my mother really, really badly. Everybody... My grandmother used to live with us. He used to beat her as well. My sister, too. I used to hide in a room and not get involved... So I think for me personally my issues were quite connected to the violence that I was witnessing and my inability to do anything about it. Why I would have felt the need to do something about it at that young age, I don’t know.”

She makes a clear connection between this perceived need to address the violence in the family and developing self-harm as a coping mechanism – she started to self-harm in her teens and continues to do so even today.

“I think in society women are brought up to be non-violent, to not do anything that is harmful to yourself or to others. In some ways, initially I think that the fact that I can’t be aggressive towards the world is what turned aggression inside of me. That’s how I used to think about it in those days that, you know, I can’t beat you up so I will just cut myself – to my dad mainly... it helps me really in dealing with my distress, you know? Every time when I have reached a point so low in my life, cutting myself sort of brings me back up and makes me normal.”

For another participant, the abuse and trauma in childhood had created extreme levels of anxiety and anger which became, as she puts it, “a pattern of emotional behaviour,” that she replicated in later life.
“I think my condition was probably depression, anxiety and that stemmed from child abuse. Other family traumas that happened. My parents were always having violent fights... And I had an eye condition and my mum covered my eye, the only eye I could see properly from, so I distorted my own childhood... I used to blame myself for things that I thought were my fault because people did not explain to me anything... and it became a pattern of emotional behaviour. I chose relationships with people and situations that sort of kept this pattern going and then it becomes depression... If you are anxious, you do not sleep, you become depressed, maybe become a bit of a misanthrope, because you are not really at peace with yourself, you are a bag of nerves really and then you become really angry. And my problem was just dealing with the anger with what happened and not really coming to a conclusion or closure.”

Bereavement, loss and other traumas

An abiding message that comes out of the narratives is the cumulative effect of different traumas and the stress that results from not addressing these traumas properly. It is difficult, in some cases, to pin-point the exact event that precipitated distress, but it is clear that unaddressed, and sometimes unacknowledged, traumatic emotional experiences had a great significance for participants in the way they made sense of their distress. One woman spoke at length about the loss of her father, being financially swindled by a partner she trusted, tensions within the family and the combined effect of these factors in causing her “breakdown.”

“...lots of different things...it was like peeling back an onion, so if it wasn't this, it was this, you know?”

In other cases, a specific traumatic event became the proverbial straw that broke the camel’s back.

“I feel [my mental health problems are] due to the struggles of life, struggles of my past lives and the traumatic experiences that have happened in my life. I think that the last straw was when my partner committed suicide... because in three months I ended up in hospital but I didn't know I wasn't very well.”

Family dynamics and tensions

Family dynamics had a key part to play in some people’s views on the causes of their distress. Perceptions of how well one coped with that dynamics and feelings of being accepted and valued within family relationships were important to people’s self-worth. In some cases, family traditions of ways of being and behaving, and embedded power hierarchies were felt to be stressful and to cause conflict.

“I think I have always had conflict with my father-in-law, that has always been there and now since he is older he has kind of calmed down a lot more and I have learnt not to let it get to me... And then there was favouritism between the sons and the daughters-in-law and that used to bother me... He will whisper in my mother-in-law’s ear and my mother-in-law will whisper it to my husband and my husband will whisper it to me and it is just never up in the air, not out in the air.”

For some participants, family cultures and notions of dignity and shame perpetuated the distress that they felt from being in traumatic situations. The feeling of not being supported in overcoming such situations, added to the experience itself, caused a sense of helplessness and loneliness. Having suffered a long period of violence, one participant had left her husband. Being told to be secretive about her marital situation and her distress was an added pressure.
“... my mum would say, don’t tell anyone... Don’t tell anyone about your problem. Even if it is just to protect us, it does make me feel also this is something bad, that’s why we need to hide it... It does give the impression of shame and embarrassment and next time if I ever feel low I’m less likely to share it with my mum. Why I’m bringing her pain and upsetting her and then you know she might feel embarrassed as well...”

**Anxieties about responsibilities and fulfilling expectations**

“Things happen around me or with me. I don’t know if the pain is from the past or present... If my son, if some friend of his says some bad things to him and he cries at home, I feel that I have not been a good mother. I don’t know, anything could trigger it... I personally felt nothing is going to happen, things would get worse. I don’t know, what’s the word? Despair.”

For women who had been in abusive situations, this sense of despair was a common one that they needed to overcome as part of their wellness process. Taking on the responsibilities of being a good mother or daughter or sister, while also feeling vulnerable themselves, took a toll on their wellbeing. Part of it was a personal sense of responsibility and part of it was familial and cultural expectations imposed on them. Either way, the feeling that they were not fulfilling these roles ‘properly’ seemed to increase stress and decrease belief in self.

One participant, originally from Ethiopia, was sent to live with an aunt in Sweden at the age of 12. While growing up she also took on the responsibility of looking after her two siblings. Then when her parents came to join her as refugees, she had to re-learn how to fit into the family, re-adjust the picture she had of her family while also taking care of them in a practical sense. She connects her “breakdown” to the various levels of stress involved in fulfilling this role, while also working and studying.

“...I had the high requirements I had with myself and also trying to see certain things in certain ways... Our family used to be like this when we were in Ethiopia and now they are here as refugees and there is all this disagreement and discord going on in between because we had not been living together for so many years. And I have to again learn to understand my mum or my dad or my brothers, you know?... And I had this, because that was the only thing that made me survive in Sweden, having that picture of where I came from and that supported me... What kept me, you know, from losing myself or losing my identity was always remembering this is how I grew up, this is where I came from and my parents and my family is like this. But when they came to Sweden as refugees there were all these issues and suddenly I was confused, you know, and tried to make sense of it but...”

For others, the responsibilities involved in raising children and parenting, especially as a single mother and with no support systems, added to the pressure and accumulated stress. Speaking of a range of issues including being a single mother to seven children, two of them with disabilities, trying to get support from social services, dealing with difficulties in school, even as she was dealing with her own experiences of abuse, one participant said that having had the time for a “breakdown” would have been a privilege.

“This is what caused the mental distress. I literally didn’t have the time to have a breakdown. I have never had the time to have a breakdown. If I had the time that might have been a privilege, do you understand? I had no time to have a breakdown. I just kept going, kept going, and what was actually happening was that my health was deteriorating, my blood pressure was going up, I had high cholesterol, my ankles began to get weak, my hair started falling out... that was the result. Did I have a breakdown or did I not? All I know is that I kept going.”
Distress as spiritual or religious experience

In the earlier chapter, we saw a participant describe her mental distress experience as a result of a spiritual connection with her ancestors and the legacy of slavery. She was wary of describing this experience within the mental health system as, quite often, spiritual crises and/or experiences of a religious nature are misunderstood or not taken into account within the mental health system.

Spirituality and faith were important parts of some participants’ identity and sense of self. In some cases, although the causes of mental distress were identified in social, personal or familial contexts, the understanding or meaning of distress was in a spiritual or religious context. For example, in the previous section, we examined the narrative of a participant who talked about reconnecting with her family after growing up away from them while having to be responsible for them when they joined her as refugees. While she located the causal factors of her distress in these events, she made sense of the experience of distress in a spiritual way.

“I only see myself as someone who had suffered a breakdown and I recovered even though I had relapsed... I don’t know, it is very difficult to say... I feel like a better person now than I was before. A process of, you know, insight and some kind of spiritual insight even if it was difficult and it was frightening, you know?... I need to have some kind of reminder that there is something else and that I should not take myself too seriously and just be, you know, humble.”

Another participant, who defined herself as a religious person, had been given a diagnosis of schizophrenia. She accepted the diagnosis as a medical condition and located the origins of her “psychotic episode” in issues related to stress, but the personal meaning she gave to her experience was within a spiritual context.

“I think it was stress, lack of understanding, bottling up my feelings, not knowing who to talk to... Sometimes it is one of those situations where you have got to take mental illness as a blessing as well... And when I say it’s a blessing, I mean maybe it could just be that it’s a gift from God as well, you know, instead of a negative thing, because there was a time when I was in denial when I didn’t understand it but I turned it around and started understanding it from a positive point of view.”

One person firmly rooted within her Christian faith (her entire narrative focused on her faith in Christ and its role in her recovery) explained her experience as ‘a trial of faith’:

“It’s just trial. I would say it is a trial of my faith whether I will deny my God whatever comes my way, even death, whether it will usurp me from the love of Christ.”

Community attitudes towards mental distress

The journey towards recovery and the ability to call upon sources of resilience becomes more difficult for some people when they are faced with negative attitudes towards mental distress within their families, immediate social environments and communities. For some, there was familial pressure not to talk about mental health problems because of the prevalence of stigmatising attitudes about it in the community.

“There is a general belief in hereditary madness... So if there was madness in a family, nobody married anybody from that family, that kind of thing. So we did not speak about it... I remember, in my 20s, once I went home after a really bad bout of cutting myself – the scars are still here – and even today the family myth is that I was attacked by a monkey! That was the story that was made up to tell the neighbours because they were quite bad visible scars.”

12. See Cornah 2006 and Ndegwa, Kilshaw and Curran 2002. It is important, however, to keep in mind that there is often a confusion between spirituality and religion and explanations of spirituality differ widely between cultures (Fernando and Keating 2009).
Other participants spoke of similar beliefs and felt the need to adhere to this pressure and hide their experiences from their community, despite this having an adverse effect on their recovery.

“[My parents] try to find me a partner and I’m going to these marriage bureaus, matrimonial websites. So I’m very conscious of the fact that I have to hide the fact that I’ve had a mental illness and it feels quite horrible actually, the fact that I have to keep lying. Sometimes I think, is this what I want from my relationship, where I have to keep lying to the person who I expect to support me in my life.”

“In my culture... mental [distress] is seen as a sign of weakness... Weakness and oh, she’s not one of us then, and to feel, to fit into that situation I’ve learned to act... I just force myself to keep sitting and acting as if I don’t feel anything and everything is normal.”

Placing recovery in personal and familial contexts

Three key things needed to happen in order to recover from the distress caused by the situations discussed above – removal of/from stressful and abusive situations, learning to make sense and cope with the effects of such situations, and receiving support for coping. In all cases where abuse and violence were core factors, the narrators had managed to leave those situations behind, through divorce, growing up or moving away. It was more difficult to learn to live with the effects of it and regain self-worth, self-confidence and a positive outlook. For some, this was an on-going struggle. Finding supportive contexts in which to heal and grow had been especially difficult for many narrators.

Addressing personal/familial contexts within mental health services

“Well, my first meeting with mental health services was when I was 14, with child psychiatry, and it was absolutely horrible. I went to see a child psychiatrist and she was just so cold – why aren’t you in school, that kind of thing. If she had been more open and more helpful maybe my life would have gone down a different route... Social services were involved at the time and they knew the family situation... I would have preferred the abuse to have stopped at home, I would have wanted reassurance, I wanted a way for me to understand my psychosis and just people actually caring... It seemed to me that the reason I was involved with social services and child psychiatry was to get me back to school... I refused to go because I was just so paranoid of people. Nothing about helping me or supporting me. If they had done their jobs I think my life would have been much different.”
The excerpt above captures a recurring theme in these narratives – that mental health services and social services did not offer support in understanding and overcoming abusive situations but pathologised the effects of abuse. The issue most often raised was that “there was no one to talk to.”

“Somebody that can talk to you and explain to you what is going on or what is happening with you and what’s best – what they know is best as well as listening to what I have to say...”

Access to counselling and talking therapies

A large number of people (19 of the 27 participants) who took part in the study had accessed some kind of counselling and therapy. Some were referred through the mental health system and some found it on their own via community groups and women's groups. While people had mixed views about its usefulness in recovery, overall, 13 of those who had access to counselling had positive views about it. Nine participants had never been offered counselling, therapy or any other non-medical intervention.

Being offered counselling or therapy was not as straightforward as it seems from the previous paragraph – one person, whose main issues arose from a history of child abuse and who entered the mental health system at the age of 14, had to wait 22 years before being offered it.

“I had to wait 22 years before I got it. After asking for it for 22 years! And it was then I started to feel better about myself. So them thinking giving me the tablet was the cheaper option, actually it wasn't.”

Counselling and psychotherapy helped most people because they valued, as mentioned earlier, having someone to talk to, and work through their distress issues and find ways of coping. For some, it was also a guide on keeping track of their journey.

“I have had counselling on a number of occasions and to me that is like my recovery, a guidance on my recovery because I might think that I am recovering but you know I don't know everything so I have sought counselling in order to sort of voice what I am going through and to kind of steer me and to re-cap, go back the next time and re-cap what's happened and talk about whether I feel that that's worked for me or not... so I have sought services because I couldn't have done it alone.”

Where it had not worked, two issues were significant: first, that the therapist or counsellor did not understand or address socio-cultural issues; and second, that they were not being offered help to cope with the personal and familial issues that people saw as the root cause of their distress.

Feeling safe within services

Another key issue that was raised was the need to feel safe within services. It was an issue for all women, but those who had experienced abuse or violence felt it more keenly. A major issue here was the absence of single sex wards and separate facilities for women13, as this narrator who had experienced child abuse says:

“...my first two times as an in-patient I was on a mixed ward and that was horrible and I don't ever want to go through that again. I almost was assaulted and it's only because I'm quite tall and a big woman and I'm not scared to use my fist it didn't happen. But I shouldn't have been put in that position in the first place and when you are very distressed and depressed, having [men] come up to you and say [abusive and intimidating things] – how is that supposed to help my mental health!”

The need to make women feel safe was not taken seriously by some professionals, according to two other participants who had specifically requested to work with female staff but were given male staff on home treatment teams.

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13. The Count Me In 2009 report says: 73% women were not in a single sex ward; 24% women reported not having access to toilet and bathing facilities designated for single sex use; 51% of all patients had no access to a lounge and day space designated for single sex use. Andrew Lansley, the Health Minister, has said that he planned to announce the end of mixed sex wards across the NHS, except in A&E and ICUs, by the end of 2010 (The Daily Telegraph, 16 August 2010). The result of this announcement is still to come.
Supporting the family as a whole

One other significant factor mentioned by a number of participants is that mental health services need to support people as a family – that recovery was not possible unless the immediate family was enabled to support the person in distress.

“As a family, not just helping me because my family are not understanding what's going on. I feel [they] are keeping me separated from them. It would have been nice if they could bring in my family and explain to my family what's going on so that they could come in from a different angle.”

One participant felt that a Eurocentric concept of psychiatry and mental health care was focused on individualism rather than the collective – in her case, the immediate family. While her distress had origins within the family and community, she saw her recovery as also rooted within these contexts. Thus, early encounters with the mental health system proved to be “confusing” because she felt the focus was placed on moving her away from her family rather than helping her learn to overcome and deal with the tensions and stresses in her relationship with her family.

“...it felt like the focus was on being very independent and also moving away from my family because my family were the cause of all my problems... Looking back, I think actually that was the worst thing they could have done because... I have been brought up in such a way that actually not having my family around is worse than having them around. And what I need to do actually is learn... how I could get what I needed in terms of feeling part of them but not get drawn into their reluctance to accept me and who I was... Looking back on it now, it was interesting but it also made me realise that that Eurocentric bias is quite challenging really.”

The process of recovery was also affected by differences in a person's and a mental health professional's perception of family obligations and the role of family members as carers. One participant had a brother who travelled from some distance to visit her in hospital and, after she was discharged, helped to support her in the process of getting better. When she wanted her care coordinator to interact with him as her carer, the care coordinator refused to see him because, according to her, he was expected to do his duty as a brother and so was not entitled to be classified a carer.

“...having your care coordinator argue with you saying that 'but he is not your carer, he is your brother, he is supposed to care for you' and I'm telling her 'no, he is my carer, he spends so much time'... She just accepts, you know, that your family are supposed to care for you, but in her role as a care coordinator/social worker it is actually to provide people with carers or you know help in the best way possible...”

The narrator, who was from an African background, understands and shares the African-Caribbean care coordinator's cultural views around families supporting and looking after each other, but feels that, in her role as a mental health professional, she needed to work with what the person seeking help would find most useful.

Supportive professionals

When services aided recovery, it was mainly through having professionals who cared about providing opportunities to build up self-confidence and supporting in practical ways, and being given a range of options to explore.

“I think [what helped me] was support. A good care team. Good means people who listen, who support you and who, not complicate things, but like I said give information in a clear way and also who get results... It is people who get together a way of supporting in what you need and it is important to have a safe place, it is important to have financial security...
Finding a psychiatrist and other mental health professionals who helped boost self-confidence was another enabling factor. When a person has been through several periods of distress, it is easy to lose track of any sense of self-worth. One participant talked about the role of her psychiatrist in reminding her of her worth:

“He said to me once: however bad things get or however mad I am ... the good parts of me don't disappear. And it sounds really stupid but it’s really obvious now. Nobody in almost 20 years had ever said that to me before.”

Supported housing (three of the participants lived in supported housing), user-led groups and voluntary sector projects offering services for mental health service users and for women who had experienced traumatic life situations were given as examples of recovery spaces where people could meet others with similar experiences, explore educational and vocational options and participate in activities that created a sense of community.

For most people, the first step in accessing these opportunities was the support from professionals working in health and social care and in the voluntary sector.

Finding closure to abuse experience

It was important, for most people whose distress was based on experience of violence and abuse, to find some kind of closure to that experience. For some, this involved the family/society acknowledging the existence of abuse and its after-effects.

“It has taken many years to understand what has happened to me but also I think a big part of it was to make others understand. I think for me it was a big issue that other people had to understand. I would say I only really thought of recovery as being part of who I am only when I could start speaking to my parents and family. So it has been about making me understand what is happening to myself but more importantly also making other people kind of... They don't have to agree with it but they had to acknowledge it. Acknowledgement is part of it, quite a big thing. I would say that is the main thing.”

One participant whose experience of child abuse, both of herself and her sister, was the main cause of her distress, explained how she had to come to terms with it in several stages. Firstly, she went about piecing together the history of abuse, “a time line” as she called it, by talking to her siblings, figuring out what memories were real and what were not, trying to understand what really went on. It is important for her to focus on the trauma that caused what she calls her “psychosis” rather than treat its symptoms. Secondly, this understanding brought her to a point where she could forgive herself and forgive her abusers, which she sees as an act of “giving the responsibility back to them.”
“...What happens is that before one gets into psychosis or develops anxiety, something happens, like a trauma, a situation... and if we do not try and piece things together and understand what happens, we don’t understand the nature of our psychosis... What I found important was to understand the core issues and to confront them. If I [were a] victim, who was accountable for it? And even though I confronted all this, I had all this anger about it because those people were supposed to protect me and they did not. But I can forgive them, then it is giving the responsibility back to them. I forgive them so they can acknowledge... I don't have to feel angry anymore because I have stopped my connection, the role I was playing in my own trauma, I am not part of it anymore.”

What this narrator describes is an enormous emotional task that requires a huge amount of courage. In her case, she had to do this alone with no support from any of the services she accessed or from her family. Confronting abusers seemed to be a preferred element in finding closure for many of those who had been abused, but not many had been able to do it. But a broader social/familial acceptance of the existence of abuse and its after-effects seems to give a sense of social justice that helps to rebuild the sense of self.

**Healing with “talk”**

While the family was the location of distress for some people, it was also the location for healing. Many participants highlighted the support of family members and significant others as a key factor in their recovery – the word ‘empathy’ was often repeated.

“The most direct things that have helped me I would say have been my mum, my dad and my family, because they have been understanding and supportive. I mean there was a time when they weren’t understanding and that caused a lot more mental distress for me, but because they started understanding and showing a little empathy, it was really beneficial for me.”

Finding a way to address the tensions and problems within familial structures and relationships, mainly through open and honest conversation, was a key aspect of recovery.

“Many years ago, at the height of my dad's violence, my mum finally gave up and tried to kill herself... She was rushed to the hospital and eventually got better. After that, we all sat down with my dad and said to him that you have to get some help otherwise we are all going to leave. So eventually he agreed and we found out that his alcoholism along with some injuries in his brain, blood clots in his brain, had created this extreme situation... [We] took him to a hospital... he underwent de-addiction and other treatments... I think that whole period of dealing with so much distress within the family – in a bizarre way it was good for all of us. A lot of things were talked about, not in a blaming kind of way. It was more about, there is something unwell about this family which needs sorting. I think all of us started our journeys of recovery from there on in some ways. I think a lot of trust was built then as well... I think there was a lot of give and take and when the family healed in some ways, I think all of us started getting better.”

Sometimes the family’s role is not in addressing the causes of distress but in understanding and being able to support the person through their journey of recovery. The stigma attached to mental distress, common across cultures, had become a barrier for some people and the family and close friends had a role in helping them overcome this stigma and propping up their sense of self.
“What helped was being able to talk openly and honestly with my family about being in hospital... Being able to talk to my colleagues, my co-workers... The biggest part of mental health is the stigma attached to the crisis somehow like you might contaminate someone, you know, and just feeling that I was an emotional drain on people... My family and friends didn't make me feel [that way] and I think that was the biggest things. Being able to talk to them about it enabled me to think through things in a much clearer way.”

Being able to develop a familial language to talk about mental distress itself has helped some people, including “laughing and joking about a mother who is up with the fairies” or “having a laugh with their mad daughter.” For people living in close relationships, an important part of recovery was the significant other’s understanding, acceptance and knowledge of experiences like voices and visions.

One participant described how she has been able to live with her voices, visions and sensory experiences – what doctors call ‘hallucinations’ – with the help and support of her husband over a period of ten years, the last four without the aid of medication. Having her experiences legitimised and not dismissed had a positive impact on her recovery.

“I have sensory hallucinations, so one of the things I had [recently] in the house I start smelling fish and chips... I just couldn't stand it. I kept saying the whole house is full of it, I can't breathe, I can't breathe, I can't stand it. My husband's reaction was interesting. He cleaned the house, put flowers everywhere, went out and got candles and joss sticks. But he didn't tell me that, no it is all fine, it doesn't smell, there is no fish and chips smell in the house. Instead he said ok, maybe we will do something about it.”

She said she also makes sure that, after every “episode,” she and her partner have a discussion about his experience of coping and looking after her, which helps to identify issues that might be frustrating for him.

**Rebuilding self, regaining control**

One of the after-effects of violence, trauma and accumulated stress is an erosion of the sense of self and control over one’s own life. Recovery, for all the narrators quoted in this section, involved rebuilding a positive sense of self and regaining some control over their lives. This process did not start until they could remove themselves from the stressful and traumatic situations – sometimes a “breakdown” allowed them to start this process.

A key first step in this journey is acceptance – of the trauma, of the existence of “distress”, of who you have become in the process. It also involves accepting one’s emotions and being able to overcome the sense of failure.

**Creativity**

For two narrators, writing their memoirs was the tool that helped this process, leading them to examine the events of their life in more detail.

“For the first time ever I had empathy for myself... I actually had proper tears for myself for the first time reading my story. I didn't feel like an alien, it didn't feel like an illness or a sick thing or a broken thing. I could see myself as a person who has gone through a lot and is reacting actually quite appropriately to the distress that has been heaped on her... It was a just reaction to a horrible situation. So that was actually the turning point in my life.”

Engaging in creative activities also helped build and maintain a sense of calm for some people. Apart from writing, art, photography, making quilts, gardening and cooking were mentioned as creative activities that gave fulfilment and a sense of calm.

**Empathy for self**

As expressed in the quotation in the previous section, empathy for self and the act of forgiving oneself is a recurring theme in these recovery narratives.
“Forgiveness, I think to a large extent being able to forgive myself for things that I felt I didn’t do as well as I could was part of the recovery because I did feel that I had let so many people down.”

There was a sense that, although women were seen as emotional beings, accepting one’s own emotion as legitimate and being able to express them without censure was sometimes curtailed. An important part of recovery for some people was learning to accept and express emotions.

“Oh, I think it’s allowing myself to be emotional and to accept my emotion... I think being honest with myself about what I feel and then allowing myself to accept those emotions and to act on them rather than suppress them.”

Control over one’s body and life

The sense of control over one’s own life – a key element of recovery – came through seeking out the required information about one’s condition and support systems and being able to be in a position where they can make decisions about their own life. It is important to note that, for some people, having to continue medication is seen as depleting the sense of control one has over one’s life – recovery, in this sense, gains a different meaning, which will be explored further later in this report.

“I would say of course it is important to have support from friends and family but most of all, self-educating. I think without you having awareness or your own knowledge of what has happened, what your condition is, it is very difficult to understand what is real and what is not from whatever your psychosis at the time. So educating myself.”

For people whose self-confidence has been eroded because of traumatic events and their after-effects, the idea of regaining self-worth is a key component in recovery. For some, self-worth came via having work, being involved in activities and meeting people.

“Part of the therapy or part of the kind of journey was going back to work and that made me feel better. It made me think, oh I am worth something. I can do something.”

“When I wasn’t working I felt not being part of society, I really felt that I was in this kind of underground society in a way and I have come out and seen people getting ready to go to work and I felt left out. While I was out during the day, I met up with women who have children or other unemployed people or other people who were unwell and I felt really that wasn’t the lifestyle I wanted. I wanted to participate in society, so I got myself a job... Work is the focus for me, that keeps routine, it gives me something to do, it makes me feel part of society and also gives me freedom in terms of money.”

It was also clear that for some women regaining a sense of self-worth and identity involved a physical transformation as well. The trauma, the distress and its treatment (including medication and being institutionalised) had a bodily effect, and exercise, controlling weight, wearing good clothes and feeling attractive were all integral parts of recovering.

“You know, I have just gone back as much as I can to do the things that I enjoyed doing in my old life. I am Miss Pampered, I kid you not. I have my hair cut every six weeks, coloured every five weeks, when the local college is open I have a weekly massage, a facial every fortnight, a pedicure every month and all this is part of me, an important part of me.”

All of this ultimately meant an effort to reclaim control over one’s life, despite the continued restrictions to the extent of control some people felt in terms of having to depend on medication, social support and other means. Recovery, in the end, was firmly rooted in the sense of control one had in living one’s life and determining its course.
“My recovery was based on saying to myself this is not all the story, I have to take control and manage all aspects of my life, no one else could do it, but also knowing when it was time to get help and how to get it.”

Spirituality and faith

As we saw earlier, for some people, mental distress was a spiritual experience or a crisis of faith. They understood healing and recovery also in that frame. And for some others, although they did not define their distress experience in a spiritual mode, spirituality and faith were key factors in keeping them well.

For some, a personal spiritual foundation was part of their identity and one that they practiced according to their own definitions. Accessing religion-based spaces can be difficult for some people; indeed one person spoke of avoiding religious spaces because of fear of homophobia and another person spoke of an incident of being rejected by a church because she was a divorcee. Nurturing a personal spiritual foundation and finding ways to practice it was important for them, given such scenarios.

“I would describe myself as a strong person who derives strength from my spirituality which is very important to me and which is where I get my identity from and not from what people may see when they look at me or what they say about me or what they think about me. And I think it is very important to have that self-identity.”

“I practice what I call my own religion really, what I have decided is right for me... At 15 I turned to my father when I was in great turmoil having just arrived [in the UK as a migrant child] and asked him, what is God? My father said to me all that you see around you and nature. And that was the most powerful answer... That really has seen me through, you know.”

Others found grounding in cultivating spirituality as a way of being and finding spirituality in nature and the environment. For some people, however, a religion-based faith was the most important thing, finding meaning in “the word of God”, communities, rituals and prayer.

A sense of community and participation

“Having a network of people around has really made a big difference. The cultural network, I have got the church there, I have got the key worker right there, I have the care coordinator there, my sister is there to phone me, so not being isolated, not allowing yourself to be isolated and people not allowing you to be isolated as well...”

The above excerpt shows the importance of a range of community and support systems that aid recovery and keeping well. The participants spoke of a number of different things they did to ensure that they had a sense of place within their immediate community, a sense of purpose and participation. For some people, “giving back to the community” through voluntary or paid work, campaigning, user involvement and raising awareness, especially in the fields of mental health and race equality, was a key part of maintaining a sense of community.

“My interests are more based around mental health issues and raising awareness and my main aim is to try and get more attention from mental health professionals and pharmaceutical companies to design drugs with less side effects. This is my main aim.”
Summary

– Many people attribute their distress to traumatic experiences in personal life and within families, including violence and abuse, bereavement, loss and other traumas, and tensions in fulfilling responsibilities. Some make sense of distress in terms of a personal spiritual crisis or crisis of faith.

– Key barriers to recovery were negative attitudes about mental distress within families and communities, and mental health services’ inability to adequately address personal and familial causes and contexts of distress as part of the recovery approach.

– Elements of recovery in personal/familial contexts include:
  – Finding closure to abusive situations and experiences and getting the support to come to terms with its effects.
  – Regaining a sense of control over one’s life.
  – Learning to accept oneself and one’s experience of distress; having others accept these as well.
  – Being able to talk openly and honestly about issues with families and significant others.
  – Gaining a sense of self-worth through work, community networks and participation.
  – Nurturing a personal spiritual grounding and/or faith.
  – Finding support in addressing these issues, both through empathetic professionals and a safe space to recover.
Many lives, many ways of healing

“... part of the therapy or part of the kind of journey was going back to work and that made me feel better. It made me think, oh I am worth something. I can do something.”

“Keeping in touch with reality. By going to day centres. I go to a place called X... There are people that care. They do not get on your case... They answer questions, if you want to plan a day trip you can do that, it makes you feel a part of it.”

“There are successes all the time in my life now... If I can have that attitude then I know I am getting somewhere... Also as a matter of enjoying life as well... And it is not about life actually, it is just having a different perspective on it.”

“Praying, it was really good because I felt less guilty, I felt empowered, I felt I had a relationship with God and once you have a relationship with God... you have no worries in the world – you feel safe...”

“One of the most precious things [in my house] is my garden... I think two years ago when I had quite a major relapse, one of the things that helped me was seeing the butternut squashes growing... in a way that was a metaphor for my recovery.”

“...learning for myself. First of all what is it, what is happening to me and even more importantly, learning how to heal myself and how to help others help me heal. I think that is the main thing.”

“...responsibilities. If I don’t do this who is going to look after my son? It is love and pressure, it is happiness and sadness, it is all mixed.”

“Things like my relationship with my niece... the children in my family have been crucial. Things like the friends I have made... Nowadays mostly my friends are people I have met through mental health service stuff... So those relationships have been really important.”

“Sometimes you get side effects on the medication which can be a lot of fidgeting or anxiety. [Massages] help me calm down, they help my system... and I find it can give me mental strength to control my thinking, my moods.”

“... being out in nature... just absorbing, particularly the colour green, but absorbing all sort of natural phenomena and that’s still something that recharges my batteries.”

“... meditation, yoga, those kind of practices... I’m trying to constantly be mindful of my sensory experiences, how I feel emotionally... why I’m reacting to something the way I am.”

“I scribble a bit that’s quite useful. Get things out of your head and just put them down on paper. That helps me.”

“The only thing that has been constant is my creativity, that’s kind of my lifeboat really... Creativity gives you control in a life where there isn’t really any and it’s a form of expression, it’s a form of catharsis...”

“... I regularly work out, my eating habits have changed. I don’t comfort eat anymore... that’s the main focus for me and that’s what’s keeping me alive I think. It’s keeping me looking well and loved.”

“... figuring out what actually helps me – having enough sleep, for example, even with the help of sleeping pills, trying to be calm and sitting still. [My] interest in making quilts comes from the idea of learning to do something that is calming.”

“I go to the temple as frequently as I want and I read the Gita and I find that really kind of helps me touch my inner self and gives me some stability...”
Bio-medical contexts of mental distress

Continuing from the question ‘what would you say you were recovering from’, we asked the participants of this study to tell us what they thought of the diagnoses given to them and how that fitted with how they made sense of their distress. Six of the 27 participants did not have a formal diagnosis; although two of them had been hospitalised; five had positive views about their diagnoses; three were ambivalent but ready to go along with the medical explanation that they had been given; and eight had clear views against diagnosis and the bio-medical model.

Finding meaning in bio-medical explanations

Asked what she was recovering from, one participant who had a diagnosis of schizophrenia described her “psychotic episode” in terms of symptoms – she was experiencing delusions and, at the time, she thought she was being attacked by spirits. Being given a diagnosis, she said, helped her to understand her experience and how to deal with it.

“... I knew there was something not quite right about me, so when I got the diagnosis it was, it kind of explained things for me... Once you know something it gives you peace of mind. First you might be nervous and slightly worried about the diagnosis, or the problem or situation it is, but once you get used to it, it becomes part of life.”

Even as she accepts the diagnosis and the medical explanation that comes with it, she also sees her experience as “a blessing,” “a gift from God.” This participant regularly attended service user groups and self-help groups and seemed comfortable with taking on a service user identity. She feels that being in touch with mental health services and having a diagnosis has helped her find new and interesting things to do.

“... it’s like there’s other things that ever since I’ve had the diagnosis I’ve explored and I’ve done so it’s not there... to hold me back, it’s there for me achieve... Having the diagnosis is not so much of a problem because it’s opened up a lot of doors for me...”

It might be that some people found it useful to understand their mental distress in bio-medical terms because it allows them to become part of a community – a community of people who have similar problems. Placing their distress experience within the bio-medical framework helped them escape the sense of isolation they felt.

“I don’t feel so bad now because I am aware that 1 in 4 people suffer from mental health problems... I know there are other people like me so I don’t feel so bad. I am with similar minded people quite a lot of the time...”

For some people, a medical understanding helped them externalise the sense of responsibility or blame that they felt within themselves. In one case, for example, the participant subscribed to a cultural belief that the problems you face in this life are the result of bad deeds in a previous one14.

14. An element of blame can be found in some culturally specific ways of interpreting madness and mental health problems. For example, the idea that mental distress is the result of ‘karma’ (the cause-effect cycle of life actions) or the work of the Devil places a significant level of responsibility on the individual and her morality and faith (Bakshi et al. 1999, Wynaden 2005).
“…What did I do wrong? Was I a rapist in my last life? Seriously, that’s how I felt.”

She currently made sense of her mental distress as arising from a long standing and debilitating physical condition. This bio-medical explanation, despite the absence of a clear psychiatric diagnosis, helped her come to terms with her experience and move towards recovery. A similar sentiment was expressed by another participant who was “very severe” with herself for experiencing mental distress.

“Well diagnosis is in some ways a little bit helpful because until I was given a diagnosis … I was blaming myself so much, that it was completely me, so that’s one thing that it did help. They put a label on it and I began to understand it. Once I had a name, I’m the sort of person who needs to look at it, understand it, digest it and then live with it or put it away... That really sort of, for me it was helpful.”

Putting up with bio-medical explanations

Some participants were ambivalent about a bio-medical explanation of their mental distress, but accepted the professional’s expertise. For example, one participant felt that she had no choice but to go along with the professionals’ views on her mental distress, even though it did not resonate with her own views.

“It is the word professionals have given me. … It’s not how I feel. It’s just to do the necessary things to get me out of that kind of chaos. I have no choice, I haven’t got any choice. I really don’t know what I was doing then... I’m happy to go with what the professional has to say. There must be a reason why they say because they are not daft; otherwise they could have just done something.”

For another participant, a medical name for her condition was a necessary step towards receiving medication which she feels keeps her stable. She was not interested in discussing her diagnosis beyond that specific use of such an explanation.

“I guess to me it’s medical terminology for the symptoms I had, that’s just what it is to me. It also becomes a label as well. So I don’t like answering the question if someone asks me what’s your diagnosis. Basically, if I stop my medication then I start hearing voices... I mean whether [the psychiatrist] gives me a diagnosis or not it’s not going to change how I’m feeling, what’s happening to me.”

In both of the cases above, the participants experienced voices and visions and found this part of their distress the most difficult to deal with. In their view, a diagnosis is a route to a practical solution in the form of medication which controls the symptoms. Medication was the main intervention offered in their cases, although one participant had a brief period of psychotherapy which she felt “didn’t seem to be helping me in any way...”

Rejecting bio-medical explanations

One participant who had accessed mental health services for over 15 years talked about how she felt “hopeful” when she was given her first diagnosis. But, over the years, she was given several diagnoses and several types of medication, none of which she felt helped her get better.

“I think the first time I went to the psychiatrist... when they explained to me that there is a chemical imbalance in my brain which was causing my visions... that was a huge relief... All I have to do now is take this medication which will correct the imbalance and I will be fine. It did not quite work out like that... After every episode you go to a different psychiatrist and they give you a different diagnosis – I’ve been given... six of them, I cannot even remember all of them and with each, medication also changes.”
She felt that this was because the biomedical explanation and interventions had not taken on board, or helped her work out, the social and familial causes of her distress. This was one of the key reasons cited by those who had very negative views about biomedical explanations.

“Well, every time I see my psychiatrist she assesses me on biological symptoms of depression you know? Ok, she might say, are you hearing any voices, are you doing this or whatever but it’s all about medication and it’s all about symptoms. It’s very tunnel visioned, it’s not about how I function day to day, it’s not about how I cope with feelings that come up day to day, how I function in my life. It’s not about that at all, it’s simply about symptoms and medication.”

Some other participants rejected bio-medical explanations of mental distress because they saw distress as valid responses to life’s trying situations. Bio-medical models, they felt, pathologised these responses instead of helping them to cope with them in a productive way.

“I believe a lot of what is labelled mental illness is just human experience being pathologised. So diagnosis is really meaningless to me.”

“I thought it was shocking at first that somebody would say to me you are actually depressed and you have got episodes of psychosis going on. I did not actually understand what all that meant... I call it life experiences and that I was not able to understand them and I was not able to embrace them and I was not able to kind of let go of them...”

There were fears attached to specific diagnoses like schizophrenia and personality disorder. Being given these diagnoses had proved detrimental to their process of recovery, due to the fear of real and anticipated stigma and discrimination attached to it.

“...if you have a diagnosis of schizophrenia, well, you can say goodbye to having a job and you could say goodbye to meeting with hope as well... Once you tell that's what you have, the fear in people is quite strong... I know and I have gone through it myself – the fear of that label is more painful than what is going on in our heads really.”

Two participants who spoke of being given a personality disorder diagnosis described it as “harmful and dangerous,” and a barrier to their journeys to recovery.

“[Being given this diagnosis] has really, really thrown me much more than I can say, because it puts the responsibility totally on me, everything is to do with my personality. So ever since then it's been a real struggle to allow myself to be me sometimes...”

For some people, the mere association with mental health services and being seen as ‘a mentally ill person’ meant stigma and isolation within their communities and families.

“... I was getting judged as well. I never attended any family functions... if I went I'd be seen as this ‘ill’ girl, so I would try to avoid people because my Dad said that if you expose yourself, expose that you are not well, they could be, oh you are a mentally ill girl... It really affected me, I was hard on myself, I wasn't out there, I had to hide myself...”

It is also interesting to see that some participants defined their experiences as different from those of ‘mentally ill’ people. They saw their distress as transient moments of crises, while ‘mentally ill’ people were seen as needing long term care within a biomedical framework.
Placing recovery in bio-medical contexts

Resonance between medical and personal meanings of distress

The main issue here was whether the medical explanation of distress and the diagnosis resonated with a person’s own meaning of their distress. For some, a medical explanation was a start to the meaning making process, and for others it was a practical way of getting help from mental health services. The key issue here is whether the therapeutic alliance beyond the diagnosis and explanations took the person’s views on the causes and contexts of her distress into consideration.

Views on medication

Eight participants were not on any psychiatric medication at the time of the interviews. 11 were on medication and others still took medication as and when necessary.

Positive views

For some participants, medication had a central role in their recovery. They felt that it gave them stability and structure to their thoughts, which they saw as key aspects of remaining well. Participants whose understandings of their mental distress were in congruence with medical explanations had more positive views of medication than those whose personal meanings differed from them.

“Medication has been a great help... If it wasn't for medication I don't know where I would be right now. I still hear voices but they are not taking over. Everything is stable.”

“I am on medication and the medication helps me a bit. I done seen things before ... that's why I ended up in hospital... [Medication] helps me to remember things and relax me a bit.”

Another participant who has been on anti-psychotic medication for over ten years counts medication as one of the main things that helps to keep her well. She went as far as to say that she would like to work within the sector to help other women understand the benefits of medication and the importance of sticking with them, “good or bad.” Here again, a complete faith in the abilities and knowledge of the professionals was evident.

“I would like to help to make [other women] know that medication is important, good or bad, just take it because the doctor gives you medication, there must be a reason why he or she prescribe it and in the long run it helps you get better and be yourself again... What I mean by good or bad is that because there are some that... make you drowsy, sleepy or whatever. That's why I said good or bad.”

Negative views

Some participants felt strongly about actively avoiding medication and finding other ways to help them keep well. One participant felt that how she functioned on medication over a period of time was very different from her self-image, and that is what made her want to find other ways of coping. She described an incident where she could not come to the help of a friend in need as the turning point.

“The medication did horrendous things. I've always thought of myself as a person who reads and writes a lot and engages in political activism. The medication turned me into a zombie. I couldn't do any of those things, and that was not me. So it took me a few years to realise that if this was getting better means, this is not me... And if that is all medication can do, then I don't want to get better.”

She then found other ways of coping, including working out ways to help her partner support her through periods where she has voices and visions, creating a safe space at home and pro-actively avoiding services.
Others felt that medication worked as a barrier in working out the core issues that caused distress.

“If you take a pill to numb your pain and you don’t know where it comes from, it does not really resolve the problem because it will manifest itself into something else…”

“I did not believe that [medication] could support me. I was feeling tired. It was actually causing me a lot more anxiety... so I did not believe in those forms. But I would take it in desperation and just feel worse... I never really had the belief that they would work deep down...”

In these cases, the narrators talked about finding other ways to cope using such methods as alternative healing, co-counselling, and building a personal spiritual grounding, while working out ways to deal with the socio-cultural and familial origins of their distress.

**Stability through medication vs. ‘real’ recovery**

As shown in the section above, there are some clear positive and negative outlooks on medication. A further factor that emerged from the narratives of those participants who were on medication and had some positive views was that many of them made a clear distinction between the sense of stability that medication allowed and recovery as a much broader, holistic ideal.

**Medication as ‘unavoidable’**

The following narrator has been on medication for bipolar disorder and said that it helped her maintain stability. However, she felt trapped within it.

“I have a feeling that if I don’t take my medication I am going to go back. So I feel there is no recovery. So now I feel trapped with my medication. It is not really recovery because you know you will fall ill if you don’t take medication.”

This narrator feels that professionals and pharmaceutical companies have an obligation to ensure that medication is a short term solution and that long term solutions should focus on accommodating other issues like family life, work and “whatever else that person needs.”

One participant called medication “an electrical cow prod,” herding her into a place that she does not really want to be in, but feels that she has no option but to take it. Help to come off medication, she feels, is not easily available within the system.

**Medication as necessary for stability**

Some participants saw medication as a necessary step to remain stable enough to work on their recovery, carving out their own paths to recovery, as evident in the following narrative:

“...the doctors think that I will be on medication for the rest of my life but I don’t necessarily see it that way. But I don’t see medication as something that says I am unwell; it is something that keeps me stable or keeps me at a place where I can function.”

Another participant who had a long history of contact with mental health services explained:

“I am not against medication because I have worked out now what medication helps me... And if it helps me to stay well enough to do things that I enjoy doing, so I take mine and if it helps me to keep in a position where I can do things that I actually love... then that is a small price for me to pay really.”

In these and other narratives, ‘real’ recovery enablers were a range of things, including non-medical healing and therapies (for example, yoga and massages), exercise, social involvement including volunteering, employment, and being able to find resilience within themselves. Medication gave some stability to explore these.
“Well, there was a time when I stopped taking medication and I had a mini psychotic episode, so this sticks out in my mind that I need a bit of medication to survive... I look at the positive benefits and do other things to manage the negative – like exercise, activities, etc.”

‘Recovering’ the body
Medication had a significant effect on some people’s body image and identity as women. Two narrators talked about its effect on their menstrual cycle, which they experienced as making them ‘not normal’ as women. They felt that sufficient attention was not being paid to the specific effects that some medications have on women and how it affects their sense of identity and self-image which are crucial in moving towards recovery.

“...when I take my medication my periods stop. This is something that really bothers me. My psychiatrist is a man and sometimes I wonder if he really understands how much it bothers me. He did tell me once ‘I don’t understand, most women come and tell me that this is a good thing that their periods have stopped.’

Though I can’t understand what kind of woman would think it’s a good thing. From my point of view it is not normal... Never had a choice of psychiatrist so I guess I haven’t really asked to change from him but I did meet the female psychiatrist once and I didn’t find her very sympathetic either.”

This explanation that a female psychiatrist should understand what it means for women in their 30s and 40s to have a normal menstrual cycle is reflected in the following narrative:

“...my psychiatrist is male and when my periods stopped I don’t think he understood what I was going through... It just doesn’t feel right for a woman not to have a period. I think that if I had a female psychiatrist may be she would understand me better but I don’t know whether she would have treated me different, I don’t know.”

Both these women feel that unless their bodies became ‘normal’, they will not be fully recovered.

Side effects of medication had a big part to play in its negative effect on recovery. Apart from its physical health implications, side effects impacted the development of a positive self and body image, crucial in most people’s definitions of recovery. Tremors and shakes, weight gain, and hair loss all made women feel less attractive and trapped in a negative body image. For the following participant, medication has a key role in keeping her stable and her symptoms under control. However, she feels it is a barrier to recovery because it has a direct impact on her self-image.

“I think [medication] affects me more than I realise because my clothes don’t fit and I can’t really afford to buy new clothes because I don’t have a job. So it affects the way I feel... I think it makes me less attractive... and maybe that affects my trying to find a partner. So I feel that in some ways my medication is a barrier to recovery.”
Summary

– Some people understood their distress within a bio-medical framework, taking on board diagnostic categories and medical symptoms and interventions aimed at controlling these symptoms. This does not exclude other ways of making meaning of the experience of distress.

– Views and definitions of recovery in this context included symptom control, accepting the knowledge and views of mental health professionals, and taking on, at least partially, an identity of a patient.

– A clear distinction emerged between the ‘stability’ brought about medication and the idea of ‘real’ recovery; medication and its side effects were seen by many as barriers to ‘real’ recovery.

– Elements of recovery in bio-medical contexts include:
  – Resonance between the medical and personal meanings of distress.
  – Being able to develop a ‘therapeutic alliance’ with mental health professionals.
  – Accepting medication’s role in maintaining stability.
  – Ability to have a positive self-image despite side effects of medication and stigma about mental health conditions.
  – Having other support systems and enablers of recovery like complementary therapies, exercise, work and social participation, and so forth.
“That you survived the crisis and you are making your way back to normality. That is my recovery.”

“I think it is a back and forth, back and forth thing. Nobody ever recovers from anything. Something that you have experienced stays with you.”

“I left home with just the clothes I was wearing and no money and seven months pregnant. And from there to where I am now – working, I have a car, I’m earning money, I don’t take benefits... People say, oh you have done well, but what’s the criteria? Who’s grading? Who’s the judge to say I have done well?”

“Being well, being able to do the simple things of everyday life...”

“...recognising the distress that you are going through, or have gone through and finding solutions to combat that.”

“Recovery from what? Is it an end to a means, is it something that you guys are wanting me to do rather than me telling you my story about what my journey is?”

“wellness is all about shutting the noise out, getting a quiet space to actually reflect”

“That word recovery means that I identify what is making me to go back to hospital and I put my mind in the sense that I don’t go back...”

“I’m definitely 100% 1 million% more in control of my life and of what I do and where I am at and who I am than I have ever been before. May be that is recovery. But within that, I still have to have the freedom to know that I can dip and I can lose it. ... I suppose that’s what pure recovery is meant to be, isn’t it?”

“...it is a continuous process for me. ... I think like anything in life we are constantly re-appraising and we are constantly doing certain things in a certain way to be in a certain place. So to me that is recovery; it is continuous.”

“Recovery... is all about self-image and how successful you feel you are in living up to your own self-image.”

“Recovery means getting into my own stride, feeling well... Also just accepting myself and not having too much pressure on myself.”

“Recovery means living the life I want and having the support in place for me to do that, having the information available so that everyone knows what choices they can make.”

“Recovery is the state you are at, at any particular time. Whether or not you are in hospital, you are in a state of recovery, as long as you are alive and you survive a crisis, you are in a state of recovery.”

“Recovery means great to me, it means there is hope for me in life... It is the hope.”
So far, we have seen that people’s understanding of recovery is very much dependent on the way they make sense of their mental/emotional distress and the meanings they give to their experiences. In the course of the interviews, different terms were used both by participants and by researchers to talk about the journey from points of distress that derailed lives and destroyed selves to points where lives were reclaimed and selves reconstituted. ‘Resilience’ and resources that aided resilience were invoked several times in these narratives.

Many recent publications, including the new mental health strategy, No Health without Mental Health (Department of Health 2011), a position paper on recovery from consultant psychiatrists (South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust 2010), and the background papers to the National Mental Health Development Unit’s (NMHDU) ‘supporting recovery project’ use the following definition of recovery:

“A deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life” (Anthony 1993).

While many service users will recognise in this definition important elements in their own recovery, the discussion so far in this report shows that there are two limitations to this definition: one, the process of change is characterised primarily as an internal personal process, and two, the meaning given to distress is one of ‘illness’. As we have discussed in the introduction, service user/survivor positions and readings of recovery from a race equality perspective have argued that definitions of recovery need to go beyond both these essentially limiting perspectives, and look at external factors that impact on people’s personal selves and identities.

An important development in mental health services in the last three decades is the formulation and use of recovery ‘models’ and ‘approaches’. There are several ‘universal’, almost self-evident, elements of what helps people (including the participants of this research) ‘get better’ and remain well in all these models and approaches. However, reservations have been expressed by professionals, service users and carers about the efficacy of using models and outcome measures to work with what is, essentially, a subjectively defined concept (Davidson et. al. 2006, Trivedi 2010). The evidence on how these various models and approaches are helping people from minority ethnic communities achieve their visions of recovery is, at best, limited, although existing evaluations have highlighted the need for adapting these approaches to meet cultural/linguistic expressions and social experiences of distress and recovery in these communities.


16. For evaluations of recovery models with BME communities, see the report of a project piloting the Recovery Star with BME service users (Imonioro 2010), and the evaluation of Wellness Recovery Action Plan with six South Asian women in Scotland (Gordon and Cassidy 2009) and Northamptonshire (Northamptonshire BME Community Wellbeing Engagement Project 2007).
In this chapter, we focus on how the participants understood recovery as it is used within services and recovery approaches, and explore whether they felt these definitions and descriptions resonated with their own definitions. We explore whether they found the terms meaningful in describing their own experiences, and the alternative ways in which people described their journeys. Given the centrality of ‘recovery approaches’ and ‘models of recovery’ in current mental health services and practice, we also wanted to find out whether the participants had come across these formal ways of working with recovery and, if they did, whether they had found them useful.

**Views about ‘recovery’ and ‘recovery approaches’**

All participants had clear pre-defined ideas about recovery and what it meant within mental health services. 12 of the 27 participants very clearly did not like to use the term ‘recovery’ as they felt that it had specific connotations within mental health services which did not fit in with their understandings. Nine people did not have a problem with using it, and felt that the term and its connotations resonated well with their own definitions and meanings. Others were more ambivalent about what the term generally meant and how it described their own journeys.

**Critiques of the term recovery**

Some people wanted to distance themselves from the usage of the term recovery because they saw it as professional-led, pressurising, and ultimately meaningless. This feeling was stronger among participants who were involved in user/survivor groups and campaigns and had a degree of familiarity with questioning how mental health services functioned.

“I was very big on the term until I have seen it just hijacked by mental health services into something it shouldn't be really. Because it has been hijacked by psychiatry as another form of social control it's meaningless to me. I understand that if you look at recovery not as a model or a movement... but because it's just been bastardised I think by the system that I don't like to use it now.”

One participant talked about not being convinced any more about the agreed wisdom that recovery approaches have their origins in the user/survivor movement. She feels that the term has its origins in clinical medicine and that its re-articulation in the user/survivor movement had lost its punch now that it has gone back into the hands of professionals. She felt that current recovery approaches had “an underlying assumption that it's to do with clinical recovery” and did not resonate with the way in which she conceptualised her own recovery.

Participants, especially those not involved in the user/survivor movement and not subscribing to a user/survivor identity, felt that the main issue for them was that the idea of recovery posited an ‘illness’ as a pre-given. One participant, for example, defines her distress in terms of “an emotional response to life events” and not as ‘mental’ distress or ‘illness’:

“It’s not a term I like or has any real resonance with me. For me, it’s much more about how services manage their clients and how a client would experience getting ‘well’. It has implications for me of being ill rather than experiencing a normal response to a life event.”

In the previous chapter we examined the emphasis that some people put on the difference between recovery as symptom control through medication and ‘real’ recovery. Their definition of recovery was based on a total lack of symptoms, the need for medication and its side effects – a ‘cure’ even – and as long as medication continued to be part of their life, they did not see themselves as fully recovered.
“I mean at the moment I guess my psychiatrist, maybe some mental health professionals, would say that I’ve recovered but then in some ways I feel that I’m not. For example, my weight – it’s too much. And I don’t have a job although from their point of view that’s not because I’m ill... I just feel, from my point of view I think that’s not being recovered. Also my periods have stopped, I don’t think that’s what you call recovery.”

Another participant, who had grown up witnessing violence and then experienced years of domestic violence as an adult, said that recovery made sense to her in terms of her own growth after being broken by her experiences, regaining her sense of self and worth.

“I went through five years of physical violence, mind games... In that sense, recovery means a lot to me, recovering from abuse like that and then learning to live again, learning to get your self-confidence back, learning to really trust someone else’s love again. But most importantly of all, learning to deal with the conflict inside me about who I was – the feminist, student activist, academic achiever type of person or the weeping, depressed, doormat who got beaten on a daily basis. Recovery, in that sense, is all about self-image and how successful you feel you are in living up to your own self-image.”

However, she said that the way the concept is currently used within mental health services did not resonate with her because it started from a point where the distress (in her case, arising from continued violence) was pathologised and medicalised. The focus was on controlling the symptoms (for example, self-harm) and not enough on equipping people to deal with the causes and effects of distress and making sure they had the necessary resources to do so.

### Recovery approaches and models

The interviewees were asked whether they had come across any recovery models while accessing services. 15 participants had not heard of recovery models or their usage in mental health services or other services they accessed. Only three participants had done work with a recovery model. Of these, one person was not sure what the model was called, but said that she found it useful.

“Made me realise I’m not doing too bad. Made me realise where I was. Helped others realise what to do for me.”

The other two participants had used the Recovery Star model\(^{17}\). One person found it useful and was enthusiastic about its use in mental health services:

“It is very good. It really does help you see where you need to work on and how you are developing and it gives a sense of accomplishment when you see that, oh, I have actually gone past this stage. It is really good.”

The other person did not find it useful because some of the concepts and the overall framework were too complicated:

“...it was too much for what it was. There is too much to think about. To try and remember to hold yourself together, too much.”

Nine others were familiar with recovery models, having attended presentations about models and through their work in the mental health field as researchers, trainers and user involvement workers. The models mentioned included the Recovery Star, Wellness Recovery Action Plan (WRAP), and THRIVE\(^ {18}\). Some of them agreed with the feeling above that a recovery model might be a useful roadmap and give some definitions and goals to people’s recovery journeys. But largely, people were not convinced that recovery models will be useful in supporting a person through her journey in a way that suits her own definitions of wellness and needs.

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17. The Recovery Star is a model and approach to recovery developed by the Mental Health Providers Forum. See [http://www.mhpforum.org.uk/recoveryStar.asp](http://www.mhpforum.org.uk/recoveryStar.asp)

Part of the reservation was that recovery models did not start from a point where a person was supported in addressing some of the socio-cultural and personal/familial contexts of distress, as discussed in the previous chapters. It started after the distress was medicalised as an ‘illness’ with psychiatric diagnoses and treatment. One participant, whose journey to wellness was based on finding closure to her experiences of abuse, through a long process of putting information together and allowing herself to forgive her abusers, felt that recovery models did not help confront the core issues that cause distress.

“[A good recovery model] should help someone to understand and come to terms with certain parts of their life… Without understanding the core issues, you are nowhere. It is not about following the steps… I think products like that do not really work because they do not enable the person to take control of their situation. The only way I was able to heal was to take control of the situation…”

This is a sentiment that was echoed in other responses too. But for some people, there was a more conceptual incongruence between the idea of recovery and the way mental health services worked. As long as coercion is a part of mental health care, whether through the Mental Health Act or through an individual’s lack of control over medication and care plans, and as long as other social care support systems are not in place, ‘recovery’ as something that is driven by a person’s specific needs and understanding of their distress would not work well within services.

“I don’t believe that you can do recovery on the one hand and then have mental health services so coercive on the other. Now with all the pressure on people to get back to work and having their benefits withdrawn – if you look at the global picture it doesn’t make sense… If people have got the basics in place like finances and social situation and haven’t got too much trauma, then I think people can move up a recovery [ladder]. All the big names in the recovery industry seem to have that security but there’s loads of people that don’t know where they are even going to be from one day to the next and they are doing recovery in their own way probably.”

Some others felt that standardising recovery through models, setting up outcome measures and quantifying people’s journeys worked against the fundamental principle of recovery or the process of a person’s progress in their life.

“I find them patronising, very rigid and actually what helped me recover was finding my own way. Having someone there as a support but they’re really there in the background to sort of sit next to me while I make my own discoveries rather than sort of to be in front leading me.”

“Someone else is telling me how I should recover but only I know how I can recover… When people tell you to do this, do that, do some of the modules on [a model], some of it is good, but some of it, they are talking about overall people, they are not talking about me.”

One participant felt that, regardless of her own personal views on recovery, the growing focus on recovery within mental health services was a positive thing.

“…the positive thing about having something called recovery is that there is now the chance that people with mental health problems are not written off. There is something that says you can recover from this whereas before… you were labelled for life and that was who you were for life. Recovery kind of says that you can make changes.”

Overall, however, the sense was that recovery models and standardised outcome measures were against the concept of recovery itself and that the way in which they are used in services today continues to put professionals in charge, despite the rhetoric of person-centredness.
Views about the term ‘resilience’

Unlike recovery, the participants in this study had no clear pre-defined ideas of resilience as a concept used within mental health and social care services, although they did have their own personal ideas about it. The references that people drew on were from everyday life and, by and large, cultural and/or political. People spoke of watching the resilience of parents as they adjusted to lives as migrants in a new country and brought up children within a context of racism and discrimination, of female relatives who survived domestic violence or other abusive relationships, and of their own children growing up and dealing with their mothers’ distress. They also spoke of collective resilience in terms of their communities, surviving colonisation, slavery and the continuing legacy of oppression and the resilience of black women.

Resilience as an enabling concept

The term resilience had a positive connotation for many people as they saw themselves as having demonstrated resilience. These positive connotations were based on the acknowledgement of an inner strength and sense of purpose that they have drawn from in their long journeys towards where they are today.

“I don’t know if you are aware of the song ‘I get knocked down but I get up again.’ Well, every time I do get knocked down I sing that to myself and I get up again. I’m not sure why I keep getting up, it’s just feeling the word strength being tattooed on my soul really.”

“It reflects for me the experience I had from being a very small child... trying to understand what was happening to me, feeling constantly knocked down, going through periods of finding my confidence and then seeing it knocked away again. Um, going down lots of wrong roads and making mistakes but always coming back again having this very strong inner sense of purpose... I feel I have been resilient and for me, it’s a really useful term.”

Others looked on it as an active process of building up resistance to the adverse effects of life’s traumas – a little like strengthening the body through exercise and good diet in order to avoid being ill or having a vaccine against infections. Resilience, for them, was learning how to do practical things that would keep them well.

“Resilience means trying to build up, a bit like having antibodies I suppose. And you have to sort of do exercises, mental health exercises... like not isolating yourself... not allowing yourself to become overtired, getting the right amount of sleep... You build up resilience by ensuring these things, keying in factors that mean that you have time for yourself. I know it sounds lame, but how many people actually do these things on a regular basis?”

For one participant, who believes that she has dealt with the trauma from her past, resilience now is a matter of having enough self-awareness to identify what life’s pressure points are and actively setting out to minimise them. “Being watchful,” as this participant puts it:

“...now I have to be aware, I have to be watchful, what I eat, who I let into my life, what things I relate to and what people, so I don’t let in those things that make my pattern of anxiety become strong. So maybe too stressful jobs or having many sleepless nights ... Living with people who are completely insecure, they don’t make an anxious person healthy. That’s me being resilient, that’s me being watchful...”
Resilience as a disabling concept

In a previous chapter, we saw that there was an association between black women and ‘strength’ – a ‘strong black woman’ stereotype – that disadvantaged women and their emotional health. Some of the participants felt that the idea of resilience and its association with black women and their communities was partly responsible for this stereotype and that it worked against women’s emotional and mental development. Some participants felt that not being able to demonstrate resilience in their life – by being distressed, needing help and support – increased their sense of self-doubt and failure.

“I understand it as like somebody who keeps going and keeps going and it is a bit of a strength, a fighting spirit and a bit of stoicism and I don’t really... I think that is actually what helped me feel worse, that interpretation made me actually believe that I had to have the strength and I was weak if I did not have the strength and that message was, it was too damaging, you know, because I wanted to feel weak....”

The expectation of resilience is the issue here, that it allowed no space to feel vulnerable and not feel guilty about being vulnerable.

“...people say to you all the time, oh you are strong and you think – I don’t want to be strong! I want to let you know that I’m actually vulnerable and sensitive... [The expectation of resilience] does not allow for space for somebody – for me – to feel crap on a day when you cannot get up, and be un-resilient.”

‘Bouncing back’, ‘staying power’, ‘true grit’, ‘doing battle’, ‘perseverance’ – these were other words and expressions used to define what resilience meant to people. In all of this, people saw resilience as something positive they had within them, and that being able to draw on it helped them get through adversity. But there was an undercurrent of having no choice, having to keep going – ‘endurance’ – as well.

“Well, against all odds I’m here. It is what I have to do, it is the work I have to put in to keep going. It is a full time job.”

One participant said that she had to demonstrate resilience in her life on a daily basis; she had no choice. However, she felt strongly that using the word to talk about how women coped would increase the expectation of resilience which, added to the expectations on women to perform their roles against all odds, would be further unhelpful to women.

“I don't think we should be using that because it seems like you are telling me, be like concrete and bricks, keep your trust and head high and let everything hit you and don't complain, don't say it's pain, you are resilient, aren't you?”

What this participant highlights is the dangers in seeing resilience as a personality trait that all humans are expected to have. All the excerpts above touch on the idea that the desire and ability to overcome adversities and bounce back is something that everyone has inside them. However, the capacity to draw upon it or turn it into a resilient way of life requires support systems outside of oneself. As we have seen in the first part of this report, people draw on collectives, communities, families and care services for support and emotional sustenance that helps them be resilient.
Summary

– Views about how recovery has been defined and practised within mental health services varied, with many people finding that the definitions did not resonate with their own understandings.

– Some people had an overall awareness of recovery models, but only three had actually worked with them. The overall view was that, while some models were useful in providing a road map for people to work out their recovery paths, they did not help in confronting the core issues that cause distress.

– Critiques of recovery approaches included:
  – That they were professional-led and pressurising.
  – That they took a limited view of mental distress as ‘illness’.
  – That they did not help people in addressing the causes and contexts of distress.
  – That they would not work within mental health services as long as coercion remained within services and treatment was mainly medically oriented.

– The concept of ‘resilience’ was seen both as enabling and disabling. Positive aspects included the acknowledgement of inner strength and a sense of purpose that many people recognised in their own journeys. Negative aspects included the expectance of ‘endurance’ and a perceived lack of space, and respect, for vulnerability.
Part 3
Conclusions
Placing the report in current policy and political context

This report is being written at a time when significant policy and political changes are occurring across society. The publication of three key white papers – Liberating the NHS (DH 2011b), A vision for adult social care (DH 2011c) and Healthy lives, healthy people (DH 2011d) – and the mental health strategy, No health without mental health (DH 2011a) together spell out a very different context for mental health service delivery. A widely acknowledged positive aspect of the current policies is that mental health is to be treated as an integral part of the overall health and wellbeing of communities.

The “Call to Action” document, accompanying the strategy and signed by a range of mental health charities, professional bodies and ministers (DH 2011e), includes a commitment to ensure that “more people with mental health problems will recover”:

“More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live.”

The ‘supporting recovery project’, a collaboration between the National Mental Health Development Unit, the NHS Confederation and the Centre for Mental Health, sets out to support organisational development in recovery. In the last three years, there has been a series of publications, including professional position papers, guidelines for professionals, recovery models and top tips on recovery and how to develop a ‘recovery orientation’ within services. Clearly, the policy and political scenes seem to be ready to shift mental health practice from ‘treatment and cure’ to ‘recovery’.

The new mental health strategy also focuses quite clearly on personalised services and improving people’s access to psychological therapies. Taken together, this could mean the development of truly effective services.

However, there are some persistent issues that need to be discussed alongside these policy aspirations. The latest Mental Health Bulletin (NHS Information Centre 2011) shows, as we have seen, that there has been an increase in the number of people using inpatient care for the first time since 2003-04. But what is interesting about this increase is that the number of voluntary patients fell by 6.6% while there was a 30% increase in the number of people detained under the Mental Health Act (MHA). This shows the extent of ‘compulsion’ within mental health services, which becomes even more substantial when we look at women and black communities. The number of women detained under the MHA and coming into hospital via the criminal justice system rose by 85% since 2008-09; the proportion of detention increased across all minority ethnic groups while...
there was a sharp fall in the number of voluntary patients. The Bulletin states:

“These figures suggest that NHS mental hospitals are increasingly used to care for and contain people who pose a risk to themselves or others”.

The discussion of ‘compulsion’ is pertinent – **Is it possible to think about and develop a ‘recovery approach’ that is person-centred when there seems to be an increasing focus on containment and risk within mental health services?**

Against this background, we now present the key findings from this study and its implications for supporting black women on their journeys to recovery.

**Meaning making in recovery**

The narratives of the women interviewed for this project show that **there is a clear link between how they understand and make sense of their mental/emotional distress and their ideas about recovery**. What helps each person in finding ways of coping with distress involves a series of processes:

a. Being able to express personal views on the causes of distress and the contexts from which they arise, including racism, sexism, violence, abuse and other traumas.

b. Finding acknowledgement and acceptance of their views in formal service delivery spaces.

c. Getting support in addressing these causes and being able to overcome – or at least make peace with – distress generating experiences.

d. Being able to find a ‘therapeutic alliance’ with professionals in regaining a positive sense of self, identity and belonging.

**Recovery approaches**

The effectiveness of recovery approaches that start from the point of an identifiable distress episode (often termed as ‘illness’ and given a psychiatric diagnosis) is not able to meet the needs of black women, as shown in this study. **Any approach to recovery should take on board the ‘pre-story’ of distress, acknowledging that a person needs to recover not only from ‘mental distress’ but from the core causes of that distress.**
While recovery is a ‘personal’ journey, the narratives of the women in this study show that, for many people, it is collective and not individual in process and socio-political in nature. A sense of worth in self is linked to a sense of worth in the community and identity. The focus on the individual in recovery approaches will need to be broadened out to include ways of overcoming socio-political oppression and the limits these pose on people’s quality of life. To put simply, recovery approaches focusing on getting black women back into employment and education are not going to be effective unless they are also equipped to deal with systemic and structural oppressions that they face in society.

Developing a transcultural approach

The experiences of the women interviewed for this study has shown that mental health service delivery remains Eurocentric in nature, and focuses on distress as ‘illness’, treatment as primarily medication, and care in terms of compulsion and risk management. Given the scarcity of recovery narratives from transcultural positions in recovery literature, it is reasonable to argue that the recovery approaches being developed today have had little engagement with cultural perspectives of minority ethnic communities. The narratives examined in this study show that understandings of distress as legitimate responses to life events, spiritual crises, ‘breakdown’ due to trauma and stress and other cultural and personal explanations, need to be developed as part of a transcultural approach to recovery.

Role of medication

Another major finding from this study is that there are widely varying views on medication and its role in recovery. Some of the narrators had clear negative views about medication and its side effects, especially its effect on their identities as women, and saw it as a barrier to recovery. Others found some use in medication as helping them develop some degree of stability. However, there was a clear distinction being made between ‘medication as stability’ and ‘real recovery’. More work needs to be done to explore the actual effect of the continued use of medication and its role within recovery approaches.

‘Talking’ and recovery

Given the centrality of meaning making in recovery, it is not surprising that the need to talk about their experiences came up as a key aspect of black women’s recovery and healing process. There are two aspects to this. The first was an expectation of a humane approach to healing, where people had a chance to talk and be listened to by professionals within mental health services and by significant others within their communities and families. The second was a clearly highlighted need to have more access to talking therapies, counselling and other forms of therapeutic alliances where there was a space for exploring the causes of distress and the contexts of recovery.

It is not clear, from existing literature and from this study, why talking therapies are not offered more often as a first option for black women given the importance of meaning making and understanding distress. There is a clear need for more research into the need, efficacy and availability of talking therapies for black women.
Focusing on what helps

We have resisted an ‘elements of recovery’ approach in presenting the findings of this research, although many of the elements listed in many recovery approaches have been discussed within the contexts of the narratives – for example, hope, self-determination, being listened to, and developing a positive sense of self. At this point, however, it would be pertinent to list the various contexts and processes that the narrators of this study have found enabling in their journeys.

- Space for exploring and making sense of their distress.
- Overcoming or coming to terms with experiences of oppression, stressful interactions and other causes of distress.
- Gaining a sense of worth in self and community and a positive sense of identity and belonging as black women.
- Religion, faith and/or a personal spiritual foundation.
- Access to healing systems and therapies, including yoga, meditation, massages and other complementary therapies, and peaceful environments.
- Creative activities like writing, art, photography, and gardening.
- Enabling social interactions, including paid and voluntary work, relationships, friendships and community activities.
- A sense of social justice and community participation through campaigns for race, gender and social equality, against violence, user/survivor movements, community development initiatives.

Telling our stories

This research arose from a conviction that black women’s narratives about mental/emotional distress, healing and recovery were underrepresented in the knowledge base on mental health and recovery. The narratives analysed in this report make an important contribution to this knowledge base. It is significant that many women found the very act of narrating their stories enabling and considered it part of their recovery process. Indeed, for some, this was the first time they were asked to tell their stories and be given a forum and framework within which to develop and tell their story. This in itself, we believe, is a significant achievement of this project.

There needs to be greater investment in creating more such opportunities for black women as telling our stories have important personal and political functions.
Terms and concepts used to describe journeys through mental distress

Resilience  Liberation
Survival  Living
Rebirth  Moving on
Journey  Recovery
Freedom  Strength
Transformation  Discovery
Endurance  Control
Self-determination  Empowerment
Emotional strength  Healing
Social justice  Independence
Getting better


Recovery and Resilience: African, African-Caribbean and South Asian Women’s Narratives about Recovering from Mental Distress

The Mental Health Foundation is conducting a study of women from African, African-Caribbean and South Asian backgrounds, exploring their experiences of mental health, recovery and wellbeing. We would like to invite you to participate in this study.

The purpose of the study is to collect your views on:
– How you understand mental health and mental distress.
– What recovery means to you.
– What has been helpful to you in your recovery.
– How you maintain your wellbeing.

Taking part will involve talking to one of our researchers about your experiences. All researchers involved in this study are also people with direct experiences of mental distress and recovery.

If you would like to take part in this study, please read the rest of this document which tells you more about the study and what it involves. Then please contact Jayasree Kalathil by phone or email.

Jayasree Kalathil
Research Consultant
Jayasree@survivor-research.com
Participant Information Sheet

This sheet gives you more information about the study and what it involves. Please read this carefully before you decide whether or not to take part. If you have any questions, please ask us.

What are the aims of the study?

The purpose of the study is to collect your views on:
- Your story about your experience of mental distress and getting better.
- How you understand mental distress/mental health problems.
- Recovery and getting better.
- What has helped you in getting better.
- How you maintain your wellbeing.

Who is organising and funding this study?

The study is hosted by the Mental Health Foundation, a national charity that provides information, carries out research, campaigns and works to improve mental health services. It is funded by the National Mental Health Development Unit.

The project team consists of chief investigator Dr Dan Robotham, Senior Researcher at the Mental Health Foundation, Lead Researcher Jayasree Kalathil and four researchers (all researchers have direct experience of mental distress).

Who is eligible to participate?

If you are a woman from African, African-Caribbean or South Asian background living in London, and have lived experience of mental distress but consider yourself to be recovered, you are eligible. We are looking to recruit 24 participants for this study.

What does participating in this study involve?

A member of the research team will conduct a face-to-face interview with you which will last up to 1 ½ hours. The interview will be conducted at a time and place convenient to you. You will have the option of having someone with you (for example, a friend) if you feel that is appropriate.

You have the right to withdraw from the study at any time without giving any reasons. Even after the interview, if you feel you are no longer comfortable with the study, you can withdraw and all the information collected from you will be destroyed.

What will happen to the information I give you?

The interview will be recorded using a digital recorder. This is to make sure that your views are represented correctly in the study. The information you give will be used along with the information from other participants to write and publish a report and guidance on working with African, African-Caribbean and South Asian women on recovery.

How will you keep the information I give you confidential?

As soon as the interview recording is typed up, it will be erased. If you do not want to use your own name in recording your story, you can choose a fictional name to protect your identity. Any information that might identify you or your social networks will be changed or made anonymous. The information you give will be used only for this study and it will be stored at the Mental Health Foundation on computers protected by user names and passwords in accordance with the Data Protection Act 1998. Only the research team will have access to this information.
The only exception where a breach of confidentiality might be required is if there were issues around child protection, risk to yourself or others, or malpractice. We would discuss this with you and explain our professional duty of care before breaking confidentiality.

What are the benefits of taking part?

The benefits for taking part are that you will be sharing your experiences of getting well and staying well and helping others learn from your experiences.

Will I be paid?

We believe that those who contribute to studies like this should be rewarded for sharing their experiences. In accordance to government guidance on this, we will pay a voucher for £20 for taking part in the interview. In addition, we will pay travel and any other expenses you might have in coming to attend the interview.

What are the risks of taking part?

There are no major risks in taking part in this study. However, the interviews will explore your experiences of mental distress and accessing mental health services. For some people, this might bring up some unpleasant memories. If this happens, we have set up procedures to help you access the support you might need. Please also feel free to discuss the study with any support systems that you might already have before you decide to participate.

What should I do if I decide to participate?

If you decide to participate, please contact Jayasree Kalathil. Jayasree will ensure that you have understood the purposes of the study and what is expected of you. Then you will be asked to sign a consent form, a copy of which will be given to you to keep along with this information sheet.

What if I have a complaint about the study?

Despite all best intentions, sometimes things can go wrong. If this happens, please inform us so that every effort can be made to put things right and to prevent such errors in the future.

If there is a complaint about this study, you can discuss it with Dr Eva Cyhlarova, Head of Research at the Mental Health Foundation (0207 803 1100). She will then investigate the complaint and will try to resolve the problem. If problems are not resolved within a reasonable time, the Mental Health Foundation will automatically pass the complaint to the CEO, Dr Andrew McCulloch. If the response from the relevant Foundation staff and CEO are not satisfactory, complainants should write to the Trustees. Staff will advise and help people through this process.

Who has reviewed this study?

The study has been reviewed and approved by the Social Care Research Ethics Committee.

Contact information

If you have any questions about the study, please contact Jayasree Kalathil at jayasree@survivor-research.com.

Alternatively, you can contact Dr Dan Robotham at drobotham@mhf.org.uk.

Thank you for reading this.
Recovery and Resilience: African, African-Caribbean and South Asian Women’s Narratives about Recovering from Mental Distress

Interview Questions

Note to interviewer: Before you begin, make sure you have followed all the steps in the guide for interviewers: that you have explained the study and the interview process, the consent form is signed, the tape recorder is switched on. Remind the interviewee that they do not have to answer questions that they don’t want to answer and that they can stop the interview at any time.

Please also remind the interviewee that there are no right or wrong answers and to ask for clarifications if they don’t understand what a specific question is getting at.

If after about an hour into the interview, you feel that it might take longer than the allotted one and a half hour, check with the interviewee whether they are okay with going ahead. If they are not, make sure that you still keep at least 10 minutes for the post interview questions and summing up.

Remember to validate the interviewee’s experiences by acknowledging their experiences. It sometimes helps to share some of your own thoughts if you feel comfortable, but please make sure that these comments are kept brief and does not disrupt the flow of the interview.

Introduction

[Note: The aim here is to get an idea of the person behind the story. Focus on the “now” – their current life. Ask prompting questions to suit the person.]

1. Could you tell me a little about yourself – how would you describe yourself based on your current life?

Prompts:
- What do you do (as in work, keeping themselves occupied etc.)?
- What are your interests and hobbies?
- Family, marriage/relationships, children, their social networks

History and experience of mental distress and recovery

[Note: Again, be clear that you are asking them about their recent experiences and what has helped them to get here. Focus on discussing the positive aspects of their journey. Then use the prompts to draw more out]

2. You are participating in this study because you have had some experience of mental distress or mental health problems and are on a journey of recovery or getting well and moving on. Could you tell me what has helped you to get where you are today?

Prompts:
- What in your journey has contributed to you feeling better? What helped you heal? [Note: Keep in mind that “feeling better,” “healing” etc. are subjective. Encourage them to talk freely about the various aspects of what they think have been important in their journey. These may include a person, an incident, a series of things, medication, a process... Use your discretion to ask questions according to the context to go into details. Encourage them to explain things]
- Has this changed over time?
- How would describe this journey?
- What were some of the key moments in this journey?
3. What would you say you were recovering from?  
**Note:** Different people may give different answers here. For example, someone might say they were recovering from trauma of abuse or violence. Others might say from negative experiences of life generally, or a spiritual breakdown, or racist/sexist experiences in society or community, or “schizophrenia”, “depression”. Use the prompts and be flexible in following up their stories.

**Prompts:**
- What do you think your mental health problem or mental distress has been due to?  
  **Note:** Validate the interviewee’s experience by using the term they use for “mental health problem” or “mental distress”.
- How did [the person's experience] affect your wellbeing?
- Did you use mental health services? If yes, ask for details
- Have you been given a diagnosis by a mental health professional? If yes, ask for details
- What is your opinion of this diagnosis?  
  **Note:** The purpose here is to find out how they see their diagnosis – do they agree or disagree with it? Do they understand it? Does it make sense to them?

**Impact of race, gender and other socio-cultural aspects on experience**

4. This study is specifically looking at the experiences of women and what helps them heal and get better. Has being a woman had an impact on your experience?

**Prompts:**
- Has discrimination based on the fact that you are a woman had an impact?
- Has being a woman made a difference in the type of care and support you received?

5. This study is also specifically looking at women from African, African-Caribbean and South Asian groups. Has your race or culture had an impact on your experience?

**Prompts:**
- Have you experienced discrimination based on your race and culture?
- [If yes] Do you think this has had an impact on your mental health and recovery?
- Has your race or culture had an impact on the care and support you received?

6. Are there other social or cultural aspects that affected your experiences?

**Interpretation of the concepts of recovery, resilience**

7. “Recovery” is a term that is now commonly used within and outside mental health services. What does this term mean to you?

**Prompts:**
- Is this a term that you like to use?
- Does this term explain your experience of getting better or feeling okay?
- Have you come across any recovery models?  
  **Note:** Examples of recovery models, if they ask you, are Wellness Recovery Action Planning (WRAP), the Recovery Star, THRIVE, DREEM, etc. You don't have to go into details of these and if the interviewee does not know what these or other models are, assure them that the question was not a test but just to see how much people were aware of these models since they are being used so widely in services.
- Did you find these useful?  
  **Note:** Ask this question only if they do know of any of these or other models.
8. Another term that is commonly used for moving on after experiencing mental health problems is “resilience.” What does this term mean to you? 

**Prompts:**
- Is this a term that you like to use?
- Does this term explain your experience of getting better or moving on with your life?

9. Is there another term you find helpful in describing your experiences of healing or getting better?

**Views about what enables recovery and resilience**

10. Looking back at your journey, what do you think was the most important thing that helped you get better and move on with your life?

**Prompt:**
- What keeps you well?
- If it was an ideal world, if there were no limits and you could create what you liked, what type of care/support would you have chosen?

[Note: You are coming to the end of the interview now. Describe some of the positive things that came out of the interview and refer to positive aspects of the interviewee's current life before asking the next question so that you end on a positive note.]

11. How do you see your future? What might be the next steps in your journey?

**Post Interview**

12. I have come to the end of my questions. Thank you for your time and sharing with me your experiences and views. Could I now ask you what you thought of the interview?

13. [If you are from the same community as the interviewee] Could you tell me how it felt to be interviewed by a person from your own community or cultural background?

**OR**

[If you are not from the same community as the interviewee] Could you tell me how it felt to be interviewed by a person not from your own community or cultural background?

14. Do you have any questions for me?

15. Would you like to receive a copy of the transcript of your interview?

[Note: Thank the participant for their time and input and make sure that they are alright. If they need to talk with someone about the interview, give them the signposting information sheet and also the contact numbers of the research team and encourage them to get in touch.]