

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

http://create.canterbury.ac.uk

Copyright © and Moral Rights for this thesis are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given e.g. Platt, Suzanne (2016) How do people with a mental health diagnosis construct an identity? D.Clin.Psych. thesis, Canterbury Christ Church University.

Contact: create.library@canterbury.ac.uk



SUZANNE PLATT BSc (Hons)

HOW DO PEOPLE WITH A MENTAL HEALTH DIAGNOSIS CONSTRUCT AN IDENTITY?

Section A: What is the link between identity and psychological wellbeing and/or distress? A review of the empirical literature.

Word Count: 7992 (8075)

Section B: Examining how service users talk about their mental health diagnosis and its impact on self and identity: A Foucauldian Discourse Analysis.

Word Count: 7976 (8340)

Overall Word Count: 15968 (16415)

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

MAY 2016

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I would like to thank all of the participants who have given their time to take part in this study and for research group who offered valuable consultation for the materials and focus group planning. I would like to give huge thanks to Neil Springham (external supervisor) for his help in recruiting participants and for his guidance on conducting focus groups. I would also like to give huge thanks to both Sue Holttum and John McGowan (internal supervisors) who were supportive of the project from beginning to end. I really enjoyed the lively conversations! Finally I would like to thank family and friends who have provided me with patient support throughout this process.

Summary of the Portfolio

This thesis examines how people construct an identity in the context of a mental health diagnosis.

Section A provides a critical overview of the theoretical and empirical literature examining the link between identity and psychological wellbeing and/or distress which span several theoretical and epistemological positions.

Section B examines how service-user research group members construct an identity when they have (or have not) received a mental health diagnosis. Participants presented with 'illness' and 'recovery' identities and used a variety of discursive tools to construct their identities.

Table of Contents

Section A: Literature Review

| Abstract | 8 |
|---|----|
| Introduction | 9 |
| Self and identity | 9 |
| Epistemology of self and identity | 10 |
| Major theories of identity | 10 |
| Identity development | 10 |
| Identity construction and self-concept theories | 11 |
| Social and discursive theories of personal identity | 14 |
| Identity and mental health | 15 |
| Literature Review | 16 |
| Method | 17 |
| Search strategy | 17 |
| Search results | |
| Table of results | 19 |
| Review of empirical literature | 26 |
| Identity and psychological wellbeing and distress | 26 |
| Identity development studies | 26 |
| Identity construction studies | 31 |
| Self-concept studies | |
| Social and discursive studies | 35 |
| Discussion | |
| Clinical Implications | 41 |
| Research Implications | |
| Conclusions | 43 |
| References | 44 |

Section B: Empirical Paper

| Abstract | 54 |
|----------|----|
|----------|----|

| Introduction | 55 |
|--|----|
| Psychiatric diagnosis | 55 |
| Identity and mental health | 56 |
| Illness identity | 57 |
| Recovery and survivor movements | 59 |
| Discourse analysis | 60 |
| Present study | 60 |
| Research questions | 61 |
| Method | 62 |
| Design | 62 |
| Participants | 62 |
| Materials | 63 |
| Service user consultation | 63 |
| Procedure | 63 |
| Ethics | 64 |
| Data analysis | 64 |
| Rigour and quality of analysis | 64 |
| Results | 65 |
| Illness identity | 66 |
| Having a life-long mental illness | 66 |
| Them and Us | 72 |
| Legitimising and supporting a disease model | 74 |
| Recovery identity | 77 |
| Using a diagnosis for self-improvement | 77 |
| Rejecting the disease model in favour of own explanation | 80 |
| Discussion | 82 |
| Limitations | 84 |
| Implications | |
| Conclusions | 86 |
| References | |

Section C: Appendices of Support Materials

| Appendix A: Boolean search phrases | 94 |
|--|-----|
| Appendix B: Flow diagram of search results | 95 |
| Appendix C: Appraisal criteria for quantitative studies | 96 |
| Appendix D: Questioning schedule for focus groups | 98 |
| Appendix E: Information sheet for participants | 99 |
| Appendix F: Consent form | 102 |
| Appendix G: Demographic questionnaire | 103 |
| Appendix H: NRES Ethics approval letter | 104 |
| Appendix I: Trust R&D approval letter | 104 |
| Appendix J: NRES end of study form | 104 |
| Appendix K: Summary of feedback for R&D and NRES ethics | 105 |
| Appendix L: Abridged study for participants | 106 |
| Appendix M: Willig's (2008) six stage Foucaudian Discourse Analysis guidance | 108 |
| Appendix N: Abridged reflexive research diary | 108 |
| Appendix O: Discourse analysis progression trail | 113 |
| Appendix P: Annotated transcripts | 120 |
| Appendix Q: Guidance for article submission to Social Science and Medicine | 120 |

Section A:

What is the link between identity and psychological wellbeing and/or distress? A review of the empirical literature.

Word Count: 7992 (8075)

Abstract

Background: The literature on self and identity spans several psychological domains and epistemologies. Having a coherent and stable sense of self and identity has been linked to psychological wellbeing and a lack of identity stability has been associated with mental distress. Aim: to explore psychological processes that underlie the complexities of identity development and its link to mental wellbeing and/or distress. Method: Four electronic databases were searched. Eighteen empirical studies were identified and were critically analysed and summarised. Results: Studies from different theoretical backgrounds detail underlying processes involved in identity formation and factors important for psychological wellbeing including: belongingness, clarity, coherence and autonomy. Processes are not solely intrinsic and are influenced by social and discursive factors that can motivate or impede identity development. Conclusions: Identity formation is not a passive process but is shaped by individual and social determinants. A critique of theoretical and methodological limitations of the studies is provided, together with clinical and research implications.

<u>What is the link between identity and psychological wellbeing and/or distress? A review</u> of the empirical literature.

Introduction

Self and Identity

The concepts of 'selfhood' and 'identity' have held fascination since as early as Aristotle in an attempt to resolve the question of 'who am I?' In modern Western society, there is preoccupation with 'selfhood' in pursuit of self-definition and fulfilment (Baumeister, 1999). These concepts command overwhelming presence within the literature across several psychological domains (e.g. social, developmental, personality) investigating components of personal, social and cultural identity (Skowronski, 2012). It is thought people are universally motivated to understand and define who they are and who they are not in an attempt to improve self-esteem and connection with community (Kroger, 2007).

There are many conceptualisations of 'selfhood' and the term is often used interchangeably with identity, yet the two constructs are discrete (Kroger, 2007). The self has been broadly described as the beliefs a person has about themselves, including their attributes about who and what they are (Baumeister, 1987). Identity is influenced by biological characteristics and psychological needs mediated through social and environmental opportunities and constraints (Kroger, 2007). However, a spectrum of understandings exists in the literature which depends on the author's epistemological stance. In order to incorporate a diverse range of theoretical, empirical and discursive accounts of identity formation, this review uses terms such as identity and self interchangeably, depending on the authors' intention.

Epistemology of self and identity

Theories of self and identity are found across varying ontological and epistemological domains and shape methodological approaches. Historically, realist perspectives view selfhood as stable manifestations of a person's behaviours, intentions and values which accurately reflect an internal reality (Kroger, 2007). People are thought to possess a 'true self' that is discovered over the course of a life time, potentially bringing self-fulfilment, continuity and coherence in life, reflecting Maslow's (1943) description of self-actualisation as the ongoing pursuit and acceptance of one's intrinsic nature. If absent can lead to a lack of fulfilment (Waterman, 1984).

From an anti-realist position, social constructionists challenge 'taken-for-granted', dominant perspectives and argue identity and selfhood do not exist within a person but are constructed within historical and cultural contexts and expressed and maintained through discourse (Davies & Harre, 1990). A critical realist position merges epistemological relativism with ontological realism. It acknowledges the impossibility of knowing truth as there are different versions created through discourse, balanced with recognising that events have an objective basis and are produced by underlying, powerful structures (e.g. economic, social, biological). It takes into account constructivism (i.e. cognitive development: Piaget 1954/2013) and constructionist (Davies & Harre, 1990) perspectives of personal identity implying 'discursive repertoires' are the medium of self-construction (Gergen, 1985).

Major theories of identity

Identity development

Erikson and Erikson (1998) viewed personal identity as a linear, autonomy-focused developmental process subject to physiological, psychological and social changes throughout the life cycle which appears to be grounded in a traditional realist position. Erikson (1968)

proposed identity development begins in early infancy as the child establishes a sense of the self as being different to their caregiver. In keeping with attachment theory (Winnicott, Shepherd, Winnicott & Davis 1992) through 'good enough' interactions, the infant incorporates the caregiver's image, providing them with a secure base from which to explore the world so new identity elements can be assimilated (Pittman, Keiley, Kerpelman, & Vaughn, 2011). Erikson (1968) proposed adolescents experience a process of identity confusion, marking a turning point in development when numerous paths are available and represents individuation, change, growth or recovery. It gives the chance for an individual to search, integrate or rejuvenate interests, talents and beliefs to resolve the 'crisis' to achieve a coherent and stable sense of self.

Marcia (1966) operationalised Erikson's stages and suggested identity development can be categorised into statuses of exploration and commitment. Identity exploration is represented as sorting through and 'trying on' different sets of values, beliefs and aspirations whereas identity commitment is concerned with choosing and adhering to specific goals and values associated with a particular identity. If successful, a person will maintain coherence along with a flexible sense of self. This linear approach to identity development is considered to be a utopic achievement and neo-Eriksonian researchers (e.g. Côté, 1996; Schwartz, 2001) endeavour to understand what is thought to be the inevitable unfolding of identity stages. However it overlooks the impact of social and environmental influences and seems to locate identity development within the individual.

Identity Construction and Self-Concept Theories

The concept of 'identity construction' is linked to a critical realist and constructivist position and proposes individuals consciously choose and 'piece together' or construct an identity which is influenced by and reflective of social and contextual ideologies (Waterman, 2004). Identity construction utilises a range of social-cognitive theories which propose the self emerges from nothing and is consciously sculpted by underlying cognitive mechanisms.

Ryan and Deci's (2000) self-determination theory suggests that people are motivated to pursue three basic psychological needs which facilitates identity construction: autonomy, competence and relatedness. The extent to which they experience these phenomena depends of on the strength of their intrinsic and/or extrinsic motivations. Intrinsic motivations are based on inner experiences and characterised by personal enjoyment and competence whereas extrinsic motivation relates to rewards situated outside of the individual such as money, status, power and attention. According to Waterman (2004), it is important to understand the motivation behind identity construction as this can determine a person's choices and lifestyle.

Complementing self-determination theory, Berzonsky (2008) claims people can engage in one of three separate identity processing styles which relates to their motivation to construct an identity. An informational style characterises people as maintaining a realistic, sceptical and active participation in seeking out and evaluating self-relevant information, a normative style reflects a passive approach where a person conforms to cultural standards, and a diffuseavoidance style describes individuals who greet identity construction tasks with procrastination and evasiveness.

The mechanisms of choosing and constructing an identity is thought to involve selfevaluative processes in order to establish 'who you are and who you are not'. People are essentially motivated to gather self-relevant feedback of abilities and skills in order to maintain a coherent sense of self, to make improvements to one's skills and to protect one's self-esteem from negative information to maintain a positive sense of self (Sedikides & Strube, 1997). Schwartz (2005) suggests the ability to manipulate and reason with an array of self-relevant information is associated with an assertive and autonomous personality however the development of this personality type was not explored regarding whether this was a trait or influenced by contextual factors (i.e. parenting, prevailing cultural expectations).

Additionally, it has been suggested, people are motivated to outwardly present to others a representation of who they believe they are (Markus & Wurf, 1987) as a way of maintaining a coherent self-narrative and a sense of a public and private self (Schlenker, 1986). This ongoing process of making sense of one's self becomes an internalised and evolving narrative reflecting integrated psychological elements (e.g. needs, beliefs, values) where identity represents a 'theory' which helps to explain the world and their experiences from an individualistic perspective (Adler & McAdams, 2007).

A commonality of these theories is the assumption of there being conscious processes of autonomy and choice and what is known as an 'existential dilemma' can be the result of having too many options laid forth where decision-making becomes arbitrary (Baumeister, 1987). In a socio-historical review of the Western conception of self, Cushman (1990) described an 'empty self' in chronic need of acquiring the 'perfect identity' as a result of increasing individualistic ideology and consumerist pursuit and held this need accountable for feelings of inadequacy and distress. He claimed there was an increasing lack of definition and purpose in people's lives which had developed from a diminishing sense of community and tradition, and criticised those in powerful positions within Western culture (i.e. media) for placing high value on filling this 'void' (e.g. with material possessions) which perpetuate feelings of dissatisfaction. According to Baumeister (1987), modern Western cultures have become obsessed with defining one's own purpose in life and an individual's disillusionment with society has turned previously outward looking perspectives inward.

Construction theories view identity processes as an autonomous task and where an individual has a degree of choice, and as reflecting an individualistic assumption held generally

within Western cultures which minimises the influence of cultural contexts. Although we may possess the capacity to self-actualise as biological organisms, we might place different constructions on self and identity according to the prevailing culture.

Social and discursive theories of personal identity

Personal identity theorists argue that identity development is one's own responsibility (Cote, 1996), however Haslam, Jetten, Postmes, and Haslam (2009) argue social identity has an important influence on the developing self. According to Tajfel (2010), a person's can define themselves in relation to a group which share similar attributes, goals and values and can be a source of belongingness and inclusion as well as marginalisation and exclusion. Self-categorisation theory (Turner, Oakes, Haslam & McGarty, 1994) extends this and proposes that people use three levels to categorise themselves: as an individual (personal identity), as a group member (social identity) and as a human being (interspecies). It also proposes a process of depersonalisation which reflects self-stereotyping where people come to see themselves more as a representative of social category as opposed to an individual. The impact of this is further highlighted by Potter and Wetherwell (1998) who criticise realist perspectives as being determined by the fulfilment of social expectation who name this as 'social manufacturing' suggesting people can conform to identities and begin to see themselves as others do in relation to what is expected of that role, also known as the 'looking-glass self' (Rahim, 2010).

This is particularly relevant for people where an identity is ascribed to a person or group of people (e.g. 'disabled', 'mentally ill', 'migrant') resulting in the gradual identification with the attributed label (Goffman, 2009). If an individual becomes associated with an devalued social group, they can internalise the socialised negative associations of the label, leading to loss of status, discrimination and a belief they will be viewed negatively which results in social distancing and further internalisation of attributed characteristics (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Within emancipatory movements, Watson (2002) argues that mainstream social sciences are implicated in producing and strengthening notions of a realist identity through the application of categories which serve as a political tool to oppress and segregate certain groups.

Identity and mental health

In the field of mental health, the need to develop a coherent sense of self is thought to be important for psychological wellbeing (Sedikides & Strube, 1997) and less on the ways identity may reflect the broader social context. A loss or disturbed sense of self has been associated with several psychiatric difficulties and the Diagnostic Statistical Manual Fifth edition (DSM-5: American Psychiatric Association, 2013) cites the occurrence of identity disturbance as an indicator of mental health difficulty, attracting the diagnosis of personality disorder. It is thought that one in twenty people in the UK would meet the diagnostic criteria for a personality disorder (Coid, Yang, Tyrer, Roberts & Ullrich, 2006) suggesting that there is pervasive difficulty in people making sense of who they are. The processes which lead to this disturbance are not explicitly linked between the different domains in psychology and much can be learned from an inter-disciplinary approach (Haslam et al., 2009). For instance, difficulties experienced in early development that are undesirable mean that identity is forged on a negative basis rather than an exploration of talents and interests (Jørgensen, 2006), and social-cognitive biases may make this process more difficult, reducing exploration and commitment to identity goals.

Social and developmental identity theories favour 'normative' explanations implying a linear process which is expected to occur for most people during late adolescence and early adulthood. 'Positive identity development' is reportedly associated with better mental health (Haslam et al., 2009) but with so many competing theories of identity, it is difficult to appreciate the mechanisms of identity formation that are important for psychological health and what could be associated with distress. For instance, these theories of social and developmental trajectory of identity overlook those who struggle to define themselves by not considering the social or political constraints placed on certain marginalised groups. This could make it difficult for them to progress through these 'normative' stages and people come to self-categorise themselves within these groups.

The theories discussed above underlie psychotherapeutic approaches of working with selfhood. In helping people experiencing psychological distress, the tenets of therapeutic practice offer ways of reconnecting or discovering the self (i.e. psychoanalytic; Strenger, 2013), re-authoring the self (i.e. narrative; Adler & McAdams, 2007), evaluating cognitions about the self (i.e. cognitive-behaviour therapy; Beck, 1979) and thus understanding the processes of personal identity construction is imperative to all approaches of psychotherapy.

Identity as a process or as a completed or unfulfilled developmental task has been extensively researched within the social psychology arena with attempts to bridge their efforts into understanding its link to psychological distress and well-being. This contribution is slowly being recognised within applied psychological domains, particularly for social identity theory (Haslam et al., 2009) but greater effort is needed to fully integrate this vast knowledge to form an inter-disciplinary psychological relationship to enable a holistic understanding of psychological well-being and distress. This is important as having a positive sense of group membership can provide people with the foundation from which to build an identity through a sense of belongingness, meaning and purpose (Haslam et al., 2009; Vignoles, Regalia, Manzi, Golledge & Scabini, 2006).

Literature review

Currently, there is no systematic review that explores the wide ranging empirical literature base that spans developmental, social, personality and clinical psychology to

determine what factors are important in the process of personal identity in relation to mental well-being and/or distress. In exploring inter-connected psychological processes that underlie the complexities of identity, we may understand the link between identity and mental wellbeing and/or distress. The literature base is vast and it is beyond the scope of this review to explore other important facets of identity (e.g. cultural, ethnic, racial, sexuality, professional) that contribute to the development of personal identity. This review will make reference to the theoretical frameworks presented above and consider:

- What does empirical research tell us about the relationship between (a) personal identity development and self-concept and (b) psychological/mental wellbeing and/or distress?
- What do understandings of identity development tell us about psychological/mental well-being and mental distress?

Method

Search Strategy

The scope of the literature search was to locate empirical articles that investigate a) the association between personal identity development and mental/psychological well-being and/or distress and b) what identity processes mediate the relationship between identity and well-being and/or distress. A systematic electronic Boolean search¹ was conducted using key words and phrases in the article title on Psycinfo, Medline, CINNAHL and ASSIA platforms (appendix A).

The titles of the resulting articles were screened to determine their fulfilment of the following eligibility criteria:

- Full peer-reviewed journal available

¹ Searches were carried out on two occasions, the latest of which was conducted on 1st October 2015.

- Written or translated into English language
- Descriptions or measures of identity profiles or processes
- Descriptions or measures of well-being, psychosocial functioning or distress

The exclusion criteria were as follows:

- Theoretical/conceptual orientation of studies that solely explore subjective 'self' phenomena (e.g. self-efficacy, self-regulation, self-esteem, self-determination) and not in relation to identity development or process and/or mental wellbeing or distress

Search results

Electronic searches yielded 395 articles (appendix B). Following title and abstract review stages and hand searching references, 44 articles were read in full and 21 were included in the literature review (table 1). All papers were evaluated using critical appraisal guidelines for quantitative research from National Institute for Health and Care Excellence (2012) and chosen as it provides comprehensive guidelines of assessing quality of the evidence-base (appendix C).

| Authors | Aim | Sample | Methodology | Main Results | Conclusions |
|-------------------------------|--|---|---|---|--|
| | | Characteristics | | | |
| 1. Brook and Garcia (2015) | Explore effects of multiple identities on psychological well-being | University students (n = 372). Female = 56%, White = 67%. Mean age = 19.1 years. | Multiple regression. Measurements taken for each identity: importance and harmony of fit with other identities. Measurements for emotions: depression, wellbeing, anxiety and stress. | Highly important identities that conflicted with each other was associated psychological distress. Important identities in harmony associated with positive wellbeing. | Rating: ++. Recognises importance of having multiple identities as opposed to looking at identity as a whole Limitation: student population |
| 2. Dezutter et al. (2013). | Investigate life meaning and identity development in emerging adulthood: | 30 universities in USA, 8492 students (72% female, 61% White) with mean age of 19.98 years. | Cluster analysis. Measures: presence of meaning and search for meaning. Also positive (psychological well- being) and negative (depression) psychosocial functioning | High meaning/low need for searching associated with positive wellbeing. Negative wellbeing associated with low meaning and lack of identity. | Rating: +. Insight into the complexity of meaning related to Eriksonian identity statuses. Limitation: student population |
| 3. Hardy et al. (2013). | Determine link between moral, identity, mental health and health- risk behaviours. | 9500 college students (73% female) from 31 universities aged 18-25 years. | Structural equation model performed. Questionnaires: identity formation, moral identity, anxiety, depression, health risk behaviours, self- esteem and meaning. | Moral identity was associated with all health outcomes. Higher moral identity reported lower mental health and health risk behaviours. | Rating: ++. Extent a person's identity is based on morality was important to health and well- being. |
| 4. Luyckx et al. (2006). | Explore identity commitment and exploration dimensions | 565 students (85% female) mean age=18.8 years | Regression analysis. Questionnaires: commitment, exploration, self-esteem, depression | Interaction between commitment and exploration can change trajectory of identity | Rating: ++. Highlights different processes involved in identity development |

Table 1: Details of empirical journals included in literature review

| Authors | Aim | Sample Characteristics | Methodology | Main Results | Conclusions |
|-----------------------------|---|--|---|--|--|
| 5. Luyckx et al. (2007). | Explore relationship between parental psychological control and identity | 364 students (89% women). Mean age 18.7 years. | Longitudinal correlational analysis. Participants assessed five times every six months and completed measures in: dimensions of identity formation, psychological control scale | The more participants perceived their parents as being psychologically controlling, the greater the difficulty in committing to identity | Rating: +. Not able to determine causality but indicated link. Other explanations such as identity pursuits conflicting with parents' choice. |
| 6. Luyckx et al. (2008). | Identity statuses and perfectionism and link to wellbeing. | 895 (76% female) from in Belgian university (mean age -19 years) | Correlational analysis performed. Questionnaires measuring: perfectionism and identity dimensions. | Personal standards of perfectionism positively related to commitment and exploration. Maladaptive perfectionism positively ruminative exploration. | Rating: +. Highlights extent to which perfectionistic personality can impact on identity development. Cause for perfectionism not explored. |
| 7. Luyckx et al. (2010). | Identity commitment and integration into self-concept | 399 (79% female) recruited in Belgian university (age17-22 years). | Likert scale questionnaires including: motivational orientations, commitment and identity integration, self- esteem and depression. | Extent identity integration occurred predicted commitment and adjustment. | Rating: ++. Feeling committed and certain about one's identity led to integration and positively related to psychological adjustment. |

| Authors | Aim | Sample Characteristics | Methodology | Main Results | Conclusions |
|------------------------------|--|---|---|---|---|
| 8. Luyckx et al. (2012). | Identity processes, coping strategies and personality | 458 (85% female) college students | Correlation: Measures: coping strategies indicator, Big Five Personality, Identity development processes | Identity exploration linked to problem solving, ruminative exploration linked to avoidance | Rating: ++ Coping strategies and identity are entwined and reinforce each other over time |
| 9. Manzi et al. (2006). | Cohesion and enmeshment and link to identity and wellbeing. | 124 adolescents in Italy and 109 adolescents in the UK (17-21 years). | Regression analysis study. Measures: family cohesion and enmeshment, identity threat, life satisfaction, depression, anxiety. | Well-being positively predicted by family cohesion and negatively by enmeshment. Enmeshed families negatively influence identity development. | Rating: ++. Looks beyond individual to inter-relational factors of identity development. |
| 10. Manzi et al. (2009). | How new identities are accommodated during life stage transition in UK and Italy. | 192 college leavers (age 17-20) and 246 first time parents recruited (age 21-53). | Participants specified 12 identities, rated how central, marginalised, expected or feared identities were. Questionnaires: emotional wellbeing, perceptions of life transition. | Individuals achieving identity accommodation in line with expected/desired possible selves associated with greater emotional well-being | Rating: ++. Success of transition and accommodation of new identity can be protective against anxiety and depression. |
| 11. Mason- Schrock (1996) | Transsexuals' narrative construction of the 'true self' | Community group attended by transsexuals (10-26) over 8 month period | Discourse analysis: examined how individuals explored and established positive identity within the transsexual community | Biographies detail how discursive tools helped people to shape personal identity which affirmed group membership. | Rating: +. Highlighted importance of belongingness and how language can facilitate identity development |

| Authors | Aim | Sample Characteristics | Methodology | Main Results | Conclusions |
|-------------------------------|--|--|---|--|---|
| 12. Ritchie et al. (2011). | Over three studies, examining associations amongst stressful life events, self- concept clarity, SWB and neuroticism | 1) 292 (221 female) recruited via internet (age range 18-59 years). 2) 172 students (65 female). 3) 77 (41 female) students | A correlational design was used for all studies. Measures included: meaningless scale, self- concept clarity, neuroticism and SWB | Self-concept clarity mediated the association between stress and well-being, independently of neuroticism. Meaninglessness was negatively associated to self-concept clarity | Rating: ++. Experiencing psychological stress as a result of difficult life events can undermine self- concept clarity. |
| 13. Roberts & Cote (2014). | Examine prolonged transition to adulthood and link to wellbeing/distress | Study 1: 196 (131 female) aged 18-48 yrs. Study 2: Online crowdsourcing of 1489 (49% female) aged 18-41 yrs. | Study 1: Factorial analysis to create inventory for identity transition and resolution. Study 2: Examine identity resolution and link to wellbeing | Inventory demonstrated overall excellent internal consistency Participants aged 30+ with low identity resolution had poorest emotional and mental health. | Rating: ++. Prolonged identity formation can have consequences for psychological health. Good generalisability |
| 14. Schwartz et al. (2010). | Examining positive and negative sides of emerging and link to psychosocial functioning. | 9034 students (73% female, mean age 19 years) recruited in USA from 31 universities | Cluster analysis performed. Questionnaires: dimensions of identity development, identity synthesis and confusion, positive and negative psychosocial functioning and health- compromising behaviours | In addition to support Marcia's original identity statuses, new profiles emerged: Carefree associated with anti-social behaviours and lower sense of meaning. | Rating: ++. Study offers insight in the underlying mechanisms that could determine the trajectory of certain lifestyles based on choice. |

| Authors | Aim | Sample Characteristics | Methodology | Main Results | Conclusions |
|--------------------------------|--|---|---|--|---|
| 15. Schwartz et al. (2011). | Examine the daily dynamics of self-concept clarity and identity processes and their impact on distress | Recruited in The Netherlands, 580 adolescent students (45% female) aged 11-15 years. | Participants asked complete questionnaires for five consecutive days at baseline, 3 and 6 months. The measures included: self- concept clarity, anxiety and depression | Self-concept fluctuated on a daily basis. Strength of commitment to identity helped to maintain self-concept clarity. Reconsideration or uncertainty about identity predictive of anxiety and depression | Rating: ++. This study examines identity processes on a micro-level and captures the fluctuation of self- concept that isn't often considered in identity studies |
| 16. Schwartz et al. (2015). | Identity in young adulthood: Links with mental health and risky behaviour. | Recruited in USA from 30 colleges and universities, 9737 students (mean age 19 yrs, 62% female, 15% White). | Using latent profile analysis, measures: identity exploration and commitment, identity synthesis and confusion, self-esteem, psychological wellbeing, internal locus of control, meaning, internalising and externalising problems, health risk behaviours | Four identity profiles were classified which reflected theoretical assumptions: synthesised, diffused, elevated and moderate | Rating: ++. Ethnically diverse sample but college sample. Considers types of profiles that may struggle in identity formation and could focus interventions of certain groups of people |
| 17. Slotter et al. (2010). | The influence of romantic breakup on the self- concept. | Three studies: 72 (40 female students, 76 (18-56 yrs), 69 (35 female) students | Regression analysis, content analysis and ANOVA: compare identity change at baseline and 6 months for real or imagined romantic break-up | Greater self-concept change and reduced clarity when remembering break-up. Improvement in wellbeing at 6 months | Rating: ++. Changes in content of self- concept after a romantic break-up predictive of emotional distress |

| Authors | Aim | Sample Characteristics | Methodology | Main Results | Conclusions |
|--------------------------------|--|--|--|--|--|
| 18. Soenens et al. (2015). | Examine longitudinal associations between identity exploration and distinct features of self-esteem (level and contingent) | 246 college students (66% female) participated at time 1 and four months later, | Structural equation model. Measures: identity processing styles, global and contingent self-esteem, identity commitment. | Positive associations between informational identity style and self- esteem, stable over time. Self-esteem for those with normative identity style associated with fragile self-esteem. Diffused-avoidant style associated with low levels of self-esteem. | Rating: ++. Study provides insight in the fluctuating nature of self-esteem in relation to different types of identity style and that self- esteem may influence identity motives as opposed to the other way around. |
| 19. Vignoles et al. (2006). | Two studies. What motivates people to pursue certain identities – beyond increasing self- esteem. | 82 Christians (55 female) aged 15-79 years and 115 students (82 female), mean age 20 years | Regression. Specified 12 identities and rated each on feelings of belongingness, continuity, self-esteem, distinctiveness, meaning and efficacy. Study 2 followed up at six months | All motives influenced identity construction. Elements central to people's identity shape their behaviours as they strive to maintain identity needs. | Rating: ++. Study provides support that other motives alongside feeling good about oneself influences every day actions in identity construction. |
| 20. Vignoles et al. (2008). | Three studies. Identity motives underlying desired and feared possible future selves. | 105 members of public, 233 school leavers and 246 expectant first time parents | Participants specified 10 possible future selves. Ratings: reflection of current self, likelihood of identity and how much how much it was feared or desired. | Desired most/feared less possible selves perceived as offering greater self-esteem, meaning, continuity, and efficacy. | Rating: ++. First study to examine motivational bases for desired and feared possible selves. |

| Authors | Aim | Sample | Methodology | Main Results | Conclusions |
|----------------|-------------------|-----------------|--------------------------------|--------------------------|----------------------|
| | | Characteristics | | | |
| 21. Waters & | Relations | 103 (56 | Narratives written about | Coherent narrative | Rating: ++. Suggests |
| Fivush (2014). | between narrative | female) | several personally significant | associated with positive | what is narrated and |
| | coherence, | undergraduate | life events. Questionnaires | self-view, sense of | its coherence is |
| | identity and | students aged | that measures self-evaluation | meaning and purpose | important for |
| | psychological | 18-28 years. | and functioning in social | | psychological well- |
| | well-being | | relationships. | | being, |

Review of Empirical Literature

Papers will be discussed in relation to their discipline (developmental, construction, selfconcept and social and discursive) to explore the link between identity development and psychological wellbeing and/or distress.

Identity and Psychological Well-Being and Distress

Identity Developmental Studies

Marcia (1966) categorised Eriksons's identity development stages into statutes which represent the extent to which a person explores and commits to an identity claiming people go through, or maintain a particular identity status. In linking identity statuses to psychosocial functioning, Luyckx, Goossens, Soenens, and Beyers (2006) made further differentiation of identity exploration and included exploration in depth, exploration in breadth and ruminative exploration and proposed that the interaction between an individual's exploration and commitment style can influence their identity trajectory. A combination of exploring different identity options in-breadth and in-depth is indicated as the optimum process for an achieved identity. If in-breadth exploration occurs in isolation, an individual risks experiencing identity diffusion, where they persistently and confusedly try on different types of identities without reaching achievement. Ruminative exploration on the other hand is thought to represent an exploration process whereby individuals become 'stuck' with their identity evaluations as they struggle to find the 'perfect' identity. In this study, ruminative exploration was strongly associated with anxiety, depression and poor life satisfaction. However, this was a crosssectional study that made assertions of identity being a static profile and did not explore the long-term implications of these profiles on behaviours or the impact of external factors.

To explore the 'real life' implications of identity statuses, Schwartz et al. (2010) converged Luyckx et al.'s (2006) identity status model and Marcia's original profiles and

evaluated their relationship to psychological wellbeing, risk behaviours and functioning in a large-scale cluster analysis. They identified several profiles associated with various psychological and behavioural patterns. Positive psychological health with low risk behaviours (i.e. drug and alcohol misuse, unprotected sex) was associated with a so-called 'achieved' identity (successful in-depth and in-breadth exploration and commitment). Similar results were found for people with a 'foreclosed' status (strong identity commitments without in-breadth/in-depth exploration) but they reported to experience low meaning and purpose in life. The authors suggest that individuals who make identity commitments without exploration may not be engaging in self-discovery and are more accepting of the roles expected from them.

In contrast, people who continuously explored new identity options (searching moratorium status), were highly ruminative in exploration (diffused) and appeared uninterested in identity issues (carefree diffused) were all strongly associated with depression and anxiety. Furthermore, the carefree status was particularly associated with hedonistic and risky behaviours and participants reported lower meaning in life. The authors considered this as a reflection of a reluctance to give up current youthful identity although this was not a measured variable in their methodology. This research attends to wider issues for emerging adults who are expected to find their own way in life by forging an identity. One criticism is that the study is cross-sectional and it could be that people had trouble forging an identity because they were already psychologically distressed due to lack of nurturing environments which may also lack positive identity role models which related to theories of attachment (Bowlby, 1998).

Further links between identity and psychological health were explored in a longitudinal study by Luyckx, Klimstra, Duriez, Schwartz, & Vanhalst (2012) who examined the relationship between identity exploration and commitment indices alongside coping strategies (i.e. problem solving, avoidance). They found identity statuses and coping strategies were predictive of one another, specifically, seeking support and problem-solving was positively

associated with identity commitment making and exploration in breadth whereas avoidant coping strategies were related to ruminative exploration. The authors conclude that how a person copes with difficulties in life can facilitate the process of identity formation but also hinder its development as avoidant coping was strongly associated with ruminative exploration, making identity integration more problematic. However, the associations were modest and causal direction could not be asserted.

When moving through life stages, a person has to integrate new information about themselves, which can reorganise and redirect their life trajectory. Luyckx et al. (2010) who reported that identity integration is fully mediated by the relationship between identity commitment and adjustment explored the relationship between identity integration and psychosocial functioning. For example, when someone is certain about who they are, they are more likely to successfully integrate new aspects of their identity which is positively related to psychological adjustment. Importantly, when a person's identity decisions were influenced or controlled by others (i.e. parents making decisions), they were less committed to the identity which was related to poor psychological adjustment. The results suggest that external factors influence identity development and can limit the connection a person has with the identity they are attempting to assume, which may be a reflection of personality and/or contextual differences.

Striving towards an identity goal is one of the tenets of self-determination theory (Ryan & Deci, 2000) and the extent to which a person engages in this process has been linked to personality. Perfectionism can be either adaptive in motivating people to pursue important goals but it can also be problematic when a person becomes consumed by their need for perfection. Luyckx et al. (2008) examined the association between two types of perfectionism (maladaptive and high personal standards) and dimensions of identity (exploration and commitment) and found high personal standards was positively related to identity

commitment. As predicted, maladaptive perfectionism was associated with ruminative exploration. This highlights the importance of intrinsic motivation which can either lead to a sense of identity achievement or continued exploration and psychosocial difficulties. However it is unclear whether those adopting perfectionistic tendencies already experienced psychological distress or if perfectionism caused it and therefore causality is difficult to determine.

The development of perfectionism has been linked to authoritarian parenting (Flett, Hewitt & Singer, 1995) and interpersonal factors can influence the trajectory of identity development, particularly a person's experience of early parenting and attachment (Winnicott et al., 1992). Manzi, Vignoles, Regalia and Scabini (2006) examined the nature and implications of cohesion and enmeshment within families for identity development and wellbeing. They found psychological well-being was positively predicted by family cohesion and negatively by enmeshment, which was also found to negatively influence identity development. These findings were extended by Luyckx et al. (2007) who evaluated the relationship between perceived parental control and identity formation in adolescents. They found the more participants perceived their parents as being psychologically controlling, the greater the difficulty in committing to identity was. Greater parental involvement may be initiated when a young person begins to explore in breadth alternative identity options which may conflict with the parents' own wishes. This may increase parental control rather than being the catalyst for lack of identity commitment. These studies look beyond the individual into the family dynamics and how this might influence identity development, however in both studies, the measurement of family dynamics is only from one family member's perspective.

One criticism of identity status research is the measures used to capture the identity profile portrays identity as a static phenomenon. The daily dynamics of how a person views themselves was investigated by Schwartz et al. (2011) to understand whether identity status fluctuates and its impact on mental well-being. They found people's self-concept fluctuated on a daily basis and the stronger the commitment, the greater the self-concept clarity. In contrast, reconsideration or uncertainty about personal identity was predictive of anxiety and depression. This study examines identity processes on a micro-level and captures the fluctuation of selfconcept that is not often considered in developmental identity studies. However, it is not clear whether identity changes caused mood changes or the reverse.

Another criticism of identity status studies is that they are largely concentrated on college-attending adolescents emerging into adulthood and are not generalisable beyond this sample. Roberts and Cote (2014) acknowledged identity status is relevant across the lifespan and explored this within a diverse age group. They found individuals who did not meet traditional notions of identity milestones asserted by neo-Eriksonians experienced greater physical and mental health problems but that identity resolution increased with age. Additionally, individuals aged over 30 years who had not developed an 'achieved identity' or struggled to resolve this process (known as 'identity delay') had the poorest mental health. They suggest an identity delay beyond early adulthood might have consequences for emotional and psychological health. However, the authors did not consider whether experiences of mental distress affected their identity development rather than the other way round.

Neo—Eriksonian studies offer insight into personal orientations towards identity that could determine the trajectory of certain lifestyles based on choices and opportunities. However, other internal and external mechanisms also influence the process and these studies fail to explore the underlying factors that both motivate identity development by striving towards goals. However, it can also and deter identity development by causing greater pressure and anxiety to make important, sometimes life-changing decisions. Furthermore, assumptions are made that an achieved identity status is an expected and ultimate goal during emerging adulthood and this can result in pathologising those who may be reluctant to conform to social norms and conventions (Adler &McAdams, 2007).

Identity Construction Studies

Identity construction theories are concerned with how individuals choose and piece together their identity within contextual opportunities and constraints (Kroger, 2007). Berzonsky's (2008) social-cognitive model classifies the processing styles associated with identity formation. It is thought people are motivated towards certain identities as a way of improving how they feel about themselves (Sedikides & Strube 1997). Soenens, Berzonsky and Papini (2015) examined the associations between identity styles and distinct features of self-esteem; level (measure of self-worth) and contingent (motivated by social approval). They found positive associations between an informational identity style (open and critical) and high self-esteem which was stable over time and associated with changes in contingent self-esteem suggesting some motivation for social approval. Self-esteem for those with a normative identity style (strong adherence to social standards) was more fragile particularly when threatened. Finally a diffused-avoidant identity style was associated with low levels of self-esteem and self-worth was highly contingent on social approval. This study provides insight into the fluctuating nature of self-esteem in relation to different types of identity style which may be influencing identity decisions although a direction of causality could not be determined.

Vignoles et al. (2006) argue that other equally important motives beyond self-esteem can steer people's choices in their identity construction and outline several identity motives; distinctiveness (differentiation from others), continuity (degree of sameness between past, present and future self), belonging (feelings of closeness/acceptance by others), efficacy (competency and control) and meaning (purpose in own existence). In an extensive study which measured how participants' identities were mediated by these motives, they found that all motives predicted how people consciously manage their identity either directly or indirectly with additional evidence to suggest that identity elements central to people's identity shape their behaviours as they strive to maintain an array of identity needs. Although people are motivated to maintain positive self-esteem, this study supports the assertion that other motives may influence every day actions in identity construction.

Furthermore, Vignoles, Manzi, Regalia, Jemmolo, and Scabini (2008) examined the extent these identity motives interacted with a desired and feared possible self. At a time of life transition (school leavers and first-time parents), they found that people desired most and feared less their possible selves that they perceived would offer greater self-esteem, meaning, continuity, and efficacy which was also considered to be central to their self-concept. Additionally, the feared future identities were thought to cause more frustration particularly when they perceived there would be a disruption or loss to their sense of belonging, distinctiveness and self-concept continuity. This study explored the motivational bases for desired and feared possible selves and highlighted that the need to 'feel good' about oneself is not enough in influencing the choices people make for themselves, and a sense of continuity, meaning and efficacy motivates people in pursuing certain identities.

In pursuing an identity, people explore an array of possibilities and supposedly choose and discard identities and at one time hold several different identities. Brook and Garcia (2015) examined how multiple identities interact with one another and found having many rather than fewer identities leads to better psychological well-being. However this was dependent on the harmony or 'fit' between the identities and the extent to which identities are seen as important or central to a person's self-concept. They conclude that conflicting identities caused greater psychological distress, however they were unable to make a causal inference.

Self-Concept Studies

Based on existential theory, a person's self-concept is described as "the individual's belief about himself or herself, including the person's attributes and who and what the self is" (Baumeister, 1999). Importantly, this can involve both current and future self-conceptions. How a person thinks about their future self can motivate choices and behaviours in their current lives but can also create anxiety if the future identity is feared or undesirable. In a longitudinal study Manzi, Vignoles and Regalia (2010) examined the cognitive processes of participants at two life transition stages (school leavers and parenthood) in the 'assimilation' of a new identity into their existing self-concept and the 'accommodation' of a reorganised self-concept. They found the more identities were expected or desired by the individual before the transition, the more important it was for them to assimilate and accommodate the new identity to their selfconcept which was associated with positive psychological well-being. Identities that were feared or undesirable were perceived as less important and there was greater difficulty in assimilating and accommodating them into their existing self-concept. This study highlights how a person's perception and feelings about a change in their identity can vary depending on whether it is an identity they wish for or fear with important consequences for psychological well-being.

Having meaning in one's life is considered to be important for psychological health which extends from self-determination theory as a process of personal growth based on intrinsic and extrinsic motivations (Ryan & Deci, 2000). In a cluster analysis, Dezutter et al. (2013) explored the complexity of having and/or searching for 'meaning' in life and its association to identity exploration profiles and psychosocial functioning. Those in possession of a strong sense of meaning and little need for searching alternative identities were considered to be the most adaptive and experienced greater psychological wellbeing and lower levels of depression. In contrast, people with a lower sense of meaning but greater searching for identity

33

experienced lower life satisfaction and were considered to be 'stuck'. Furthermore, depression and anxiety was observed in people who had low meaning and were not searching for identity and it was proposed this group experience the greatest difficulty in transitioning into adulthood. However this could be due to their circumstances which was not explored as a factor in this study.

Having a coherent narrative is the extent a person is able to integrate their past experiences to create a story about who they are. Identity coherence is not about "maintaining the status quo" (Vignoles et al. 2008) but is concerned with making sense of experiences and creating narratives that describe life events and is an important aspect of identity construction providing people with autonomy over the telling of their experience and is associated with psychological wellbeing (Adler & McAdams, 2007). This link was examined by Ritchie et al. (2013) to determine what internal (e.g. meaningless, low self-worth) and external stresses (e.g. life events) could mediate this process. They found people with a strong sense of meaning also had greater identity coherence and positive psychological health. Conversely people with a sense of low meaning and lower identity coherence experienced greater neuroticism. The direction of causality could not be determined and the results could be interpreted as person's self-concept is undermined by their experience of psychological distress as a result of adverse life events which could make it particularly difficult to derive meaning in life.

Narrative coherence and the significance of autobiographical memory was explored by Waters and Fuvish (2014) who examined its relationship with psychological well-being. The ability to tell a coherent narrative was moderately associated with positive self-view, sense of meaning and purpose and positive social relationships when narratives related to identity. This suggests that what is narrated is important for psychological well-being, particularly the interaction between content (identity) and quality (coherence) of narrative.

34

Interpersonal factors can also mediate the relationship between a person's self-concept and its continuity. In the context of how a romantic relationship break-down relates to selfconcept, when remembering or imagining relationship break-ups, individuals would change the content of their self-concept which was predictive of emotional distress. Slotter, Gardener and Finkel (2010) found over time, emotional distress did reduce, which the authors suggest was helpful to the process of self-restructuring. This study highlights the interdependent nature of self-concept and how people reconstruct their identities as a way of managing and moving through their emotional distress and underpins the tenets of interpersonal therapy (Markowitz & Weissman, 2004).

Finally, a person's moral identity also plays an important role in identity construction by influencing values, goals, behaviours and ideals. Hardy et al. (2013) explored the extent to which a person based their identity on their morals. They found people high in moral identity displayed positive psycho-social functioning and those with low moral identity presented with problematic behaviours. The authors conclude that although moral identity is important for self-concept, it does not safeguard against harmful and risky behaviours. This could have important clinical implications where a person may act, or be forced to act out of accord with their own moral identity (i.e. war veterans adjusting to a civilian life, Litz et al., 2009).

Social and Discursive Identity Studies

It is proposed that a well-rounded identity was made up of collective, personal, relational and public this can is associated with improved psychological outcomes and argued that external factors play an important role in identity construction (Schwartz et al., 2015). This is important when considering the types of interventions offered to people that look beyond developing personal identity and consider the importance of social processes.

From a social identity perspective, the importance of group affiliation was explored by Packer, Chasteen and Kang (2011) who examined individuals' expectations of future change in social identity in young adults (17-25 years). Social identity is an important aspect of personal identity as Haslam et al. (2009) argue that people internalise the values and aspirations of their group memberships which are important predictors of well-being and health. Participants rated their current and projected self-esteem (at 60 years) and those who strongly identified as being a young adult projected lower self-esteem and psychological wellbeing in older age compared to participants who had lower identification with current age group. This study suggests there is an important link between group membership and the development of personal identity and how prospective transitioning out of a current valued group is perhaps perceived as threatening and associated with negative expectations. The authors suggest this could lead to a prolonged identification with a group that an individual is no longer compatible with in order to maintain a desired identity (i.e. an adult strongly identifying as the cultural norms associated with adolescence) which could increase feelings of isolation and emotional disturbance.

In gaining a group identity that fulfils a sense of belonging and heightened self-esteem, from a social constructionist perspective, Mason-Schrock (1996) examined the interplay between the individual and group in exploring and establishing a positive identity within the transsexual community. The autobiographical stories of individuals attending a community meeting who described how they 'discovered' their transsexual identity were examined. Having listened to seasoned group members' biographical events of how they 'discovered' their identity, newcomers adopted similar narratives to describe their experiences using commonplace rhetoric to reinforce the communal identity that substantiates the narrative, but also affirms group membership. Furthermore, listeners responded with support and approval which affirmed and authenticated the identity of individuals resulting in enhanced feelings of belongingness, self-esteem and a sense of self-actualisation. Mason-Schrock (1996) suggests the experience of self-actualisation is likely to be the consequence of re-interpreting life events to match an essential rhetoric that helps people re-structure past events to express their sense of 'true self'. Their approach examines how individuals interact with concepts and practises that are culturally, socially and historically created by narratives.

Furthermore, in support of Vignoles et al. (2008), two particular identity motives are observed from Mason-Schrock's study; distinctiveness and belongingness. Within narratives, an assertive attempt was made by individuals to dissociate transsexual identity from other groups such as cross-dressers and transvestites, which was met with resounding approval from the group. Additionally, individuals' sense of belongingness on receipt of this affirmation increased the validity of group membership and self-esteem. This study emphasises the importance of group validation in affirming self-discovery and self-constructive experiences. Moreover, for certain identities that have been marginalised, the desire to carve out an identity in relation to a valued group has potentially important implications for overall well-being.

In contrast, when group affiliation consists of a marginalised or stigmatised group such as people labelled with mental illness, the consequences to psychological wellbeing are significant. Link et al. (1989) found stigma and stereotyping attached to mental health labels become internalised and lead to negative outcomes for people as they believe they will be devalued and discriminated against. This highlights the potential fluidity in social identities within the discursive paradigm, albeit they are strongly opposed by dominant discourses that may be continually reinforced because of social structures and institutions that come to uphold them.

Discussion

The literature presented within this review draws together established theoretical orientations from developmental, social-cognitive and social constructionist disciplines which offer insight into the psychological processes underlying how personal identity is formed and its link with psychological well-being. The factors contributing to identity discussed above include the motives and processes within the individual whilst other important factors were not explored fully such as the influence of cultural, ethnic, sexual and professional identity which would have provided a holistic perspective of identity formation.

What is evident from the literature presented is that identity development is not a passive process that occurs over time or a 'fixed reality' but that a person is both influencing and influenced by others in this process, indicating the personal and collective nature of self-hood. Similarly, factors that appear important to identity formation may contribute to all-round mental well-being and if lacking may also contribute to distress. However in most of the studies presented in this review, an association between identity and psychological well-being was observed but not a direction of causality therefore it cannot be determined whether identity development is important for well-being or whether well-being facilitates identity development.

For instance, across many studies, there are suggestions that an individual has choice in their identity and the process of choosing can depend on several factors such as being motivated towards a positive self-concept, wanting to feel connected to and distinct from others, developing a future self, parental and interpersonal influence and making sense of the past experiences by creating a coherent narrative (Vignoles et al., 2006). When these factors are threatened, blocked, absent or suspended, there may be a greater risk of experiencing psychological distress. This may be particularly relevant for people from deprived backgrounds where the infrastructure to support their needs is not being met by family, education, health and social services making it difficult for these individuals to navigate the process of identity construction by a desired age (Adler & McAdams 2007) and could be the cause of psychological discomfort.

The focus on internal processes of identity largely overlooked interpersonal experiences and relationships (i.e. attachment) and despite a few studies considering the relational impact on identity development, this was assessed from an individual's self-report and represented only one perspective of the dyad or collective. However, the studies did demonstrate the interdependent nature of identity construction and that it doesn't exist solely within the individual but is subject to the changes, delights and stresses of interpersonal life (e.g. Slotter et al., 2010).

These studies incorporate various domains of identity theory and confirm the complexity of identity development processes, but locate the mechanisms of change and construction within the individual. This could suggest autonomy in identity development which lacks acknowledgement for the processes by which society and the discursive practices play a part in. Moreover, there was a paucity in the systematic literature search for people who have no choice in their identity, which may have been ascribed by an organisation or society which can influence their developing self-concept and psychological well-being (Watson, 2002). For the many people living with labels bestowed upon them such as 'migrant', 'mentally ill' or 'disabled', the connotations of these labels can become internalised and have implications for people's psychological health (Watson, 2002) by influencing how they think about themselves and how people respond to them. As highlighted by Link et al. (1989), the stigma associated with mental illness can have serious implications for how people view themselves.

The association between identity and psychological well-being was observed across all studies. However, almost all used correlational analysis and therefore a direction of causality could not be assumed. Further consideration about whether psychological well-being facilitates active engagement in identity development tasks or whether being engaged is consequently beneficial to one's well-being could have important clinical implications. Additionally, for those struggling to commit or explore identity options, it was unclear whether this caused psychological distress or whether struggling with mental health difficulties and/or adverse life events (e.g. trauma, abuse) and social difficulties (e.g. homelessness, poverty) impedes identity development.

Although a strength of many of the studies was that they explored psychological wellbeing and distress across non-clinical populations which could capture a broad range of responses, the significant limitation was the high prevalence of European and North American student populations to achieve an understanding of identity development through self-report. This selection bias attempts to capture a group of people during emerging adulthood in a period of transition which Erikson (1968) proposed as being fundamental in identity formation but can only be generalised to other college-attending 16—21 years old in Western cultures and is not representative of all emerging adults. This sampling bias means that people who do not attend college or universities within these cultures are not represented, often because there is greater convenience in recruitment within a university setting. The lack of breadth in participant sampling means that factors influencing identity processes may or may not be present in other populations or may take on a different trajectory and be influenced by other things such as poverty, environment, migration and mental health difficulties. If identity development is thought to have a 'typical' process or trajectory then important idiosyncratic features relevant for individuals and groups may be missed in service and support provisions.

Furthermore in continuing to pursue this convenience sample, it is perpetuating the notion that identity consolidation is achieved during this period. Identity commitments are becoming prolonged (Baumeister, 1999) and yet the theoretical underpinnings of the studies allude to an 'optimal time' in adolescence where success or failure in identity formation is given weight. This overlooks the complexity of the human condition and fails to acknowledge the changing and challenging discourses that are influencing people in their inclinations of 'who to become' and 'who not to become' (Potter & Wetherell, 1998). It is interesting to consider what triggers this process and whether it is specific to individualistic Western cultures where there is a social expectation to have formed an identity by a certain age. The pressure can become internalised as an inadequacy on the part of individual where a need to categorise can be a pervasive societal ideal with significant social implications for an individual who has not conformed to these demands (Adler & McAdams, 2007). As Davies and Harre (1990) argue there is a political agenda for young people to develop a strong identity so that they can become cooperative and lucrative members of society. Furthermore, by categorising people in this way, those who do not possess autonomous identity are perhaps at greater risk of being negatively categorised and potentially oppressed.

Clinical Implications

The self and identity are fundamental issues within clinical practice where the process and outcome of psychological therapies is geared towards helping people in distress make sense of who they are, how they became that person, and helping them become someone they wish to be. Gaining an understanding of what mediates identity could help address internal processes through re-evaluating self-concepts that can alleviate mental distress. Identity and well-being aren't just about feeling good about oneself but feeling connected and distinct to others and having a sense of continuity and meaning are important factors (Vignoles et al., 2006). Clinical practitioners can be mindful of the link between psychological wellbeing and identity and the importance of providing a service where individuals have access to meaningful social groups which fits with the recovery principles (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). What is important to consider is sometimes people are unable to recover a sense of self as their experiences in life (i.e. through deprivation, early neglect) have made it difficult for them to carve out a sense of self from the beginning (Bowlby, 1998). This is important as newer forms of psychological therapies such as CBT or mindful practice may attempt to help a person understand and change their cognitions to rid themselves of negative thoughts about themselves (Beck, 1979) but may be a difficult task if their core self-concept is formed from negative early experiences (Bowlby, 1998). Additionally, Haslam et al. (2009) argues for the need to use social identity theory in the development of clinical services as the importance of group affiliation can be a strong mechanism in recovery and management of people's lives. This could be addressed in individual therapy as a way of helping people find and connect with meaningful social groups to act as a secure base from which to explore their identities.

Research Implication

The studies presented in this review were chosen as they explicitly investigated the relationship between identity and psychological wellbeing and distress. A large proportion of identity literature was not explored such as cultural, sexual, professional and gender and its link to mental health. The complexity of individual and group identity development and what mediates this process is important to understand in relation to modifying clinical services for a diverse population (i.e. to serve the needs of refugee groups) so that it is accessible and a meaningful opportunity for support. Future reviews could consolidate the different threads of identity models to find commonality in relation to mental health such as the role of attachment in identity development (Bowlby, 1998) or how cultural identity and acculturation is linked to wellbeing and distress.

The experience of mental distress is largely categorised as psychiatric diagnoses and there is growing awareness of mental health issues within media. However the construction of identity can be influenced by social factors such as stigma and stereotyping (Link et al., 1989). As Watson (2002) points out, people given pejorative labels have and continue to be at risk of internalising the attached stigma which has a significant impact on their identity development. For people labelled with a mental health diagnosis, the language used by professional networks and society as a whole perpetuates the stigma and isolation experienced within these groups and can lead to discrimination (Crowe, 2000; Link et al., 1989).

It is therefore potentially useful to explore the effects of labelling on identity development with a few studies exploring 'illness identity' (Walker, 2006; Yanos, Roe & Lysaker, 2010) and schizophrenia and self-concept. However there is a relative lack studies in the UK that explore the discourses of mental health labels and diagnosis that both facilitate and hinder positive identity development. This could offer insight into how people have come to understand their experiences through the discourses available and how this influences their identity and sense of self, positively or negatively.

Conclusions

This review has drawn together theoretical and empirical literature across a variety of epistemological domains to explore the link between identity and psychological wellbeing and distress. How a person comes to view themselves appears to be the result of a combination of developmental processes that are contingent on social and familial factors alongside conscious processes involving choosing and piecing together important goals, beliefs and values that motivate action towards achieving a desired identity. These processes are not solely intrinsic but are also influenced by social and discursive factors that can motivate or impede identity development.

References

- Adler, J. M., & McAdams, D. P. (2007). Time, culture, and stories of the self. Psychological Inquiry, 18, 97-99.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders, Fifth Edition. Arlington: American Psychiatric Publishing.
- Baumeister, R. F. (1987). How the self became a problem: A psychological review of historical research. Journal of Personality and Social Psychology, 52, 163–176
- Baumeister, R. F. (1999). The self in social psychology. Psychology Press: Philadelphia.
- Beck, A. T. (Ed.). (1979). Cognitive therapy of depression. Guilford press: New York.
- Berzonsky, M. D. (2008). Identity formation: The role of identity processing style and cognitive processes. Personality and Individual Differences, 44, 645–655.
- Bowlby, J. (1998). A secure base: Clinical applications of attachment theory. London: Routledge.
- Brook, A. T., Garcia, J., & Fleming, M. A. (2008). The effects of multiple identities on psychological well-being. Personality and Social Psychology Bulletin, 34, 1588-1600.
- Coid, J., Yang, M., Tyrer, P., Roberts, A., & Ullrich, S. (2006). Prevalence and correlates of personality disorder in Great Britain. The British Journal of Psychiatry, 188, 423-431.
- Côté, J. E. (1996). Sociological perspectives on identity formation: The culture–identity link and identity capital. Journal of adolescence, 19, 417-428.

- Crowe, M. (2000). Constructing normality: a discourse analysis of the DSM-IV. Journal of Psychiatric and Mental Health Nursing, 7, 69–77.
- Cushman, P. (1990). Why the self is empty. Toward a historically situated psychology. The American Psychologist, 45, 599–611.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. Journal for the theory of social behaviour, 20, 43-63.
- Dezutter, J., Waterman, A. S., Schwartz, S. J., Luyckx, K., Beyers, W., Meca, A., ... Caraway, S. J. (2014). Meaning in life in emerging adulthood: A Person-Oriented Approach. Journal of Personality, 82, 57–68.
- Erikson, E. (1968). Youth: Identity and crisis. WW Norton & Company. New York.
- Erikson, E. H., & Erikson, J. M. (1998). The life cycle completed (Extended Version). WW Norton & Company. New York.
- Flett, G. L., Hewitt, P. L., & Singer, A. (1995). Perfectionism and parental authority styles. Individual Psychology: Journal of Adlerian Theory, Research & Practice.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. American psychologist, 40, 266.
- Goffman, E. (2009). Stigma: Notes on the management of spoiled identity. Simon and Schuster: New York.
- Hardy, S. A., Francis, S. W., Zamboanga, B. L., Kim, S. Y., Anderson, S. G., & Forthun, L.F. (2013). The roles of identity formation and moral identity in college student mental

health, health-risk behaviors, and psychological well-being. Journal of clinical psychology, 69, 364-382.

- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health and wellbeing: an emerging agenda for applied psychology. Applied Psychology, 58, 1-23.
- Jørgensen, C. R. (2006). Disturbed sense of identity in borderline personality disorder. Journal of Personality Disorders, 20, 618–644.
- Kroger, J. (2007). Why is identity achievement so elusive? Identity: An International Journal of Theory and Research, 7, 331-348.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. The British Journal of Psychiatry, 199, 445-452.
- Link, G., Cullen, T., Struening, E., Shrout, E., & Dohrenwend, P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. American Sociological Review, 400-423.
- Litz, B. T., Stein, N., Delaney, E., Lebowitz, L., Nash, W. P., Silva, C., & Maguen, S. (2009). Moral injury and moral repair in war veterans: A preliminary model and intervention strategy. Clinical psychology review, 29, 695-706.
- Luyckx, K., Goossens, L., Soenens, B., & Beyers, W. (2006). Unpacking commitment and exploration: Preliminary validation of an integrative model of late adolescent identity formation. Journal of adolescence, 29, 361-378.

- Luyckx, K., Soenens, B., Berzonsky, M. D., Smits, I., Goossens, L., & Vansteenkiste, M. (2007). Information-oriented identity processing, identity consolidation, and well-being: The moderating role of autonomy, self-reflection, and self-rumination.
 Personality and Individual Differences, 43, 1099–1111.
- Luyckx, K., Schwartz, S. J., Berzonsky, M. D., Soenens, B., Vansteenkiste, M., Smits, I., & Goossens, L. (2008). Capturing ruminative exploration: Extending the fourdimensional model of identity formation in late adolescence. Journal of Research in Personality, 42, 58-82.
- Luyckx, K., Schwartz, S. J., Soenens, B., Vansteenkiste, M., & Goossens, L. (2010). The path from identity commitments to adjustment : Motivational underpinnings and mediating mechanisms. Journal of Counseling & Development, 88, 52–60.
- Luyckx, K., Klimstra, T. A., Duriez, B., Schwartz, S. J., & Vanhalst, J. (2012). Identity processes and coping strategies in college students: short-term longitudinal dynamics and the role of personality. Journal of youth and adolescence, 41(9), 1226-1239.
- Manzi, C., Vignoles, V. L., Regalia, C., & Scabini, E. (2006). Cohesion and enmeshment revisited: Differentiation, identity, and well-being in two European cultures. Journal of Marriage and Family, 68, 673-689.
- Manzi, C., Vignoles, V. L., & Regalia, C. (2010). Accommodating a new identity: Possible selves, identity change and well-being across two life-transitions. European Journal of Social Psychology, 40, 970–984.
- Marcia, J. E. (1966). Development and validation of ego-identity status. Journal of personality and social psychology, 3, 551.

- Markowitz, J. C., & Weissman, M. M. (2004). Interpersonal psychotherapy: principles and applications. World Psychiatry, 3, 136-139.
- Markus, H., & Wurf, E. (1987). The dynamic self-concept: A social psychological perspective. Annual review of psychology, 38, 299-337.

Maslow, A. H. (1943). A theory of human motivation. Psychological review, 50, 370.

- Mason-Schrock, D. (1996). Transsexuals' narrative construction of the" true self". Social Psychology Quarterly, 176-192.
- National Institute for Health and Care Excellence (2012). Process and Methods Guides: The Guidelines Manual: Appendix F: Quality appraisal checklist – quantitative intervention studies. London, UK: National Institute for Clinical Excellence.
- Packer, D. J., Chasteen, A. L., & Kang, S. K. (2011). Facing social identity change: Interactive effects of current and projected collective identification on expectations regarding future self-esteem and psychological well-being. British Journal of Social Psychology, 50, 414-430.

Piaget, J. (2013). The construction of reality in the child (Vol. 82). Routledge, UK.

- Pittman, J. F., Keiley, M. K., Kerpelman, J. L., & Vaughn, B. E. (2011). Attachment, identity, and intimacy: Parallels between Bowlby's and Erikson's paradigms. Journal of Family Theory & Review, 3, 32-46.
- Potter, J., & Wetherell, M. (1998). Social representations, discourse analysis, and racism. The psychology of the social, 138-155.

- Rahim, E. (2010). Marginalized through the "Looking Glass Self" The development of Stereotypes and Labeling. Journal of International Academic Research, 10.
- Ritchie, R. a., Meca, A., Madrazo, V. L., Schwartz, S. J., Hardy, S. a., Zamboanga, B. L., ...
 Lee, R. M. (2013). Identity Dimensions and Related Processes in Emerging
 Adulthood: Helpful or Harmful? Journal of Clinical Psychology, 69, 415–432.
- Roberts, S. E., & Côté, J. E. (2014). The Identity Issues Inventory: Identity stage resolution in the prolonged transition to adulthood. Journal of Adult Development, 21, 225-238.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. The American Psychologist, 55, 68– 78.
- Schlenker, B. R. (1986). Self-identification: Toward an integration of the private and public self. In Public self and private self (pp. 21-62). Springer New York.
- Schwartz, S. J. (2001). The Evolution of Eriksonian and, Neo-Eriksonian Identity Theory and Research: A Review and Integration. Identity, 1, 7–58.
- Schwartz, S.J. (2005). Identity and agency in emerging adulthood: Two developmental routes in the individualisation process. Youth and Society, 1, 7-58.
- Schwartz, S. J., Forthun, L. F., Ravert, R. D., Zamboanga, B. L., Umaa-Taylor, A. J., Filton,
 B. J., ... & Hudson, M. (2010). Identity consolidation and health risk behaviors in college students. American Journal of Health Behavior, 34, 214-224.

- Schwartz, S. J., Klimstra, T. a., Luyckx, K., Hale, W. W., Frijns, T., Oosterwegel,
 A.,...Meeus, W. H. J. (2011). Daily dynamics of personal identity and self-concept clarity. European Journal of Personality, 25, 373–385.
- Schwartz, S. J., Hardy, S. A., Zamboanga, B. L., Meca, A., Waterman, A. S., Picariello, S.,
 ... Forthun, L. F. (2015). Identity in young adulthood: Links with mental health and risky behavior. Journal of Applied Developmental Psychology, 36, 39–52.
- Sedikides, C., & Strube, M. J. (1995). The multiply motivated self. Personality and Social Psychology Bulletin, 21, 1330–1335.
- Skowronski, J. J. (2012). I, Me, Mine: Variations on the Theme of Selfness. Social Cognition, 30, 396-414.
- Slotter, E. B., Gardner, W. L., & Finkel, E. J. (2010). Who am I without you? The influence of romantic breakup on the self-concept. Personality and Social Psychology Bulletin, 36, 147-160.
- Soenens, B., Berzonsky, M. D., & Papini, D. R. (2015). Attending to the role of identity exploration in self-esteem. Longitudinal associations between identity styles and two features of self-esteem. International Journal of Behavioral Development, DOI: 0165025415602560.
- Strenger, C. (2013). The designed self: Psychoanalysis and contemporary identities. Routledge: London.
- Tajfel, H. (2010). Social identity and intergroup relations. Cambridge University Press: New York.

- Turner, J. C., Oakes, P. J., Haslam, S. A., & McGarty, C. (1994). Self and collective: Cognition and social context. Personality and social psychology bulletin, 20, 454-454.
- Vignoles, V. L., Regalia, C., Manzi, C., Golledge, J., & Scabini, E. (2006). Beyond selfesteem: influence of multiple motives on identity construction. Journal of Personality and Social Psychology, 90, 308–333.
- Vignoles, V. L., Manzi, C., Regalia, C., Jemmolo, S., & Scabini, E. (2008). Identity motives underlying desired and feared possible future selves. Journal of Personality, 76, 1165–1200.
- Walker, M.T. (2006). The Social Construction of Mental Illness and its Implications for the Recovery Model. International Journal of Psychosocial Rehabilitation, 10, 71-87.
- Waterman, A. S. (1984). Identity Formation: Discovery or Creation? The Journal of Early Adolescence, 4, 329–341.
- Waterman, A. S. (2004). Finding someone to be: Studies on the role of intrinsic motivation in identity formation. Identity, 4, 209-228.
- Waters, T. E., & Fivush, R. (2015). Relations between narrative coherence, identity, and psychological well-being in emerging adulthood. Journal of Personality, 83, 441-451.
- Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. Disability & Society, 17, 509-527.
- Winnicott, D. W., Shepherd, R., Winnicott, C., & Davis, M. (1992). Babies and their mothers. Perseus Publishing: Massachusetts.

Yanos, P.T., Roe, D., and Lysaker, P.H. (2010). The impact of illness identity on recovery from severe mental illness. American Journal of Psychiatric Rehabilitation, 13, 73-93.

Section B

Examining how service-users talk about their mental health diagnosis and its impacts on self and identity.

Word Count: 7976 (8340)

For submission to: Social Science and Medicine

Abstract

Psychiatric diagnosis is used to categorise and treat mental health problems in the UK yet is widely criticised for struggling to convincingly categorise the experience of distress and that it is socially constructed from the culmination of historical and cultural interactions. Service-user accounts are varied and there is a paucity of qualitative research that considers the positive and negative effects of labelling. To understand identity construction in the context of a psychiatric diagnosis, the present study recruited 16 participants from a service-user research group and five focus groups were conducted. Transcripts were studied using Foucauldian Discourse Analysis. Two major identities were detected 'illness identity' and 'recovery identity'. Participants drew on multiple and competing discourses and which placed them in the position of patient and/or survivor. Medical discourses were dominant throughout the focus groups and were used in a way to convey the fluidity of the identity and how they related to their diagnosis. The study's limitations are discussed, together with implications for clinical practice and future research.

Keywords: self, identity, diagnosis, mental health, distress, labelling

Introduction

Psychiatric diagnosis

The use of psychiatric diagnosis is commonplace in mental health practice and practitioners commonly use the Diagnostic and Statistical Manual for Mental Disorders (American Psychiatric Association [APA], 2013) and the International Classification of Diseases (World Health Organisation, 2010) as guidance to evaluate, classify symptoms and diagnose mental illness. This classification system has come to be known as 'the disease model' and has received wide criticism for struggling to convincingly categorise the experience of distress, with arguments against its validity, reliability and clinical utility. (Bentall, 2003, British Psychological Society [BPS], 2013; May, 2007; Timmi, 2013). The BPS (2013) argues for a paradigm shift where greater emphasis is placed on understanding the social and psychological components of mental distress. In a more extreme position, the 'No More Psychiatric Labels Campaign' (Timimi, 2013) call for the complete abandonment of psychiatric diagnoses on the grounds that they provide a flawed foundation for understanding mental distress.

Social constructionists argue that mental illness is socially constructed and forms historical and current 'taken-for-granted' ways of understanding the distress (Eisenberg, 1988; Hacking, 2013; Harper, 1996). It is thought dominant discourses locate the problem within the individual, overlooking the myriad of social and cultural explanations which effect how they and others view their experience (i.e. poverty, domestic violence; Bentall, 2003). Willig (1999b) argues from a critical realist position that powerful structures are responsible for socialising individuals to its systems. Callard (2014) suggests that extreme positions are not helpful and perpetuate the stigma associated with mental health. In this view, the issue of diagnosis is multifaceted and Callard acknowledges the complexity of social structures that

rely on diagnosis and the categorisation of distress (i.e. healthcare, justice, welfare). Callard (2014) argues the need to view this issue as 'muddy waters', suggesting that the polarities in the debate need to move beyond whether classification should or shouldn't be used and towards an appreciation that can open dialogue to understand the highly complex processes that contribute to the opportunities and constraints of diagnosis.

Identity and Mental Health

Research into identity spans several psychological domains and epistemologies. Personal identity is broadly described as a person's subjective self-conception and expression from an individual perspective or by group affiliation and influenced by biological characteristics and psychological needs mediated through social opportunities and constraints (Kroger, 2007). A person's social identity is how a person views themselves based on their groups membership (Tajfel, 2010). Haslam (2014) suggests social identity plays an important role for individuals understanding themselves and argues that interventions that promote social groups need greater prevalence in clinical practice. Furthermore, research suggests a sense of coherence and continuity, belongingness, distinctiveness and enhanced self-esteem are important for identity development (Vignoles, Regalia, Manzi, Golledge & Scabini, 2006) which are in line with the principles of the recovery approach (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). If these are threatened or absent, opportunities for positive identity development become diminished.

These processes are largely located within the individual and adhere to a positivist epistemology. From a social constructionist perspective, people are thought to construct an identity based on the discursive repertoires available to them (Davies & Harre, 1990, Gergen, 1985). In the case of mental health, stigmatising discourses can result in people gradually identifying with characteristics associated with the label (Yanos, Roe & Lysaker, 2010). Within emancipatory movements, mainstream social sciences are implicated in producing and strengthening notions of a realist identity through the application of categories which can serve to segregate and oppress groups (Cromby, Harper & Reavey, 2007; Moncrieffe, 2010; Watson, 2002).

Illness identity

A core issue of using labels is the language and beliefs that become attached to 'disorders' where a person's past, present and future life can become viewed through this lens (Crowe, 2000) and characteristics that are stereotypically associated with 'mental illness' can become internalised (Corrigan, Watson & Barr, 2006; Roe & Davidson, 2013; Yanos et al., 2010). Although diagnosis is often welcomed as it can provide access to support, it can also function as a way to divert blame away from a person or their family for their problems, reflecting how people can become stuck in the 'brain-blame' game (BPS, 2014). The vast majority of people diagnosed with a mental illness are likely to have experienced stigma or be aware of this problem and as a result, develop beliefs about how people will respond to them, which can lead to issues of self-stigma (Corrigan et al., 2006). Individuals can withdraw from society due to beliefs that they will experience further discrimination (Link, Struening, Cullen & Shrout, 1989).

Walker (2006) describes how the concept of mental illness has evolved and become embedded in social structures with noticeable power imbalances where a person with a mental illness is socially positioned as 'the other' who is disadvantaged. In a review of mental illness and identity in mental health nursing, Crowe (2000) found significant consequences of labelling where people internalised negative stereotypes which reified their position as a patient. Moreover, in a discourse analysis study with people diagnosed with schizophrenia in the United States, Tucker (2009) found participants attempted to avoid association with the label due to its media portrayal of 'dangerousness'. Interestingly, beliefs of causality appeared to determine whether a person took on an illness identity or whether they were able to regain a sense of agency and move towards recovery.

In developing an 'illness identity' model, Yanos et al. (2010) reviewed the literature and found people who accepted and internalised the illness identity experienced a reduced sense of hope and resilience. Conversely, those who accepted the diagnosis but did not internalise the negative narrative demonstrated a greater sense of agency where they took on more positive aspects associated with an illness identity and rejected the stigmatising parts. This enabled them to link with support groups to reframe their experiences which aided the recovery process.

Pasman (2011) notes a gap in the research for the positive effects of diagnosis which stigmatising and labelling theories have overlooked such as the sense of relief in having a name for a problem which could reduce self-blame for previous undesirable behaviour which can increase self-esteem. In an interpretative phenomenological analysis, Young, Bramham, Gray and Rose (2008) interviewed eight adults recently diagnosed with ADHD and detailed a six-stage model of psychological acceptance of the diagnosis including: relief and elation, confusion, anger, sadness, anxiety and accommodation and acceptance. The latter stage marked a period of interpersonal change and growth rather than a passive acceptance of an illness identity. In a grounded theory study, Williams and Healy (2001) developed an 'exploratory model' to convey how participants who had recently received a mental health diagnosis made sense of their distress and suggest diagnosis played an early, important role in 'sense-making' and beliefs about the cause of distress were not fixed but would fluctuate between biological, psychological and social explanations. These studies highlight the complex journey a person can make when given a label

Recovery and Survivor Movements

The concept of recovery is adopted in UK mental health services and is based on a person-centred approach helping people develop hope, resilience and agency for recovering a meaningful life (Anthony, 1993) and by providing a holistic view of distress that focuses on the person (Mental Health Foundation, 2015). A major review of service users' experiences suggested five key processes of recovery: connectedness, hope, optimism, meaning in life and empowerment whilst being respectful of culturally specific factors such as spirituality and collectivist notions of recovery for individuals of Black and Minority Ethnic (BME) origin (Leamy, Bird, Le Boutillier, Williams & Slade, 2011) which reflect Vignoles et al.'s (2006) motivations for identity development.

The survivor movement challenges the disease model as being reductionist, diminishing hope, medication-driven and disempowering (National Survivor User Network, n.d). A survivor can be described as a person having journeyed and endured their traumatic experience of mental health and/or services and is committed to campaigning for change (National Survivor User Network, n.d). In an interpretive interactionism study, Adame and Knudson (2007) found people diagnosed with psychiatric conditions viewed themselves and their distress as 'chemical imbalances' and 'broken brains' but those who positioned themselves as 'psychiatric survivors' were able to construct an alternative narrative to the disease model. Arguably this could open opportunities for people to assume more powerful positions where they can claim and reframe an identity on their terms and empower others with similar experiences.

Discourse Analysis

Social constructionist researchers take a critical stance regarding positivist assertions of a fixed reality by challenging 'taken-for-granted' assumptions and highlighting alternative ways of viewing the world. A person's choices, agency and sense of self are thought to be influenced and limited by the discourses available, creating versions of reality (Willig 1999a). Identity therefore is viewed as a dynamic and fluid process and as a social action or accomplishment (Willig, 2008). Discourse analysis is particularly useful for exploring the dynamics of identity in relation to psychiatric diagnosis, as how individuals talk about such categories may give insight into the subject positions enacted by their discourses (see Davies & Harre, 1990).

Although discourse analysis is usually conducted from a social constructionist epistemology, it is often criticised for working primarily at an epistemological level and lacking the social action required to make real change (Willig, 1999b). A critical realist position merges epistemological relativism with ontological realism by acknowledging the different versions of truth created through discourse balanced with recognising that events have an objective basis and are produced by underlying and powerful structures (e.g. economic, social). These are regarded less as permanent fixtures and more as patterns created and continually reinforced by the use of accepted discourses, and therefore subject to change.

Present study

How we view, describe and categorise ourselves has important implications for overall wellbeing and can also be the source of distress (Sedikides & Strube, 1997). The experience of mental distress itself can cause isolation, despair and frustration, made more difficult when people experience stigma (Bentall, 2013). The literature largely explores the negative impact

of psychiatric diagnoses, particularly in adopting an illness identity (Yanos et al., 2010). In exploring the ways in which people talk about their experiences of being diagnosed, discourse analysis can identify problematic discourses as well as positive ones.

There are currently no discourse analysis studies within the UK that explores the talk of service users and the ways in which all categories of psychiatric diagnosis has influenced how they view themselves. Furthermore, there are few studies that consider both the positive and negative experiences of diagnosis and the perceived effect on identity, the majority detailing an illness identity (e.g. Tucker, 2009; Walker, 2006). This may suggest a bias within the literature and paradoxically perpetuates a negative narrative which might overlook alternative experiences and other potential identities and subject positions to illness (Pasman, 2011). For applied psychologists, this can be important to understand idiosyncratic limitations and/or opportunities of mental health diagnoses which could enable practitioners working with people with or without a diagnosis to consider the importance of these categories including issues of group identity (Haslam, 2014).

Research questions

The following questions were explored:

- a. How do members of a service-user research group construct their identity in the context of their mental health diagnosis?
- b. What implications does this have for social positioning?
- c. What opportunities does a mental health diagnosis afford and/or close down?

Methods

<u>Design</u>

From a critical realist position, Foucauldian Discourse Analysis was used to analyse the data which can explore the power relationships expressed in language and talk (Willig, 2008).

Participants

A purposive sampling method recruited members of three service user research groups within a highly populated geographical area who had lived experience of mental health difficulties. The inclusion criteria were:

- Over 18 years old
- Current or past mental health service-user
- Member of a local service-user group

Of 24 people who expressed an initial interest, 20 consented to participate. Following this, two people withdrew due to personal circumstances and 16 attended the five separate focus groups comprising of nine women and seven men (age range 30-55 years). Three participants were currently working full-time, four were volunteer researchers, three were students, three were not working, two were retired, two were volunteer workers and one participant did not disclose their occupation. Fourteen participants had been given at least one diagnosis and these included: schizophrenia, anxiety, depression, personality disorder, bipolar disorder, stress, psychosis, adjustment disorder, obsessive compulsive disorder and body dysmorphia. Two participants had not received a diagnosis, six participants reported having

two diagnoses, five had three diagnoses and two participants had more than three diagnoses. Participants had used mental health services varied between 18 months and 27 years.

Materials **Materials**

The question schedule for the focus groups was devised by the author using Bamburg, De Fina and Schiffrin's (2013) discursive approach to examining identity (appendix D). An information sheet (appendix E), a consent form (appendix F) and a demographic questionnaire (appendix G) were also created by the author.

Service user consultation

Members of one service-user research group were consulted on two separate occasions for feedback on the information sheet and questioning schedule through general discussions and a reflective role play. The critique of the original questions in the schedule described some questions as being "too wordy" or "jargony" and amendments were made to the schedule and approved by the consultation group.

Procedure

Three service user-led research groups were approached and given information sheets and an informal presentation outlining the details of the project. Contact details were taken from the people who expressed interest in participating and were emailed or telephoned within two weeks to ascertain whether they still wished to participate and to arrange focus group timings.

The use of focus groups has been recommended as a useful way of doing discourse analysis (Smithson, 2000) and Krueger and Casey's (2008) recommendation for focus groups of 3-4 participants was followed as this allowed for sufficient depth of the topic. Participants

attended one focus group which consisted of members of their research locality group as stated as a preference.

Participants were asked to complete the demographic questionnaire and focus groups lasted between 75 and 90 minutes followed by a 10 minute debrief session. At this point, participants were asked to confirm their consent and given the option to withdraw. All focus groups were recorded and the author transcribed each of them verbatim.

Ethics

Ethical approval was gained from the Bromley Research and Ethics Committee (appendix H) and Research and Development approval was obtained from a local NHS trust (appendix I). The guidelines from the BPS (2010) and university were followed and all participants provided informed consent. An end of study form (appendix J) and an abridged version of the study was sent to the Research and Ethics Committee and R&D department (appendix K) and participants (appendix L).

Data Analysis

Willig's (2008) six-stage approach to Foucauldian Discourse Analysis was used: identifying discursive constructions, discourses, action orientations, positioning, practice and subjectivity (appendix M).

Rigour and Quality of the Analysis

The findings reported here are one interpretation and there are a number of different ways the texts could be read and regular supervision meetings were used to discuss discourses. Lincoln and Guba (1985, cited in Houghton, Casey, Shaw & Murphy, 2013) recommend employing four criteria to determine the rigour and quality of qualitative research: credibility

(value and believability), dependability (reliability), confirmability (neutrality and accuracy) and transferability (extent findings applies to similar contexts). The credibility of this work was achieved through attending several peer debrief meetings following focus groups and throughout the analysis where excerpts of transcripts were discussed. As the researcher is part of the evaluation process, reflexivity was required to evaluate dependability and confirmability and this was achieved by completing a bracketing interview with a fellow researcher to identify any assumptions and personal experiences related to the interview topic which could influence the way in which the data are analysed (Fischer, 2008) and a reflexive research diary (appendix N) was kept. Furthermore, rigour for dependability and confirmability was supported by providing an audit trail to outline decisions of the research process. Mays and Pope (2000) suggest providing an account of the evolution of early classifications (discourses) and a discourse analysis progression diary (appendix O) and an annotated transcript (appendix P) was maintained. In providing these detailed accounts of the progression of the analysis, the quotes portray thick descriptions of the discourses and subject positions outlined in the results and the transferability of the research was enhanced. Journal publishing notes are also included (appendix Q).

Results

The participants presented with two types of identity. An 'illness identity' seemed to position participants into a patient role and a 'recovery identity' appeared to position participants as an 'expert by experience' or 'survivor'. Medical discourses were largely present throughout the focus groups and often used alongside occasional psychological and social discourses. The extent of how people related to these discourses in terms of agency seemed to vary depending on the identity being talked about.

The research questions will be addressed by presenting over-arching discourses of the two identities, their subject positions and opportunities and limitations for these identities. In line with social constructionist perspectives of identity (Davies & Harre, 1990, Gergen, 1985), participants were not fixed toward one identity, but occupied different positions which appeared to fluctuate depending on the context discussed. In the absence of a definitive and universal description of mental health and/or distress, the language used in this paper will take on many discursive descriptions, depending on the interviewees' preferred discourse.

Illness identity

The seems to be two main discourses associated with an illness identity were 'having a life-long mental illness', 'them and us' and 'legitimising and supporting a disease model'. Within these over-arching discourses, smaller repertoires are discussed in the context of social positioning and associated limitations and opportunities.

Having a life-long mental illness

Participants used discourses to describe themselves as 'having' an illness whilst recognising stigmatising discourses about mental health diagnoses. As they adopted an illness narrative, they appeared to reorganise perceptions of themselves and of mental health generally, dispelling previously used discourses such as 'dangerousness as an aspect of schizophrenia' which is often associated with this label (Tucker 2009):

"when I was diagnosed with schizophrenia at first, I didn't believe them. Before I had schizophrenia, I had the same stigma as everyone else...thought it was violent people...to be labelled it myself, it took me a long time to actually accept that I had it" (Gavin²).

The social positioning for a person who takes on an illness identity could mean they are viewed by themselves and others through a diagnostic lens and they cease to be a person with a history or a future (Crowe, 2000):

"it was just really really scary and the doctors and the staff just spoke to me, not as a person, they didn't care that I had a life before I was in there [hospital]. They just talked to me like I was someone who was really really ill and they didn't take the time out for me" (Sally).

As their lives had changed abruptly and having faced numerous challenges (e.g. hospitalisation, stigma), their previous identity was historical:

"I'm living a completely different life to the one I was living before...it changed just overnight...I just wanted it to go back to the way things were" (Gavin)".

All behaviours, thoughts and feelings appeared to be located within the person and other potentially contributing factors such as relational or situational difficulties are overlooked:

"When people read about the diagnosis, every last action or behaviour then becomes a part of your diagnosis and [reactions to situations] can just be brushed under the carpet as opposed to be taken seriously" (Miranda).

Looking beyond the diagnosis appeared to be difficult and the discourse of 'seeing the illness, not the person' denied the possibility of a person's distress being taken seriously. Part

² Names have been changed

of the difficulty is probably the contentiousness of such a discourse, since one's own family may be implicated (unconsciously or not). It seemed diagnosis served a function for some participants to divert blame towards a biological disorder as a way to negotiate difficult social territory. Furthermore, in accepting the diagnosis as an indicator of an underlying biological disorder, it offered participants a way to divert blame away from their actions:

"I appreciated receiving a diagnosis because it made me feel less freakish. I generally just thought I was quite a nutter so it was quite nice to be told I had something" (Miranda).

This can help to justify and/or defend against possibly pejorative discourses of blame about previous behaviours that may have caused harm or upset to others:

"I can relax and know why I'm doing it, it is for a reason. It's not just because I'm just playing up or misbehaving...I got aggressive with my mum and I think that was the illness...and that the diagnosis was right" (Rosie).

Despite acknowledging the stigmatised identity, participants sometimes used the diagnosis to preserve a positive identity as someone who wouldn't behave in this way without there being a medical condition:

"That [diagnosis] completely validated that I wasn't in control...these had been inbuilt in me before I had a chance to take sort of any responsibility for it. So I was able to pass the buck a little bit more as opposed to a lot of self-blame" (Miranda).

This may also have a downside, in possibly leading to self-fulfilling prophecy:

"when you're given a diagnosis and a label, you sort of absolve yourself of responsibility as well so you do engage in worse behaviour in some ways" (Kyle).

68

This is a clear example of the label seeming to increase the identity as mentally ill, even to the point of acting into it. It also seemed necessary to reframe previous assumptions about mental health so as to view the self in a more positive and empathic light:

"I probably had a bad view of mental health myself...I always looked down on people as well but now I don't. I'm completely the reverse, I think I'm more understanding than the average person" (Sam).

Participants also used discourses of 'diagnosis as explanation' which appeared to provide clarification for their difficult experience, which is at odds with claims that functional mental health diagnosis is simply descriptive and should not be taken as providing causal explanations (American Psychiatric Association [APA], 2013):

"when I was told I had a schizophrenia...I was shocked and I felt really bad then at the same time then I also felt relieved that I knew what I had and then I can move on" (Sam).

However, the differing light in which various diagnoses are held made a difference to people's ability to accept them:

"as soon as you get a diagnosis [psychosis], it's common everyone has it...my second was the schizophrenia, that came as a shock because I think it's just like stigmatism" (Sam).

Most participants had received more than one diagnosis and drew on discourses of 'getting the right diagnosis leads to the right treatment and recovery' as receiving the 'wrong diagnosis' seemed to have consequences:

"With bipolar, [hope] was taken away, 'you're bipolar have some antipsychotics, learn to live with it'. When I was diagnosed with something else, with it came some hope that ok, no guarantees but it could actually improve" (Miranda) and

"I'm in a better place to deal with it as I've had treatment and I've got the right medication but when I wasn't on medication it was just so difficult" (Sonya).

It also gave opportunities for others to understand them better and give support:

"people can help by having a bit of an understanding of how to deal with things with you...understand more about how I react to things differently and maybe slightly more forgiving at times" (Derek).

This discourse of 'diagnosis as explanation' is easily understood when applied to a long-term physical condition (i.e. multiple sclerosis). There has been a well-intentioned push for mental illness to be viewed as 'illness like any other' (Read, Haslam, Sayce, & Davies, 2006) which adds to the widespread belief in an underlying biological disorder, which has taken hold in the public mind. Whilst there are clear and objective causes for certain physical conditions, the same cannot be applied to mental distress where social and environmental factors are often implicated in its cause or maintenance (BPS, 2014).

In accepting a diagnostic label, participants drew on 'life-long and permanent' discourses' in relation to their identity. This could maintain their position of patient and could potentially close down opportunities for alternative identity discourses to develop, making it difficult to view themselves and their life beyond the label:

"It's acknowledging its part of you but then at the same time, for me it kind of always been part of me" (Sarah) and "you'll always be diagnosed...You want to be positive but you can't because of the issues you're having" (Gavin) and

"I don't have any symptoms anymore but it's probably the medication doing it" (Gavin) and

"I wouldn't say [I'm] cured. I've got a borderline brain I'd say" (Miranda).

This suggests the illness discourse as one of 'long-standing disability' which continues to position people in a 'patient' role where opportunities for work or recovery are diminished because of the implied personal deficits:

"he [social worker] said she'll be no good at this...because of my diagnosis and I don't see myself in the same light now...it's really hard having mental health because I can't work, the stress makes me ill so I'm unworkable" (Claire).

The stigma and fear of discrimination also closes down opportunities to share experiences and participants withdrew and attempted to keep their mental health difficulties private, sometimes leading to withdrawal from society (Link et al., 1989):

"My diagnosis is one where the only thing people know about it is when someone gets killed or stabbed or someone who is at the extreme end of paranoid schizophrenia, that's why I wouldn't want it broadcast around anywhere" (Pete),

This diminishes opportunities for people to get support as they are safeguarding against stigma and negative beliefs of others or the anticipated difficulty people may have in understanding the diagnosis: "it's a lot easier to turn around to someone and say I suffer from anxiety or depression than it is to turn around and say BPD cos then you have to convince them it's real" (Miranda).

Other discourses of 'powerless to make own decisions' were used where participants who had assumed an illness identity looked for the direction of a professional which maintains the power imbalance and puts the professional in the position of 'expert', reifying 'them and us' divisions:

"I just wondering if anyone actually gets diagnosed well, if you can be diagnosed back....cos you're on medication, they put you on medication and then you get better...if you come off the medication you get ill again...if you're on medication, you'll never be diagnosed well. (Gavin).

Them and Us

The widespread beliefs and stigma associated with mental health which can maintain a 'them and us' divide with concerns about how other people may react (BPS, 2014; Link et al., 1989):

"it's sane people's image of a schizophrenic who goes on a mad rampage" (Pete).

This may cause potential barriers to being open about one's mental health, causing dilemmas of questioning whether to share their diagnosis with others which may limit opportunities for making wider social connections through fear of further stigma (Link et al., 1989):

"I haven't told anybody about it, not cos I feel ashamed but cos I don't want people to feel awkward around me" (Pippa) and

"I might have to say I've got mental health problems, or should I just leave it. You know it's one of those questions that arises" [Sam] and

"with BPD I'm slightly wary about who I interact with because of how I may behave or react to certain situations...sometimes alienate yourself from other people who you might want to be with" (Tony).

Discourses of 'normality' could also serve to maintain separation within society where participants viewed people without mental health difficulties as different:

"I find people with that more interesting than the average ordinary person. Don't get me wrong, I like normal people too because you get that sense of normality" (Sam)" and

"There's more of a story with someone with mental health" (Debbie)

In creating divisions between those who have and have not got a mental illness, in/outgroup membership is maintain and potentially closes down opportunities for social mobility. Furthermore, discourses of 'them and us' could be viewed as an attempt to assert a person's social identity whereby participants defended against normalising discourses of psychological distress:

"you get people who just have had a yucky day....What real depression is, when you need medication... to unblock the chemicals in your body and people don't understand that you know" (Claire).

73

Those not accessing mental health services, without a diagnosis or using medication may be positioned as 'normal'. Thus, the need for explaining one's distress as a biological illness legitimises certain kinds of support and treatment but at the same time, denies the possibility of 'being normal', placing people in an impossible dilemma. By not accepting an illness identity, participants could be placed in position of defending and trying to validate their distress as a way of connecting with a group that could offer support:

"I don't know about mental illness but with depression perhaps there's kind of such a wide spectrum...I feel really depressed but because it's such a wide spectrum one person's depression is not another person's depression" (Pippa).

Legitimising and supporting a disease model

Still within the over-arching discourse of 'illness identity', participants appeared to use discourses that suggested they were socialised to a disease model to explain their experience which can maintain stigma and misunderstanding (BPS, 2014; Read et al., 2006):

"a diagnosis is something like a confirmation to some extent that there is something that needs treating or looking at...the confirmation that there is something else going on (Kyle).

In attempting to make sense of their experiences, participants sought validation through a legitimised system, placing professionals in an authoritative and expert role and the participant in the position of 'patient' whereby distress is reified as something one 'has got':

"I really wanted to know what my diagnosis is so I can look up things and know what I'm going through so it was like who to believe...what's the truth then, what should I be looking up and what have I actually got" (Sonya) and "the team decided yes I definitely did have OCD and at the point I thought "great somebody else believes and listens to me"... not having the diagnosis was the bigger problem. By not having it, nobody took me seriously and so much of my life was wasted..." (Debbie)

Discourses described 'uncertainty' and 'distress' in the absence of a medical explanation where:

"not knowing what my diagnosis was worse...I really wanted to know, I was so hurt with what was going on...I was hurt when I thought it might be psychosis...but I'd rather be hurt and know what I have got" (Sonya).

With a lack of a clear explanation being offered, participants would self-diagnose:

"it was always me that would suggest what was wrong...I wish that someone had come along earlier and said that's what's wrong and you can start dealing with it from then on" (Kyle).

Although this portrayed a greater sense of agency, it seemed to suggest a wish to be acknowledged by a professional system which maintains its expert position:

"they are in these positions, they should know what's going on and be able to give you a correct diagnosis" (Tony).

This seemed necessary for Tony as he was required to provide validation of an illness to support absence from work as he was being positioned as 'faking it'. Without the diagnosis from a credible source:

"they thought I was putting it on" (Tony)

Having their internal distress acknowledged by others seemed to be an ongoing battle for participants who drew on discourses of 'having to prove something was wrong' which can lead to crisis point. A diagnosis seemed to provide confirmation and validation of an illness which had previously been denied:

"It got that desperate and nobody really wanted to believe it....that was the real big challenge, people not accepting that you can be unwell..... which actually made me do something quite drastic and the relief actually when I was in the hospital although it was hell on earth, it was a big relief happened...I wasn't having to be this strong person. I didn't have to pretend everything was alright" (Carly) and

"you know when there's something wrong with you but you're not quite sure, you're just not aware of it and it seems like that it was the only way I could find out and get a diagnosis was for something dramatic to happen" (Debbie).

Furthermore, participants were generally supportive of the function of diagnosis and defended against change as it served many functions and the absence of it increased uncertainty and fear of further isolation and stigma:

"To take away completely would be belittling" (Miranda) and

"It might make you think you were really going mad...in the stereotyped way like... if you don't have the diagnosis or you don't have the right one, you'd be thinking 'what is it, what's wrong with me''' (Carly).

This seems to fit with a broader discourse of illness being widely seen as something to be recognised so that sufferers get help and support. The identity as someone who is ill positions people as legitimately receiving support, and there may be other unspoken discourses, such as blame by family members or those who provide benefits, who might otherwise confer an identity and social position of being lazy, difficult or uncooperative people. This suggests people may be caught between 'blame or brain' discourses (BPS 2014), specifically they are either blameworthy for not doing what others want them to, or there is something wrong with their brain as the only alternative possibility. No other discourse is easily available or generally accepted, such as discourses about how life events and early experiences can affect people's mental well-being which could position them as being 'recovering/recovered', 'survivor' or an agent of their own wellbeing.

Recovery Identity

A recovery identity was observed across all focus groups and participants appeared to draw on a variety discourses that gave more detail to experiences of mental distress and how they were rebuilding their lives. The major discourses were 'using a diagnosis for selfimprovement' and 'rejecting a disease model in favour of own explanation'. Both over-arching discourses appeared to position people as 'survivors' and 'expert by experience' and increased opportunities for autonomy and recovery:

Using a diagnosis for self-improvement

Naming a problem appeared to be as important as having an explanation. Without a name, a person may still identify as 'mad' but of an unknown variety as the person is still experiencing the distress and seeks answers to develop ways of coping and being informed:

"It's better the devil you know...it doesn't matter what the diagnosis is, once you've got the diagnosis you know what you're dealing with, you know how to research it to find out how to get better" (Debbie) and "if the label comes with the education and you learn how to apply that to your personal situation then it's like a combination of the two [diagnosis and education]" (Kyle).

This may position people as agents of their own recovery at the same time as claiming a social identity of someone who is ill who can work with the experts to help themselves. This could be seen as positive, even though it positions a person as dependent on the expert for guidance. It is clear one is doing everything possible to help oneself however it raises the question of possible unspoken discourses, such as potential accusations of not working towards recovery.

The importance of having a positive social identity (Haslam, 2014) was observed in the discourses of 'diagnosis giving opportunities for contact and belongingness with others with similar experiences' which is important for recovery (Leamy et al., 2009) and identity development (Vignoles et al., 2006):

"being with other people who have experienced similar things...for me it's been really helpful" (Carly).

Furthermore it provided participants with opportunities to reach out to people who may otherwise struggle to seek support and share and maintain hope:

"you've been through what they've been through...I think this helps them to open a little bit... they can see 'oh he's going through it, he's at the end of the tunnel and he's come out of it now perhaps there's hope for me" (Derek).

For other participants, they made attempts to draw on other identities for their wellbeing alongside the illness identity:

78

"sometimes it's nice to go out...where you're not reminded all the time about the reason why you're not working or you're on meds...It's just something that's a normality, a bit of fun...doing something meaningful that wasn't mental health" (Derek).

Whereas for others, the illness identity appeared to be less of a defining characteristic

"I don't know if I really think about my diagnosis now...sometimes I can get a bit anxious and things and then I think is that my diagnosis?" (Rosie).

This appeared to offer alternative explanations for distress which ceases to locate the problem within the person and strengthens participants' position of 'power' and agency where they are able to be critical of 'taken-for-granted' assumptions of distress (Willig, 1999b):

"it's external things that affect you internally and you don't know what you're going to meet on a day to day basis or how you're going to manage certain situations" (Carly) and

"What's happened in the environment and social can make you or get you where you are today as opposed to just being schizophrenic" (Miranda).

"when you get diagnosed with something like bipolar, it's often seen as a medical issue....that realisation that it's nothing to do with something wrong in your brain or your personality, it's something that's happened...it completely shifts it" (Carly).

For others, there were discourses of how having a name can have positive impact on personal recovery:

"to me diagnosis can be positive....it means you finally know what you're tackling and it can give you a jumping off point for getting more information, getting access to treatment, getting access to support and help, finding others you've got a similar diagnosis and getting support from them" (Debbie) and

"I'm much more aware of what I need to not get anxious and I know what my triggers are much more and I know what I need to do to keep myself feeling good...I think that's been a helpful thing really" (Carly)

Discourses of 'strategies to build resilience and determination' to recover from mental illness were prevalent which showed participants carrying on with life despite the challenges:

"as well as having diagnosis and being told what you have and what medication, there's an element where you need that determination to get well as well, I think that's very important for your recovery and knowing yourself very well" (Sam) and

This potentially places participants in a position of being a 'striver' and motivated to move towards recovery, whilst maintaining an acceptance of the medical explanation.

Rejecting the disease model in favour of own explanations

From a position of 'survivor' and 'expert by experience', participants used discourses to reject an illness identity, demonstrating autonomy for defining their own experiences:

"For me describing I have a mental illness is a problem cos it gives me the feeling that it's something that I can't do anything about and that lack of control" (Pippa).

Furthermore participants used discourses that defended against the limitations often associated with mental health diagnoses:

"a diagnosis has never stopped me, it's just there, you're aware of it, it doesn't necessarily stop me" (Miranda) and

"My coping mechanism for my illness is to not ignore it, but tell myself that I haven't got one...I've gone on to live a full life and work and study... that's how I've functioned and recovered from the illness because of my inner strength and belief to combat it" (Pete).

Additionally, participants drew on discourses of being a survivor of mental health services and being critical of the treatment they received which appeared to actively defend against being in a passive role:

"I stepped out of the service I was in because of the treatment I was under cos I disagreed with them quite a lot and I actually told them...I didn't think I was bipolar" (Miranda).

Participants also used critical discourses against diagnosis, describing it as being an inhuman act:

"I don't believe in a diagnosis...it's not right...It's ideal for baked beans, a tin of baked beans than myself" (Claire) and

"I like them to know who I am, not what I'm suffering from" (Claire).

This positions Claire as an advocate for change against a system where seeing the person, not the illness is firmly asserted as a way they wish to be viewed which ties in with the survivor movement principles (Anthony, 1993).

Discussion

This study took a critical realist position and aimed to explore how participants negotiated their identity in relation to whether they had or hadn't received a mental health diagnosis. In doing so, it was hoped that both the positive and negative experiences would be elicited. The analysis identified two main identity profiles; illness identity and recovery identity. Although it may appear that these identity profiles occupied opposing ends of the spectrum of how a person relates to their mental health, the analysis observed an integration of these identities which conveys the complexity and fluidity of identity (Bamburg et al., 2013), specifically when people are able to use their diagnosis as part of the recovery process.

When people spoke of their diagnosis, it followed that they would use medical discourses which positioned them as a patient and potentially closing down opportunities for autonomy as they sought 'expert guidance' within a legitimised system. For many participants with a diagnosis, they appeared to 'own' and 'accept' a biomedical explanation for their distress and in receiving the 'right diagnosis', they also received the 'right treatment' which gave them a way of understanding and/or absolving previous difficulties. A diagnosis seemed to offer initial 'sense-making' as well as validation and access to a support network that was felt to be important for their recovery.

It seemed that getting diagnosis that to describe their experience and seen as 'right' was more important than getting no diagnosis as participants were able to make sense of their experience in a society where people tend to be blamed when they find life difficult and external

82

causes are often invisible, so that their only recourse is perhaps to claim illness (Yanos et al., 2010). This could be viewed alongside Young et al.'s (2008) psychological acceptance model where people move through a complex journey of initial relief to acceptance and growth. However there seemed to be a state of permanence for these labels where some participants were reluctant or unable to assert agency in removing the label themselves with assumptions that it was the professionals that had the expertise to do so which could maintain their illness identity and a power imbalance (Crowe, 2000).

Identities that adopted recovery discourses seemed open to alternative explanations for distress of social and personal circumstances alongside biological causes. This reflects the tenets of the recovery model where people are creating their own narratives for their distress (Mental Health Foundation, 2015). For some, the recovery discourse empowered them to reject diagnoses that didn't fit with their experience at the same time as continuing to use medical discourses in a way that was meaningful to them. Throughout the focus groups, participants acknowledged the stigmatising effects of labelling however when considering the arguments for abandoning diagnoses, participants appeared to defend its utility. This may suggest that in becoming socialised to the 'disease model', service-users are presenting a complex relationship that can both facilitate and hinder identity development.

In reviewing the analysis, it is important to consider all sides of the function of a diagnosis and the relationship people have with it. In the absence of categories that attempt to explain symptoms, it may be a containing and validating experience where someone feels that another person has taken them seriously (Young et al., 2008). In fact, those who described being in a recovery position were able to consolidate patient and recovery identities that gave them hope, resilience, support and information for them to rebuild their lives. With this more complex view, it is important that the varied discourses and relationships people have with

their diagnosis is shared widely to improve public and professional understanding of human distress to tackle the polarity of 'brain or blame' explanations (BPS, 2014).

Limitations

Discourse analysis research has been criticized for being overly interpretative and intellectualising of experiences (Willig, 1999b). In evaluating the discourses available in the focus groups, there is greater risk that how the researchers interpret the data may in itself be a reduction of the experience in the mechanics of language, something that this epistemological position is against. Furthermore it is difficult to ascertain whether the intent of the speaker was to convey this message or whether it was interpreted as such by the listener and discussions with supervisors and the bracketing interview were an important part of safeguarding against such biases (Fisher, 2009; Mays & Pope, 2000).

It is also important to consider the potential participant bias in the study and the discourses, identities and experiences represent only the self-selecting participants who were at a stage in their recovery which enabled them to be reflective of their experiences of diagnosis. For those recently diagnosed or struggling to maintain a sense of hope or empowerment in relation to their distress, their experiences and ways of talking about diagnosis may present differently. As the study was being conducting within the NHS context, this could further influence what and how issues of mental health are talked about (Willig, 1999a). Furthermore, the participants were experienced and dedicated members of a research group who regularly take part in focus groups. I observed them to remain close to the topic of diagnosis which could have attracted more of a medical discourse. Had the topic been alternatively framed (i.e. experience of diagnosis in relation to your recovery), this may have allowed experiences and discourses to be discussed. As noted in the analysis, issues of 'them and us' appeared to be prevalent discourses which could have been enacted in the focus groups

where they could have experienced the researcher as representing a professional status which could influence their discussions.

Implications

This study attempts to offer a complex and nuanced perspective of diagnosis and how this can be part of enacting a person's identity. The focus group context may have shaped how people talked, such as how they enacted certain identities in this context. By exploring both positive and negative experiences, the study addressed the paucity of studies approaching the positive and negative effects of diagnosis (Pasman, 2011) that aimed to be considerate of all the voices and experiences. Furthermore, it acknowledges the complexity of the issue and what Callard (2014) calls the 'muddying' of the waters.

The prevalence of medical discourses through the focus groups could indicate missing discourses of social explanations of mental distress which may reflect the relative lack of funding research and media attention (BPS, 2013). This suggests participants could be stuck within a 'brain versus blame' (BPS, 2014) dilemma where talking about alternatives to the disease model can induce the blame game. Future research could examine these issues in relation to recovery.

For clinical practice, it may help practitioners to consider the wide variety of experiences and perspectives and the complexity of how a diagnosis interacts with a person's self-concept. It could help them in the assessment and intervention process of how, when and whether a diagnosis would be helpful or not based on individual assessment rather than the philosophical and professional perspective of the practitioner. Based on the values of participatory action research (Hutchinson & Lovelli, 2013), future studies could utilise the 'expert by experience' position of service-user research groups to help others recently

diagnosed to begin a journey of 'psychological acceptance' (Young et al., 2008) to helpfully develop more balance relationship with their diagnosis. As Haslam (2014) notes, the importance of social identity and the values that a group can create can provide a powerful clinical intervention which can support individuals in their recovery.

Conclusion

The study examined the talk of service users attending a focus groups to understand how they may have negotiated an identity in relation to the psychiatric diagnosis they may or may not have received by mental health services. The rationale of the study was to add to the existing literature that examines the impact of receiving a diagnosis on self and identity and the aim was to consider both positive and negative experiences from service-user perspectives. Foucauldian discourse analysis provided an opportunity to examine how participants talked about their experiences of receiving a diagnosis, how they attempted to make sense of 'who they were' in relation to others and how this positioned them socially. The results outlined two major identities: illness and recovery which suggested that participants had a complex relationship with diagnosis. Although medical explanation were often sought to reduce selfblame, get help and begin recovery it also caused many dilemmas for participants' relationships and future outlook. It seemed that a diagnosis had the power to maintain a permanent perspective of how participants came to view themselves. This was talked about as being both helpful as it gave opportunities for self-improvement and recovery but it also maintained stigma and isolation and a 'them and us' divisions. The implications of the research could help practitioners, regardless of their professional stance towards diagnosis, consider the complexity and importance diagnosis plays in a person's life and how this can be both a helpful and unhelpful process, depending on how the individual makes sense of this experience.

References

- Adame, A.L., & Knudson, R.M. (2007). Beyond the counter-narrative: Exploring alternative narratives of recovery from the psychiatric survivor movement. Narrative Inquiry, 17, 157-178.
- American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders (5th Ed.). Arlington, VA: Author
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. Psychosocial rehabilitation journal, 16, 11.
- Bamburg, M., De Fina, A., and Schiffrin, D. (2013). Discourse and Identity Construction. In Schwartz, S.J., Luyckx, K., and Vignoles, V. (2013). Handbook of Identity Theory and Research. London: Springer
- Bentall, R.B. (2003). Madness Explained: Psychosis and Human Nature. London, England: Penguin Group.
- British Psychological Society. (2010). Code for Human Research Ethics. Retrieved from http://www.bps.org.uk.
- British Psychological Society. (2013). Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift. DCP position statement. Retrieved from <u>http://www.bps.org.uk</u>
- British Psychological Society. (2014). Understanding Psychosis and Schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with

reality and what can help. The Division of Clinical Psychology. Retrieved from <u>http://www.bps.org.uk</u>

- Callard, F. (2014). Psychiatric diagnosis: the indispensability of ambivalence. Journal of Medical Ethics. DOIi: 10.1136/medethics-2013-101763.
- Corrigan, P.W., Watson, A.C, and Barr, L. (2006). The self-stigma of mental illness: implications for self-esteem and self-efficacy. Journal of Social and Clinical Psychology, 25, 875-883.
- Cromby, J., Harper, D., and Reavey, P. (2007). Moving beyond diagnosis: Practising what we preach. The Psychologist, 20 (5), 298-299.
- Crowe, M. (2000). Constructing normality: a discourse analysis of the DSM-IV. Journal of Psychiatric and Mental Health Nursing, 7, 69–77.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. Journal for the Theory of Social Behaviour, 20, 43-63.
- Eisenberg, L. (1988). The social construction of mental illness. Psychological Medicine, 18, 1-9.
- Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. Psychotherapy Research, 19, 583-590.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. American psychologist, 40, 266.
- Hacking, I. (2013). Lost in the Forest. [Review of the book DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.] London Review of Books, 35, 7-8. Retrieved from <u>http://www.lrb.co.uk/v35/n15/ian-hacking/lost-in-the-forest</u>.

Harper, J.D. (1995). Discourse analysis and 'mental health'. Journal of Mental Health, 4, 347-357.

- Haslam, S.A. (2014). Making good theory practical: Five lessons for an Applied Social Identity Approach to challenges of organisational, health and clinical psychology. British Journal of Social Psychology, 53, 1-20.
- Houghton, C., Casey, D., Shaw, D., & Murphy K. (2013). Rigour in qualitative case-study research. Nurse Researcher, 20, 12 -17.
- Hutchinson, A., and Lovelli, A. (2013). Participatory action research: moving beyond the mental health 'service-user' identity. Journal of Psychiatric and Mental Health Nursing, 20, 641-649.
- Kroger, J. (2007). Why is identity achievement so elusive? Identity: An International Journal of Theory and Research, 7, 331-348.
- Krueger, R.A., and Casey, M.A. (2008). Focus Groups: A Practical Guide for Applied Research.Fourth Edition. Sage Publications Inc: California, USA.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. The British Journal of Psychiatry, 199, 445-452.
- Link, G., Cullen, T., Struening, E., Shrout, E., & Dohrenwend, P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. American Sociological Review, 400-423.

May, R. (2007). Working outside the diagnostic framework. The Psychologist, 20, 300-301.

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. British medical journal, 320(7226), 50.

Mental Health Foundation. (2015). Retrieved January 04, 2016, from <u>https://www.mentalhealth.org.uk/</u>

Moncrieff, J. (2010). Psychiatric diagnosis as a political device. Social Theory and Health, 8(4), 370-382. doi:10.1057/sth.2009.11.

National survivor user network. (n.d.). Retrieved January 04, 2016, from http://www.nsun.org.uk/

- Pasman, J. (2011). The consequences of labeling mental illnesses on the self-concept: A review of the literature and future directions. Social Cosmos, 2, 122-127.
- Read, J., Haslam, N., Sayce, L., & Davies, E. (2006). Prejudice and schizophrenia: a review of the 'mental illness is an illness like any other' approach. Acta Psychiatrica Scandinavica, 114, 303-318.
- Roe, D., and Davidson, L. (2005). Self and narrative in schizophrenia: time to author a new story. Journal of Medical Ethics: Medical Humanities, 31, 89-94.
- Sedikides, C., & Strube, M. J. (1995). The multiply motivated self. Personality and Social Psychology Bulletin, 21, 1330–1335.
- Smithson, J. (2000). Using and analysing focus groups: limitations and possibilities. International journal of social research methodology, 3, 103-119.

Tajfel, H. (2010). Social identity and intergroup relations. Cambridge University Press: New York.

- Timimi, S. (2013). No more psychiatric labels: Campaign to abolish psychiatric diagnostic systems such as ICD and DSM (CAPSID). Self & Society, 40(4), 6-14. Retrieved from <u>http://ahpb.org/index.php/about-self-society</u>.
- Tucker, I. (2009). "This is for Life": A Discursive Analysis of the Dilemmas of Constructing Diagnostic Identities. Forum: Qualitative Social Research, 10. Available at <u>http://www.qualitative-research.net/index.php/fqs/article/view/1376/2872</u>.
- Vignoles, V. L., Regalia, C., Manzi, C., Golledge, J., & Scabini, E. (2006). Beyond self-esteem: influence of multiple motives on identity construction. Journal of Personality and Social Psychology, 90, 308–333.
- Walker, M.T. (2006). The Social Construction of Mental Illness and its Implications for the Recovery Model. International Journal of Psychosocial Rehabilitation, 10, 71-87
- Williams, B., and Healy, D. (2001). Perceptions of illness causation among new referrals to a community mental health team: "explanatory model" or "explanatory map"? Social Science and Medicine, 53, 465-476.
- Willig, C. (1999a). Applied Discourse Analysis: Social and Psychological Interventions.Buckingham, England: Open University Press.
- Willig, C. (1999b). Beyond Appearances: Critical realist approach to social constructionist work. In Nightingale, D.J., and Cromby, J. (1999). Social Constructionist Psychology: A critical analysis of theory and practice. Buckingham, England: Open University Press.
- Willig, C. (2008). Introducing Qualitative Research in Psychology: Second Edition. Maidenhead, England: Open University Press.

World Health Organization. (2010). International statistical classification of diseases and related health problems (10th ed., text rev.). Retrieved from <u>http://apps.who.int/classifications/icd10/browse/2010/en</u>

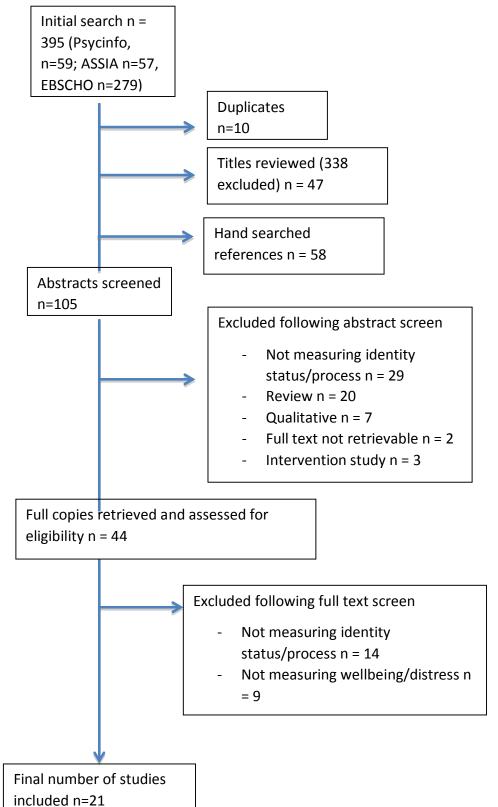
- Young, S., Bramham, J., Gray, K., & Rose, E. (2007). The experience of receiving a diagnosis and treatment of ADHD in adulthood: a qualitative study of clinically referred patients using interpretative phenomenological analysis. Journal of Attention Disorders. DOI: 10.1177/1087054707305172
- Yanos, P.T., Roe, D., and Lysaker, P.H. (2010). The impact of illness identity on recovery from severe mental illness. American Journal of Psychiatric Rehabilitation, 13, 73-93.

Section C: Supporting Materials

Appendix A: Boolean search phrases

(self*' OR 'identity' OR 'ego') AND ('formation' OR 'develop*' OR 'discover*' OR 'construct*' OR 'defin*' OR 'actual* OR' realis*' OR 'process' OR 'motiv* OR social) AND ('wellbeing' OR 'well-being' OR 'mental' OR 'distress')

Appendix B: Flow diagram of search results



Appendix C: Example of Guidelines of Appraisal Criteria for Quantitative Studies (NICE, 2012b).

- Is the source population or source area well described?
- Is the eligible population or area representative of the source population or area?
- Do the selected participants or areas represent the eligible population or area?
- How was selection bias minimised?
- Was the selection of explanatory variables based on a sound theoretical basis?
- Was the contamination acceptably low?
- How well were likely confounding factors identified and controlled?
- Is the setting applicable to the UK?
- Were the outcome measures and procedures reliable?
- Were the outcome measurements complete?
- Were all the important outcomes assessed?
- Was there a similar follow-up time in exposure and comparison groups?
- Was follow-up time meaningful?
- Was the study sufficiently powered to detect an intervention effect (if one exists)?
- Were multiple explanatory variables considered in the analyses?
- Are the study results internally valid (i.e. unbiased)?
- Are the findings generalisable to the source population (i.e. externally valid)?

| ++ | Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias. |
|---------------------------|--|
| + | Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design. |
| _ | Should be reserved for those aspects of the study design in which significant sources of bias may persist. |
| Not reported (NR) | Should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered. |
| Not applicable (NA) | Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case–control studies). |

Rating criteria for stidues

Appraisal of literature review studies

| Studies | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 |
|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| Population (well sourced and representative) | + | + | + | + | + | + | + | + | ++ | ++ | + | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | + |
| Methods (minimised bias, control sample, confounding variables identified) | ++ | ++ | ++ | ++ | + | + | ++ | + | ++ | ++ | + | ++ | ++ | ++ | ++ | ++ | ++ | + | ++ | ++ | ++ |
| Outcomes (complete and reliable) | + | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | NA | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ |
| Analyses (sufficient power, appropriate) | ++ | + | + | ++ | ++ | + | ++ | ++ | + | ++ | NA | ++ | ++ | ++ | ++ | + | + | ++ | ++ | ++ | ++ |
| Summary (validity and generalisability) | ++ | + | + | ++ | ++ | + | ++ | ++ | ++ | ++ | + | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ |
| Overall rating | ++ | + | + | ++ | ++ | + | ++ | ++ | ++ | ++ | + | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ |

Questions for focus groups

| Potential constructs for exploration | Proposed Questions | | | | | |
|--------------------------------------|---|--|--|--|--|--|
| | What does it mean to think about yourself? | | | | | |
| Self-concept and identity | How do you describe/think about yourself? | | | | | |
| | What, if anything, does your diagnosis say about you? | | | | | |
| | What, if anything, has your diagnosis done to your sense of self? | | | | | |
| Subject positions | What have you lost/gained through having a diagnosis? | | | | | |
| | How do you discuss your diagnosis with others? | | | | | |
| | Has the diagnosis affected how your introduce yourself? | | | | | |
| | Are there particular situations when you wouldn't mention your diagnosis? | | | | | |
| | What is your thinking behind this decision? | | | | | |
| Change over time | What was it like when you didn't have a diagnosis? | | | | | |
| | How has your relationship with your | | | | | |
| | diagnosis changed over time? | | | | | |
| | How do you see yourself now compared to when you were first diagnosed? | | | | | |
| Relationship to diagnosis | What do you think about diagnosis in general? | | | | | |
| | Jonerun. | | | | | |
| | What do you think about diagnosis from your personal experience? | | | | | |
| | How has your diagnosis affected you? | | | | | |
| | Positively or negatively | | | | | |

Appendix E: Information sheet for participants (version 3)

Information about the research

Study title: Mental health diagnosis and you

Hello. My name is Suzanne Platt and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

Mental health is a broad subject and affects thousands of people's lives in many ways across the UK. People are beginning to talk more about what it's like to live with a mental health difficulty and also what it's been like to receive a psychiatric diagnosis.

Language and how it is used can be powerful and over the course of history, how different mental health difficulties have been named and the meaning of these names has changed overtime. This has meant how it is talked about has also changed. This can influence how society views people experiencing distress and how support is offered. Similarly, a person's diagnosis can change, and over the course of a person's life it can shape how they come to view themselves and potentially impact on things they are able to do with their lives.

Being able to understand the processes of language in relation to distress, both currently and historically, can offer insight into the relationship people have with their diagnosis and its impact, if any, on their lives. For some people, it is not diagnosis but distress that affects them most, while others say that diagnosis itself has a big effect, in one way or another.

There are no studies in the UK that seek to explore how service users talk about mental health diagnosis and its impact, good or bad, and this study offers an opportunity to critically reflect on this.

Why have I been invited?

You have been invited to take part in this study as you have lived experience of mental health difficulties and may or may not have a diagnosis, and we would like to learn about what this experience has been like for you.

Do I have to take part?

It is up to you to decide whether or not to join the study. If you agree to take part, you will be asked to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you are interested in participating, you will be asked to attend one of four focus groups with other ResearchNet members lasting for 1.5 hours each. Each focus group will be facilitated by me and will explore your experiences and views related to mental health diagnosis. Each focus group meeting will be audio-recorded and transcribed with all personally identifiable information removed or anonymised.

Expenses and payments

Travel expenses of up to ± 10 can be claimed to contribute to the cost of travel to the focus group.

What will I have to do?

The focus groups will explore the following topics:

- How is diagnosis helpful or unhelpful?
- Your experience of diagnosis
- How, if at all, did a diagnosis impact on your sense of self?
- What opportunities and limitation did you experience because of your diagnosis?

What are the possible disadvantages and risks of taking part?

You may decide to talk about your past experiences in the focus groups which may be upsetting and it is recommended you organise support for this.

What are the possible benefits of taking part?

You can choose what you discuss in the focus groups. You will be contributing to research that explores the possible impact of diagnosis on identity. This will give you an opportunity to critically reflect on diagnosis with other group members. Although there is no intended clinical benefit, this research can offer professionals insight into how mental health diagnosis impacts on how people come to view themselves which in turn may challenge their own assumptions and enrich their practice. It is possible that you will also find it an interesting experience to discuss the issue.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason at any point until your focus group is completed. After the focus group, there will be a short debrief where you can decide whether or not you are happy for your data to be used in the study. If you decide to withdraw after this point, your data will still be used but we will not use any direct quotes from you within the report.

Complaints

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of the study, you can contact me (Suzanne), Sue Holttum or John McGowan (Salomons' supervisors of the project) or Neil Springham (supervisor at Research Net) who will do their best to address any issues of concern to you. The full contact details are at the end of this information sheet.

If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director and Clinical Psychologist, Christ Church Canterbury University, Salomon's Estate, Broomhill Road, Tunbridge Wells, TN3 0TG. Email: paul.camic@canterbury.ac.uk.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The focus groups will be audio-recorded and transcribed and all information will be kept strictly confidential and stored on secure computers in locked offices and in locked filing cabinets and all identifiable information will be removed so that you cannot be recognised.

After the study has finished, a CD containing the anonymous focus group transcript will be kept in a locked filing cabinet in a specified office in Christ Church Canterbury University. This will be kept for 10 years. It will not be possible to identify you from this data, because when I transcribe the focus groups I will change names of people and places, and any other identifying information.

There are some limitations to confidentiality and if we feel concerned about your safety or the safety of anybody else then we will discuss this with you and may inform a member of a clinical team to ensure that you receive support.

What will happen to the results of the research study?

It will not be possible to identify you in the results or in the report but we may include anonymised quotes from the focus groups. The results will be used to form part of a doctoral thesis for a doctorate in Clinical Psychology at Christ Church Canterbury University. A report about the study will also be submitted to the Journal of Mental Health. If you wish, when the project has finished we will send you a letter describing the major findings and letting you know where the findings will be published.

Who is organising and funding the research?

The study is being organised and funded by Canterbury Christ Church University.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by an independent research panel at Canterbury Christ Church University and by a local NHS research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it, you can leave a message for me on a 24-hour voicemail phone line at 03330117070. You need to put in the new 24-hour voicemail. Please say that the message is for me [Suzanne Platt] and leave a contact number so that I can get back to you. You can also send me an email:s.e.platt502@canterbury.ac.uk.

Other contact details: Sue Holttum: Tel: 0333 011 7113email: <u>sue.holttum@canterbury.ac.uk</u> John McGowan: Tel: 03330117107email: john.mcgowan@canterbury.ac.uk Neil Springham: email: <u>neil.springham@oxleas.nhs.uk</u>

Appendix F: Consent form (version 3)

CONSENT FORM

<u>Centre Number:</u> <u>Study Number:</u> <u>Participant Identification Number for this study:</u> <u>Title of Project:</u> Examine how service-users talk about their mental health diagnosis and its impacts on self and identity. <u>Name of Researcher</u>: Suzanne Platt

Please initial box

1. I confirm that I have read and understand the information sheet dated 21/07/2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw my data up until the focus group has completed and after this point, the researcher will retain and use my data for analysis but no direct quotes will be used.

3. I agree that anonymous quotes from my interview may be used in published reports of the study findings

4. I agree to take part in the above study.

Name of Participant_____ Date_____

Signature _____

Name of Person taking consent _____ Date_____

| Signature | |
|-----------|--|
|-----------|--|

Appendix G: Demographic questionnaire

Participant Number:

Thank your participation in this study. Please answer the following questions:

| 2) | Gender: Age: Marital status: | | | |
|--------|--------------------------------------|-----------------|-----------------|---------------------------------|
| | | | | |
| , | education Are you service user of | | | |
| | How long have you or services? | r the person yo | u care for been | |
| 8) | | mental health | | noses you have been given since |
| Anxi | ety | | | |
| Atten | tion deficit hyperactivi | ty disorder | | |
| Autis | m spectrum condition | | | |
| Bipol | lar Disorder | | | |
| Depr | ession | | | |
| Eatin | g disorder | | | |
| Obse | ssive compulsive disor | der | | |
| Perso | onality disorder | | | |
| Psyci | nosis | | | |
| Schiz | cophrenia | | | |
| I have | e not been given a diag | nosis | | |
| Prefe | r not to say | | | |
| | | | | |
| Other: | | | | |
| | | | | |

.....

Appendix H: Ethics approval letter

Removed for electronic submission

Appendix I: Research and Development Approval (trust name removed)

Removed for electronic submission

Appendix J: NRES end of study form Removed for electronic submission

Appendix K: Summary feedback for Research and Development and Ethics

Runcie Court, David Salomons Estate Broomhill Road Tonbridge Wells TN3 0FT

Email: seplatt502@canterbury.ac.uk

Dear Mr Pseudonym,

This letter is to inform you that the research project entitled: "Examining how service-users talk about their mental health diagnosis and its impacts on self and identity" has been completed and submitted for marking. Please find below a brief summary the findings from the research project.

Summary of findings

Psychiatric diagnosis is used to categorise and treat mental health problems in the UK yet is widely criticised for struggling to convincingly categorise the experience of distress and that it is socially constructed from the culmination of historical and cultural interactions. Service-user accounts are varied and there is a paucity of qualitative research that considers the positive and negative effects of labelling. To understand identity construction in the context of a psychiatric diagnosis, the present study recruited 16 participants from a service-user research group and five focus groups were conducted. Transcripts were studied using Foucauldian Discourse Analysis. Two major identities were detected 'illness identity' and 'recovery identity'. Participants drew on multiple and competing discourses and which placed them in the position of patient and/or survivor. Medical discourses were dominant throughout the focus groups and were used in a way to convey the fluidity of the identity and how they related to their diagnosis. This study attempts to offer a complex and nuanced perspective of diagnosis by exploring both and positive and negative effects of diagnosis that aimed to be considerate of all the voices and experiences.

Examining how service-users talk about their mental health diagnosis and its impacts on self and identity.

Introduction

Psychiatric diagnosis is used to categorise and treat mental health problems in the UK yet is widely criticised for struggling to convincingly categorise the experience of distress. The stigma associated with mental health is significant and it is thought that people can begin to view themselves in a negative way or to think of themselves as being 'permanently ill' (illness identity: Yanos, Roe & Lysaker, 2010) based on what is culturally associated with their diagnosis. However, service-user accounts are varied and there is a lack of qualitative research that considers the positive and negative effects of diagnosis (Passman, 2011).

Discourse Analysis

It is thought a person's choices and sense of self are influenced and limited by the discourses available to them (Willig 1999b). Discourse analysis can be helpful in examining how people talk (discourses) about their experiences and what this might mean for how they are viewed by themselves and other people.

Present study

The literature largely explores the negative impact of psychiatric diagnoses, particularly in adopting an illness identity (Yanos et al., 2010). In exploring the ways in which people talk about their experiences of being diagnosed, discourse analysis can identify problematic discourses as well as positive ones.

The following questions were explored:

- 1) How do members of a service-user research group construct their identity in the context of their mental health diagnosis?
- 2) What implications does this have for social positioning?
- 3) What possibilities does a mental health diagnosis afford and/or close down?

Method

The present study recruited 16 participants from a service-user research group and five focus groups were conducted. The author transcribed the audio-recorded files verbatim.

Results

The participants presented with two main types of identity. An 'illness identity' seemed to position participants into a patient role and a 'recovery identity' appeared to be position participants as an 'expert by experience' or 'survivor'. Participants used medical terms throughout the focus groups and alongside occasional psychological and social discourses. The major discourses associated with an illness identity:

- 'having a life-long mental illness' (a diagnosis was a permanent fixture and participants may be positioned as 'patients')
- 'them and us' (noticing differences between people with and without and diagnosis and struggle to have a voice with a professional system)

The major discourses associated with a recovery identity were:

- 'using a diagnosis for self-improvement' (getting the right diagnosis can lead to support and treatment and can help people to have confidence in rebuilding their lives)
- 'rejecting a disease model in favour of own explanation' (having endured difficult and sometimes traumatic treatment in services, participants found their own explanations often still using medical discourses to make sense and begin recovery. This positioned them as 'survivors'.

In line with social constructionist perspectives of identity (Davies & Harre, 1990), participants were not fixed toward one identity, but seemed to have multiple identities which fluctuated depending on the context discussed.

The results suggest that participants had a complex relationship with diagnosis and that although medical explanation is often sought to reduce self-blame, get help and begin recovery, it also caused many dilemmas for participant's relationships and future outlook and it seemed that once diagnosed, it would form a permanent part of how a person viewed themselves.

Limitations

Participants were at a stage in their recovery which enabled them to be reflective of their experiences of diagnosis and for people recently diagnosed or not in a stage of recovery, their experiences and ways of talking about diagnosis may present differently. As the study was being conducting within the NHS context, this could further influence what and how issues of mental health are talked about (Willig, 1999b).

Clinical/Research Implications

This study attempts to offer a complex perspective of diagnosis by exploring both and positive and negative experiences that aimed to be considerate of all the voices and experiences. For clinical practice, it may help practitioners to consider the wide variety of experiences and perspectives and the complexity of how a diagnosis can (or not) influence a person's self-concept. It could help them in the assessment and intervention process of how, when and whether a diagnosis would be helpful or not based on individual assessment rather than the philosophical and professional perspective of the practitioner.

Contact details

Researcher: Suzanne Platt (Canterbury Christ Church University) Email: <u>s.e.platt502@canterbury.ac.uk</u> Address: Salomons Centre for Applied Psychology, Runcie Court, Broomhill Road, Tunbridge Wells, TN3 0FT Supervisors: Dr Sue Holttum (CCCU) Dr John McGowan (CCCU) Mr Neil Springham (Oxleas NHS Foundation Trust)

Appendix M: Willig's (2008) Six stage Foucauldian Discourse Analysis that was used as a guide to analyse the transcripts of the focus groups:

1) Discursive constructions: To identify sections of the text that refer both explicitly and implicitly to the discursive constructions of: mental health, illness, diagnosis, self and identity.

2) Discourses: To identity how discourses are used to refer to the discursive constructions and the different ways they are talked about

3) Action orientation: To consider what is gained, produced and the function of the discourses

4) Positioning: to consider what subject positions are being taken up or assigned within the network of speakers

5) Practice: to consider the relationship between the discourse and practice what opportunities are opened up and closed down in this interaction

6) Subjectivity: to explore the different ways of seeing the world and how the discourses construct social and psychological realities.

Appendix N: Abridged reflexive research diary

<u>Nov 13</u>

I was in a lecture today on psychiatric diagnosis and some of the faculty were reflecting on their experiences/thoughts of it. I was really struck by something Angela said and she thought the relationship people have with their mental health diagnosis made a difference to how they viewed themselves. I'd been reading 'Madness Explained' by Richard Bentall and have since thought about the positive and negative effects of diagnosis. In my work in IAPT, I met many people who seemed to feel very connected to having had a diagnosis in the past. I'd like to develop this idea further, specifically about how identity may have been shaped by it and how it may have helped/hindered their relationships with family, services and the wider community. I feel strongly that diagnosis can't be all bad, that there is a middle ground to explore.

<u>Nov 13</u>

I've contacted Sue Holttum and John McGowan who have both agreed. I'm very excited that I have support in my ideas and from people who are really passionate about this topic. We're doing discourse analysis – which I'm really happy about. I'm a bit worried that I've never done qualitative research before and it feels a bit difficult to grasp what it is and how I do it but I've been reassured by external supervisor Neil that I'll get the hang of it!

Dec 13

I'm beginning to feel a real sense of ownership over the project and finding it difficult to discuss some of the ideas with all the supervisors who perhaps have a different take on diagnosis so I'm keen to retain a core of the values and direction of the project but not closed to new ideas. I've done a bracketing interview with a fellow researcher and we talked about my motivation to do this particular topic. I got the sense that some arguments and some presentations of the argument against diagnosis were from an 'intellectual' perspective and sometimes from people who didn't have lived experience themselves. I wondered where the voices where from people who actually valued a diagnosis and for whom it had helped. I felt

that the argument I was presented with were one sided and I didn't agree with the abandonment proposal (CAPSID) as again, it wasn't providing us with an alternative model.

<u>Jan 14</u>

I was struck today on placement when I assessed someone who came in and said "I think I've got borderline personality disorder, I used to think I was bipolar but I've been doing a bit of research and I think it's definitely a personality disorder". This person really wanted me to agree with his self-diagnosis and it made me this just how important it can be to be defined within a category. For this person, the seemed to want validation that this was a biological/personality problem, that was out of their control and which could explain certain behaviours. It got me thinking seriously about my own perspective on diagnosis, whether to give or not to give and how the power had been handed to me to agree or not. Such a huge responsibility and what guides you? As a psychologist, I think psychologically about problems but to exclude the function of diagnosis, is that exerting my power in a helpful way?

<u>May 14</u>

I'm really behind! I've had some personal difficulties going on and have had to have time off and I'm struggling to get the proposal together. Feels like I won't get any of this done. I've had to postpone a meeting with the research participants. So much to do. Thankfully i'm getting good support from my manager and supervisor.

June 14

I went along to meet with the research group for consultation and with my external supervisor Neil. It was a very unexpected (and nerve racking) opportunity to test out my questions and my rationale for the project. I was faced with about 10 service-user researchers who were all interested in my project. I struggled to articulate the project or my interest in it and it was helpfully fed back how important it was for me to be able to do this. It was so refreshing to be quizzed so directly and be asked repeatedly to clarify points. Neil sprung a surprise fish bowl exercise with and 2 other researchers to practice some of my questions. Some of the questions I asked didn't prompt conversations and people were concerned that they didn't answer the questions in a helpful way and that other questions were too intrusive. I noticed that I was struggling between being a therapist and being a researcher.

<u>July 14</u>

My MRP proposal meeting went really well and it needed a few amendments but it's got approval. Now onto doing the ethics. I came a bit unstuck with questions about the epistemology. John, Sue and I all think the MRP is critical realist, Neil think it's more social constructionist. My review panel wanted to know more about this and I just couldn't make sense of the difference. I feel this is going to come up again and hope that it becomes clearer over time.

<u>Sept 14</u>

After a break and few problems with IRAS – the ethics application is in! Got so much other work that the MRP seems to have taken a back seat whilst going through the ethics checks etc.

<u>Nov 14</u>

Ethics approval granted, R&D approval granted. I'm ready to go. I now have to set up meetings across all the focus groups and I also need to understand discourse analysis. A bit worried about getting things done and having the energy needed to complete the MRP as had additional personal difficulties.

<u>Jan 15</u>

Following my meeting with Sue and John yesterday, I feel my enthusiasm for the project coming back after having a bit of a break from it which is due to having to juggle all the other demands of the course with personal issues too. We talked about the section A part mainly which hasn't been on my mind very much as all the work has gone into setting up section B but I feel I can follow my heart in section A and focus on self and identity. Neil seems just as enthusiastic about the project as me and now I'm getting worried that I won't do it any justice – that I won't ever understand discourse analysis or that i won't be able to do into sufficient depth with the data as I'm juggling lots of other demands.

<u>May 15</u>

Had a bit of break from working on the MRP but have set up all the focus groups now which will taking place throughout June. Feel more on top of it now.

June 15

First focus group completed. I think it went ok but I'm a bit worried that my inexperience as a focus group facilitator meant that I wasn't a very good researcher. Neil and I have talked about the difference of being a researcher and therapist – that you have to be a bit bolder and go for it in your questioning which is at slight odds with a therapeutic role – well certainly my take on it – as I'm much more tentative and allowing the person I'm with do the leading. Such rich discussions though and I was surprised at how task focused they group members were.

June 15

I'm learning so much from doing these focus groups. To talk about mental health, diagnosis, life and everything else so frankly is an experience I haven't yet had in the therapy room. The participants are so thoughtful about what they've been through and want to help – want to get their voices heard I'm feeling a bit of pressure to convey what they've said so it does get heard. I'm also a bit worried that discourse analysis may take away some of their intentions and I don't wish to reduce their experiences down to the mechanics of language.

July 15

All done with the focus groups. Each one was so different, I think it would have so interesting to go back for follow-up focus groups to carry on some of the discussions. One comment that really stands out for me is "can we ever be diagnosed well?" I was so struck by that comment and it came towards the end of the focus group but such a powerful statement that I felt needed further unpacking. Who gets to decide when you're well? Time to begin the transcription and I can't wait

Sept 15

I'm really struggling with section A. I think I've bitten off more than I can chew. I don't see the link between section A and B anymore and I don't know how I will link them.

Dec 15

Got feedback on my section A - I am so pleased that I don't have to rewrite the whole thing. I have just spent so long it that I couldn't see the value but I've got renewed home. Transcriptions all done – now to get on with the analysis! The end is in sight now – it certainly feel like this a year ago.

<u>Jan 16</u>

Back to work after a well-earned break. I didn't do much work over Xmas which was a good decision (although I did feel guilty) but my batteries are recharged! I'm really to get on with DA, particularly now my section A is in a good place.

<u>Feb 16</u>

I've been feeling a bit hopeless about the MRP – it doesn't feel lie it will ever make sense or get written. I'm doing things with it constantly, I've spent HOURS analysing with but there's no thread – there's no structure to hold it together. I'm not on my own, other trainees are feeling the strain of all the juggling. I said to Neil the other day "I still don't get DA" and he said "yes but you will get DA". He's been saying that from the beginning, that to understand DA, you have to do it. I'm waiting for the penny to drop, for an 'a-ha moment'.

Had a conversation with another trainee today and was so surprised that I could hold a long conversation about DA and the different epistemologies. I was convinced I didn't understand but Neil is right – talking it out can show just how much you do know. It made me think again about the position I hold towards diagnosis and I think it's a 'grey' position, I can't be pro and I can't be anti. There's pros and cons to both, surely it's down to what's most helpful to the person and for them to decide whether or not they should or shouldn't have a diagnosis. The problem as I see it is not in the diagnosing, but I how professionals use that power and how they can exclude service users from that process.

<u>Mar 16</u>

Just got to the end of an amazing but incredibly stressful placement and now have 5 weeks off to finish off the MRP. Thankfully I've been chipping away at it to avoid the mad rush at the end so feel in a good enough place to be able get on with it. I read a really interesting article by Callard which seemed to sum up why I was initially interested in this topic. She talks about the over-simplification of the opposing arguments – pro and anti-psychiatric positions and calls for us to see the mud in the water, that this issue isn't clear cut and what we're getting into is a 'them and us', sort of parallel to what is coming out in the discourses with the participants. It's such a complex issue and the positive effects of diagnosis don't get talked about as much in our teaching which I feel creates a bit of a bias. What does this mean for us as practitioners – if we are opposed to diagnosis, how do respond to service-users who actually value diagnosis?

<u>Apr 16</u>

Final stages – I've had feedback on section B and so pleased that it's getting there. I'm still getting a bit confused about the epistemology but some good supervision made me realise that the MRP isn't about that, it's about the participants and I'm sticking with that!

Appendix O: Discourse Analysis Progression

The following discourses were noted during the transcription process and the first read of the transcripts:

Seeking validation for distress Left feeling uncertain about why distressed when do not have a diagnosis Medical explanation trusted as reflecting internal reality Socialised to diagnostic criteria Rejected diagnosis that didn't fit with experience – greater agency Accepting whatever doctors recommend as legitimate – passive recipients – trust in profession - patient Diagnosis leads to treatment or inadequate treatment Diagnosis leads to getting medication to ease symptoms Having a diagnosis VS using a diagnosis - how a person relates to the diagnosis agency/patient Consequences of getting the wrong diagnosis – further distress, stuck on medication, attracting other diagnoses Being viewed through a diagnostic lens Diagnosis as an explanation of previous behaviours - remove self-blame Previous life forgotten Making sense of previous behaviours when know more about diagnosis Self-diagnosing when professionals get it wrong or don't offer explanation Diagnosis is for life – will always describe something about you Them and us – normal people don't get mental health. Sense of belongingness with people who have a shared experience – social identity Diagnosis – helps gain understanding of self and behaviours and can aid self-improvement and recovery Short-hand communication Other people's reaction to diagnosis – stigma Medical discourse - patient identity Changing diagnosis - language changes but experience stays the same Distress worse than receiving diagnosis Keeping to self – concerned about stigma Opportunity for treatment VS untreatable Internalised negative connotations of label Transformative – valued/devalued by self and/or others

| Focus group | Discourses | Action orientation | Positioning | Practice | Subjectivity |
|----------------|---|---|--------------------------------|--|---|
| 1 | Seeking medical explanation for distress | Owning the diagnosis as being reflective of inner experience | Patient Ill | Reassurance seeking Wanting answers | Socialised to medical view of distress |
| | Having to place trust in professionals | Criticising those in power Devaluing professionals | Patient Survivor | Critical yet accepting of diagnosis | Distrust |
| | Having no choice or opportunity to be involved in diagnosis | Giving up power – taking medication without explanation or need | Patient Survivor Ignored | Struggle to assert agency | Powerlessness |
| | Alternative explanations – social/psychological | It's not all in the brain | Recovery | Opportunities for different discourses | Complex and holistic understanding of distress |
| | Getting 'right' diagnosis = 'right' treatment | Getting help that has opportunity to be helpful for recovery | Patient Ill | Being active in treatment | Socialised to medical view of distress |
| | Them and Us | Maintain difference, safeguarding against further stigma, notions of normality | Abnormal Different | Increase social identity | Distancing between service users and general public |
| | Diagnosis as a way to reduce self-blame | A wish to blame an illness for behaviours that have been undesirable. Also deflects blame from family that may have contributed to distress | Patient Ill Blameless | Behaviours attributed to underlying biological cause, absolve responsibility | Better for it be a brain problem than face being blamed or family to be blamed |
| | Using diagnosis for self- improvement | Diagnosis has a function – to be able access services, support | Recovery Striver | Using diagnosis on own terms | Empowered |
| | Rejecting diagnosis | Label doesn't define a person | Survivor Agent | Claiming power back – asserting agency | Empowered Critical |

| Focus | Discourses | Action orientation | Positioning | Practice | Subjectivity |
|-------|---|---|-----------------------------------|--|---|
| group | | | | | |
| 2 | Labels are inhuman | Critical of psychiatric diagnosis, rejecting of own diagnosis | Person | Claiming power back – asserting agency | Empowered Critical |
| | Seeking medical explanation for distress | Owning the diagnosis as being reflective of inner experience | Patient Ill | Reassurance seeking Wanting answers | Socialised to medical view of distress |
| | Them and Us | Maintain difference, safeguarding against further stigma, notions of normality | Abnormal Different | Increase social identity | Distancing between service users and general public |
| | Professionals not fully understanding mental health | Critical of those in power Devaluing professionals Not feeling understood – service is not helping internal distress | Survivor | Critical yet accepting of diagnosis | Distrust Poor relationships with services |
| | Using diagnosis for self- improvement | Diagnosis has a function – to be able access services, support | Recovery | Using diagnosis on own terms | Empowered |
| | Rejecting diagnosis | Label doesn't define a person | Survivor Agent | Claiming power back – asserting agency | Empowered Critical |
| | Physical health viewed through mental health lens | Critical of lack of joining up between mental and physical health services | Patient | Fighting to be taken seriously by all care providers | Poor relationships with services |
| | No diagnosis – not believed | Lack of validation from a legitimised system | Rejected Suspended identity | Seek validation | Not being listened to |
| | Barriers to disclosing | Fear of stigma and rejection and being taken seriously | Alone in coping Segregated | Pretending to be ok, not telling others | People won't understand |

| | What mental health is and | Defending against normalising | 'Really ill' | Maintaining them | Defensive |
|-------|-----------------------------|--------------------------------------|-----------------|-----------------------|-------------------------|
| | isn't – forging the | discourse | Expert by | and us and social | |
| | boundaries | | experience | identity | |
| Focus | Discourses | Action orientation | Positioning | Practice | Subjectivity |
| group | | | | | |
| 3 | Medication as a reminder | Permanence of being ill, "never | Patient | Following what | Reduced hope that |
| | of illness | diagnosed well" | I11 | professionals advise | things will change |
| | Barriers to disclosing | Fear of stigma and rejection and | Alone in coping | Pretending to be ok, | People won't |
| | | being taken seriously | Segregation | not telling others | understand |
| | Seeking medical | Owning the diagnosis as being | Patient | Reassurance seeking | Socialised to medical |
| | explanation for distress | reflective of inner experience | Ill | Wanting answers | view of distress |
| | Permanence | Having to live with this forever | I11 | Accepting of position | View self as having |
| | | | Patient | | life-long disability |
| | Using diagnosis for self- | Diagnosis has a function – to be | Recovery | Using diagnosis on | Empowered |
| | improvement | able access services, support | | own terms | |
| | Others being dismissive of | Own needs not being validated or | Alone in coping | Stop seeking support | Isolated |
| | distress | supported | | Proving distress | Beliefs of 'going mad' |
| | | | | through drastic | |
| | | | | measures | |
| | Wrong diagnosis, | Power rests with professionals to | Patient | Accepting | Uncertainty |
| | changing diagnoses | decide 'what's wrong' | III | professionals | |
| | | | Powerless | decision making | |
| | Getting 'right' diagnosis = | Getting help that has opportunity | Patient | Being active in | Socialised to medical |
| | 'right' treatment | to be helpful for recovery | Ill | treatment | view of distress |
| | Try to ignore diagnosis | Diagnosis is not central to identity | Survivor | Carrying on with life | View self in a positive |
| | due to stigma attached | | Expert by | | light, acknowledging |
| | | | experience | | the challenges |
| | | | | | |

| | Supportive of function of | Defending against change and | Defender | Safeguarding against | Better the devil you |
|----------------|---|---|--|--|--|
| | diagnosis | need for validation | Advocator | further stigma and uncertainty | know |
| | Confused about identity based on diagnosis | Public conceptions are of 'dangerousness' (schizophrenia) | Patient | Avoid disclosing, Review identity | Ashamed Confused |
| Focus group | Discourses | Action orientation | Positioning | Practice | Subjectivity |
| 4 | Using diagnosis for self- improvement | Diagnosis has a function – to be able access services, support | Recovery | Using diagnosis on own terms | Empowered |
| | Supportive of function of diagnosis | Defending against change and need for validation Pro-diagnosis | Defender Advocator | Safeguarding against further stigma and uncertainty | Better the devil you know |
| | Making distinctions between those in recovery and those who are not | Making a distinction within group of people with mental health, those that use the help and those that don't | Powerful Superior | Blaming and accusing of others not working towards recovery | Hold the view that some people with illness identity |
| | Confused about identity based on diagnosis | Public conceptions are of 'dangerousness' (schizophrenia) | Patient | Avoid disclosing, Review identity | Ashamed Confused |
| | Physical and mental health teams not collaborating – left having to be the expert | Critical of lack of joining up between mental and physical health services | Expert by experience Educator Fighter | Having to fight against fragmented system to get suitable support | Professionals and the NHS are useless |
| | Seeking medical explanation for distress | Owning the diagnosis as being reflective of inner experience | Patient Ill | Reassurance seeking Wanting answers | Socialised to medical view of distress |

| | Them and Us | Maintain difference, safeguarding against further stigma, notions of normality | Abnormal Different | Increase social identity | Distancing between service users and general public |
|----------------|--|---|-------------------------------|--|---|
| | Autonomy and self- determination | Life is limited but accepted and make adjustments to lifestyle and choices | Recovery | Accepting help and making adjustments to lifestyle for self- improvement | Living with illness, not suffering. Internal source of resilience |
| | Getting 'right' diagnosis = 'right' treatment | Getting help that has opportunity to be helpful for recovery | Patient Ill | Being active in treatment | Socialised to medical view of distress |
| Focus group | Discourses | Action orientation | Positioning | Practice | Subjectivity |
| 5 | Seeking medical explanation for distress | Owning the diagnosis as being reflective of inner experience | Patient Ill | Reassurance seeking Wanting answers | Socialised to medical view of distress |
| | Barriers to disclosing | Fear of stigma and rejection and being taken seriously | Alone in coping Segregated | Pretending to be ok, not telling others | People won't understand |
| | Diagnosis as a way to reduce self-blame | A wish to blame an illness for behaviours that have been undesirable. Also deflects blame from family that may have contributed to distress | Patient Ill Blameless | Behaviours attributed to underlying biological cause, absolve responsibility | Better for it be a brain problem than face being blamed or family to be blamed |
| | Rejecting diagnosis | Label doesn't define a person | Survivor Agent | Claiming power back – asserting agency | Empowered Critical |
| | Belongingness in group of others with similar experience | Sense of acceptance from others with mental health problems | Recovery Hopeful | Strengthened group identity and | I'm not alone in the world and others understand |

| | | | improves sense- making | |
|---------------------------|------------------------------------|-----------|--------------------------------|----------------------|
| Supportive of function of | Defending against change and | Defender | Safeguarding against | Better the devil you |
| diagnosis | need for validation | Advocator | further stigma and uncertainty | know |
| Using diagnosis for self- | Diagnosis has a function – to be | Recovery | Using diagnosis on | Empowered |
| improvement | able access services, support | Striver | own terms | |
| Them and Us | Maintain difference, safeguarding | Abnormal | Increase social | Distancing between |
| | against further stigma, notions of | Different | identity | service users and |
| | normality | | | general public |

Appendix P: Annotated transcript from focus group 5.

Removed for electronic submission

Appendix Q: Guidance for author for article submission to Social Science & Medicine journal.

Removed for electronic submission