AN INVESTIGATON EXPLORING THE BIOLOGICAL AND AFFECTIVE PATHWAY TO PSYCHOSIS

BY

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Contents

Thesis Overview

Chapter 1

Chapter 2

Chapter 3

<u>Thesis Overview</u>

This thesis comprises of three chapters, one for each placement completed as part of the MRes Clinical Psychology.

Chapter One

The first chapter details work completed to aid the understanding of mental health literacy. The term mental health literacy was first coined in 1997 to describe knowledge and beliefs held about mental disorders.

This placement aimed to summarise information from multiple sources, collate and compare this information, and highlight key and recurrent themes. These themes would be used in the development of items for a questionnaire on mental health literacy.

A review of current literature within this topic area was conducted to identify key themes which were then grouped into categories and used as a foundation for further data collection. Thematic analysis for both transcripts of pre-conducted interviews with mental health service users and focus groups within an independent school was conducted. Items were integrated and statements from each source were marked and modified to be used as items for a questionnaire.

Research identified those aged fifteen to twenty four to be less knowledgeable about mental health, however given the increased risk of development here it seems necessary that these ages be targeted most strongly, along with those of an older age to provide first aid when individuals come seeking help (Jorm, 2012).

This work gives an indication of both the detrimental effects of knowledge currently available and also the need for far greater resources. It was a consistent finding throughout the 3 sources of data that informal sources of help are perhaps sought initially as an alternative to professional. If this is the case then more effort should be put into making sure information available

through the media and on the internet is accurate and that encouragement is made not to use this help as a substitute.

This research has aided the understanding of the current status of mental health literacy and aided the development of a measure to determine exactly what is known and where more information is sought. Results of this would highlight targets for interventions with the hope of improving knowledge, recognition and treatment.

Chapter Two

The second chapter of this thesis contains narrative commentary on a presentation given on social recovery in psychosis. For this placement, a comprehensive literature review was conducted on behalf of the Early Intervention Service for Psychosis.

Social recovery is a relatively new term in psychosis research and generally refers to aspects of recovery outside of symptom recovery and that managed by pharmacological treatment. The pattern of recovery seen at the Early Intervention Service consists of three different groups. 15% recover adequately enough to require low intensity treatment, 15% recover poorly requiring high intensity treatment and the main 70% recover adequately enough not to require intense intervention, however often fail to perform adequately in areas outside of that managed by current interventions. More recently a change in focus has been made highlighting the important of social and vocational functioning and the protective nature these may serve.

A review of 18 articles was conducted; this review was then condensed into a presentation consisting of an introduction, method, results and conclusion section. Each slide is presented within this chapter and detailed commentary from both the literature review and oral presentation are contained beneath.

This review demonstrated that looking at recovery in terms of just symptomatic remission is insufficient as quality of life still suffers as a result of functional disability. Social factors serve as good predictors of functional recovery and these factors may also protect against relapse. In light of this, interventions have begun incorporating symptomatic and functional treatments.

Based on the research discussed, a potential protocol for EIS is at baseline, 3 or 6 month clinical reviews, the presence of demographic and clinical variables associated with divergent outcomes could be considered. Based on this, patients could be streamed accordingly. Through this, resources can be maintained or reduced based on evidence and early discharges can be evidence based.

Through the literature presented, intervention work can begin to incorporate aspects of treatment that will aid all areas of functioning. Through streamlining, aspects of functioning can be targeted earlier and aid recovery as a whole through protective effects rather than debilitative ones.

Chapter Three

The final chapter of this thesis contains a report on research conducted into the pathways to psychosis. Psychosis research has identified overlaps between psychosis and neurodevelopmental disorders such as autism. Based on this it has been suggested that diagnosed autism or autism like traits may serve as a predictor or pathway into psychosis. On the other hand, research has also highlighted the predictive nature of stressful life events such as childhood trauma or abuse in the development of psychosis. Based on this, two theories have been postulated. 1) A biological pathway to psychosis exists wherein genetics, brain anatomy and comorbidity serve as precursors. 2) An affective pathway to psychosis exists, wherein stress acts as a precursor for psychosis. Within this study, data from a larger study of autism and psychosis were analysed to explore the hypothesis that either pathway leads to psychosis.

The purpose of the current work was to explore susceptibility to developing psychosis through the presentation of autistic like traits amongst individuals with psychosis. Through this, it will be possible to determine whether it is the actual traits or the diagnosis of autism causing underlying vulnerability (stress) or fundamentally biological mechanisms. It was hypothesised that in reflecting both the biological and affective pathway to psychosis, amongst those experiencing first episode psychosis two groups would be prevalent and defined by differential outcomes.

Results supported the hypothesis that of the two groups, one would be characterized by greater biological influence and one group would be characterized by greater influence of stress. The predominance of group 1 suggested that within this sample, participants experience greater influence of childhood trauma and less influence of autistic traits. This suggests that of the hypothesised pathways to psychosis, the majority of this sample fall within the affective pathway, wherein stressful life events rather than biological influences trigger psychosis.

The implications of this research highlight the inadequacy of current diagnostic tools. Categorising based on diagnostic criteria also give implications for treatment, however an individual with psychosis may also have autistic traits that would benefit from alternative interventions not deemed effective for psychosis. With this, treatment methods could be combined to target aspects of illness affecting functioning outside of that required for an official diagnosis. It is important future work investigates the implications for those who display autistic traits but do not yet have a diagnosis of psychosis, as well as those who have experienced trauma.

Reflective Summary

Throughout this course a consistent theme has been the need for reflection. Research is never done without purpose and it is the purpose behind a piece of research or a piece of work that enables both self and research discoveries.

This course has developed both my confidence and knowledge of psychological research through both taught modules and practical placements. Each of my placements has either in part or solely relied on a literature review, which until now I had not done independently. A review of current literature is the foundation of any piece of research in order to decipher what is already known and what needs to be done to discover what is lacking. I am therefore glad I have had the opportunity to develop this skill under the supervision of a number of supervisors. Deciding what articles are relevant to the research question was a great challenge but one that I feel I have now gotten to grips with.

Another learning curve for me during this course was conducting focus groups with students to gauge their knowledge of mental health. This was both challenging and enlightening as before this I think I naively thought that my knowledge of mental health would be similar to everyone else's; but of course I have been studying aspects of mental health even before my undergraduate degree. The amount that is not known about mental health and hearing from interviews with service users exactly how their experience differs from the general consensus, was startling.

Taught modules developed my competency to complete tasks required during each placement. In particular, learning how to analyse qualitative data permitted me to do so for large quantities of data. This is something that before this course I have not had the opportunity to do. Similarly, I have been tested in terms of my statistical skills. Before this course it had been a year since I had last broached the statistics world and this course has rejuvenated the core skills needed for any type of analysis. It also enabled me to develop my skills beyond that which I had learnt at undergraduate level.

The first two placements prepared me for the third in terms of aiding my confidence in skills I had somewhat forgotten. Both gave me an insight into the fundamental stages of the research cycle. The need for good quality work is evident to ensure research is acknowledged. Review and analysis skills, along with data collection are useful and necessary parts of research.

Through the use of supervision and my own reflections I have developed both in myself and as a researcher. The skills I have learnt here I am hoping will prepare me for further studies and ensure that my academic and practical abilities run along the same path, developing as one.

CHAPTER 1

DEVELOPING A MEASURE OF MENTAL HEALTH LITERACY

Abstract

Background: Jorm et al. (1997) first coined the term Mental Health Literacy to describe the knowledge and beliefs that people hold about mental disorders. This research aimed to discuss what is already known and where gaps lie, as well as efforts that have already been made to change this. *Method:* Thematic analysis was used to explore 3 data sources; a review of the literature surrounding both mental health literacy and illness perceptions, interviews with eleven individuals attending Youthspace: an organisation aimed at raising awareness and providing support to anyone in need of help and information about mental health, and focus groups of students held at an independent school. Data was integrated; statements were highlighted and modified to improve understanding and develop items for a questionnaire. *Results:* Consistent themes were found across sources. Mental health difficulties often were perceived as being recognised through a lack of control and behaving unlike the majority. Interviews demonstrated a delay in treatment and a distrust of some professional services. Family support is often a key feature of recognition, help seeking and treatment. However, stigma was also recognised as being an impacting factor. Focus groups identified knowledge is there for those who seek it, however outside of education and personal experience, the incentive to do so may be lacking. *Discussion:* Analysis enabled 153 statements to be identified to aid with the development of a measure of mental health literacy. An understanding of knowledge already held and where knowledge is lacking has been identified for future research to explore.

<div align="center">Background</div>

In England, the number of people who experience poor mental health is increasing (McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith (2008). In 2007 it was estimated that 8.65 million people in England experience poorer mental health. The costs of providing services for these people are estimated to have been £22.50 billion. Within this population, many who experience mental ill health are not in contact with these services. McCrone et al., (2008) estimated in their report that 35% of those living with depression and 51% of those with anxiety disorders are not receiving help. As well as this, amongst children and adolescents, conduct and eating disorders can go without being diagnosed and without receiving treatment.

In the last decade research has highlighted the differing levels of informedness about mental health. Jorm et al. (1997) first coined the term Mental Health Literacy to describe the knowledge and beliefs that people hold about mental disorders. Such knowledge and beliefs affect the recognition of mental disorders, as well prevention and the ability to manage disorders; either through self-management or effective treatment. This is important given the impact of treatment delay on prognosis (de Haan, Linszen, Lenior, de Win & Gorsira (2003).

Once it is clear where gaps in knowledge lie and the effect this has on illness prognosis, interventions can be target gaps to ensure support reaches all audiences. The following research will discuss what is already known and where gaps lie, as well as efforts that have already been made to change this.

What is Mental Health Literacy?

Knowledge of mental health can be categorised into knowledge about recognition, prevention, help seeking, causes and risks, self-help and first aid help (Jorm., 2012). Attempts at measuring mental health literacy have used vignettes describing a person with a mental health disorder. Typically, these vignettes will describe either depression or schizophrenia according to the ICD-10 and DSM-IV diagnostic criteria. Participants are then asked whether they thought the person

had a mental illness or not and how they could best be helped. These questions covered opinions about treatment, prognosis and causes for the described behaviours. Following this, multiple choice questions were asked about causes and risk factors (Jorm et al., 1997).

In keeping with the above categories of mental health literacy, such studies have demonstrated that rather than applying strict labels of depression or schizophrenia, individuals apply more normalised labels such as stress (Jorm et al., 2006). Normalising behaviours may make seeking professional help less likely. In a survey of 28 countries a delay of up to years, was found when seeking help for anxiety, mood and substance use disorder during the year in which the disorder first presents (Wang et al., 2007). Delay was dependent upon the type of disorder, with anxiety going untreated for 3 to 30 years; mood disorders 1 to 14 years and substance abuse 6 to 18 years.

Research suggests that prevention methods are tailored to specific risk factors for mental disorders. Depending on the cause or trigger of a mental illness, the method of prevention may differ. For instance, childhood trauma vs. a genetic marker. Increasing knowledge of causes and risks enables individuals to know which are modifiable. For example, the effects of parental conflict on psychological stress (Kelly, 2000).

Ideas about causes and risks of depression are generally in line with evidence provided by national surveys of depression (Finlay-Jones 1998; Parker 1988). The evidence suggests that schizophrenia is less understood, based on results showing beliefs about the causes of schizophrenia to be less accurate and the inability to recognise symptoms as a sign of disorder. Knowledge seems to be heavily influenced by education and direct contact (Jorm et al., 1997).

Knowledge of help available seems to be more skewed in the way of informal sources such as family support, rather than professional sources such as psychologists. More people see psychiatric medications as harmful and seek support from friends or family (Jorm et al., 1997). However, family functioning can affect recovery (Keitner et al., 1995). If these informal sources

4

lacked knowledge of mental health, it is unlikely the individual seeking help would gain the most effective treatment initially without outside support.

Knowledge of mental health first aid for supporting others is often accurate but insufficient. A review of randomised trials and consensus data from consumers and mental health professionals revealed that whilst encouraging professional help is in line with professional recommendations, a significant number of recommendations were not suggested. These included self-help methods of regular sleeping pattern, doing something you enjoy and taking part in physical activity (Morgan & Jorm., 2009). Knowledge of effective self-help strategies may aid coping in the initial stages of illness and provide guidance for those offering support until professional treatment is attained (mental health first aid).

Illness perception

Mental health literacy can also be understood in terms of illness perception. Illness perception has been measured using a variety of assessments which have demonstrated that patients seem to cluster around 5 key cognitive components (Moss-Morissa et al., 2002):

1. Identity: labelling the illness and its symptoms. This relates to recognition and how recognition may differ depending on the type of illness and its presenting symptoms.

2. Cause: personal ideas about how such symptoms developed. This may affect help seeking and the ability to come to terms with illness.

3. Time line: how long will this illness last. This may be affected by recognition or decisions about help seeking. This may vary depending on the illness.

4. Consequences: what the individual expects to happen as a result of this illness. This may be affected by outlook prior to recognition and again may vary depending on the type of illness.

5. Cure/Control: how the individual will recover and control the illness. The may be affected by social circumstances, decisions about help seeking and the severity of the illness.

These perceptions can give answers to the behaviours surrounding mental illness, such as when help is sought or what help is sought. This study aims to gain a more in depth view from the perspective of close spectators and lay members of society.

What does this mean?

Mental health literacy is important in ensuring people experiencing mental illness receive appropriate treatment and support. Seeing the amount of people who experience a mental health problem, virtually every British citizen may encounter someone suffering from a mental illness. Knowledge of how to recognise and support mental illness plays a key role in helping those who experience mental health problems, through encouragement to get treatment as soon as is necessary.

Mental Health Literacy is often measured through the use of vignettes (Swami, 2002). However, there are alternative measures that have been created based on factors found to affect mental health literacy (Davis et al., 2008). Participants may have knowledge outside of the questions asked in response to vignette reading. Knowledge of mental health literacy is based on a character description of two individuals which seems insufficient as disorders such as depression and schizophrenia take many forms and although stereotyped behaviour may be evident, understanding of mental health should encompass a more holistic view.

The purpose of the current work is to develop items for a mental health literacy questionnaire in an aim to determine more holistically what is known about mental health without relating it to two specific individuals which is often found through the use of vignettes. This measure would be useful in assessing the prevalence and quality of knowledge held by the general population, as well as highlighting any misperceptions that may be held.

Method

The aims of the current research were to:

- Summarise information on Mental Health Literacy from multiple sources

- Collate and compare information across sources.

- Generate items to aid the development of a questionnaire into mental health literacy

Three approaches were used to fulfil these aims.

Approach 1: Review of previous research

An online database search with the search terms [mental health] AND [literacy OR knowledge] was conducted using PsycInfo, medline, Web of Science and Science Direct. Using the inclusion criteria of English as language of first publication, publication from 1990 onwards and being relevant to the topic, 7 articles were identified. A forward and backwards citation search was then conducted to support conclusions drawn from the literature. A review of the literature surrounding both mental health literacy and illness perceptions in relation to mental health was undertaken to identify key themes and cognitive components such as recognition, help seeking, risk factors and implications (Jorm, 1997; Moss-Morissa et al., 2002). Recurrent themes were identified and grouped into categories identified throughout the literature review. If items could not be categorised into themes within the previous literature, a new category was created. These themes and categories were used as a foundation for further data collection.

Approach 2: Secondary analysis of individual interviews

Secondary analysis of interviews with eleven individuals attending Youthspace; an organisation aimed at raising awareness and providing support to anyone in need of help and information about mental health, was completed. There were six male interviewees and five females, ages ranged from 17 to 23. All had recently begun attending Youthspace and had been receiving professional support for 1-2 years. The individuals interviewed presented with low moods

following trauma or long periods of self-harm. These interviews had been held prior to the beginning of the research and were completed as routine treatment not for the sole purpose of this research; consent was given for this data to be used in secondary analysis as part of further research. Interviews were semi structured in that the interviewer asked participants to describe their history and the events that brought them to Youthspace, including past treatment and behaviours. The participants spoke for an average of 20 minutes.

Thematic analysis was used to pinpoint and record patterns within each data set. Recurrent patterns in the topic and focus of conversation were labeled. Stand out statements within transcriptions were coded, codes were then reviewed and identified as themes depending on similarity. Interpretation was then made through their frequency and co-occurrence; comparisons were also made with themes identified within the literature review.

Approach 3: Focus groups with adolescents

Eight focus groups of 6-8 students were held at an independent school. Participants were Psychology students aged 16-18. The focus groups lasted 30 minutes after an introduction was given and time allowed for debriefing (see Appendix A). Participants were told that the purpose of the focus group was to assist with the development of a questionnaire for mental health literacy. As the focus group is not a piece of research itself but was conducted purely to aid the development of a questionnaire, consent was not given. However, participants were free to 'opt out' of discussions.

The agenda for discussion within the focus group was determined using the themes identified through thematic analysis of interview transcripts and previous literature. Questions were split into six domains: recognition, timeline, help seeking, consequences, causes and support. Each domain had a number of probing questions to facilitate discussion and participants were encouraged to discuss topics amongst themselves rather than answering questions specifically (see Appendix B). Questions were devised by using identified themes as a basis for discussion, recurrent statements

made were used as questions and written to not lead answers and allow free discussion. Focus groups were transcribed verbatim.

Item generation:

Thematic analysis was used to qualitatively analyse the data. This method was deemed suitable due to its pinpointing and examination of themes within data. Six phases of coding are used to establish themes: data familiarisation, initial code generation, theme searching amongst codes, defining themes and reporting final conclusions (Braun & Clarke, 2006). Following the focus groups, the data from each approach were integrated as so: based on the findings from each source, statements were highlighted and modified to improve understanding and develop items for a questionnaire. All statements were added to a table and labelled within a category. Statements were identified as positive or negative and were grouped into categories to be used in a mental health literacy questionnaire. Duplicates were removed and items were reorganised to clearly show categorisation (Appendix D).

Results

Analysis of previous literature revealed 5 key themes:

Theme 1, the consistent use of vignette's as a portrayal of mental health: A frequently used method for assessing Mental Health Literacy is to present participants with a vignette of someone with either depression or schizophrenia. Participants would then be asked a number of open and closed questions about their perception of this vignette and specific aspects of mental health. This research however gave no indication of how participants came to their conclusion, such as the potential influence from factors outside of vignettes.

Theme 2, previous findings demonstrated knowledge inconsistencies: Results showed that knowledge of how to prevent mental disorders is uncertain as it depends on what the participants attributes as a cause for the disorder. Participants also tended to normalise behaviours described, attributing them to day to day problems over genetics or illness. Those who were correctly able to identify the person as suffering from a disorder were more likely to attribute more definitive causes (Jorm et al., 1997).

Theme 3, sex differences: The ability to correctly identify the person in the vignette as having or developing a mental disorder depended on the sex of both the participant and the person in the vignette. Of the respondents who received a vignette depicting a female, 41% stated that women were more likely to suffer from depression and 31% schizophrenia. Respondents who knew someone who they saw as similar to the vignette were more likely to correctly recognise the disorder (Jorm et al., 1997).

Theme 4, stigma and stereotyping: Although most respondents had knowledge of the types of treatment available, most saw informal sources of help such as seeking advice from family/friends as more beneficial than drug or psychological treatment. Knowledge of self-help treatments is there, however is somewhat lacking (Jorm et al., 1997).

Theme 5, help seeking: When asked about supporting someone with a mental illness respondents stated that they would encourage professional help, however this is slightly contradicted by the negative perceptions of such help (Jorm, 2012).

Illness perception literature demonstrated similar themes, to begin with an illness needs to be labelled and recognised as such. An individual may have specific ideas about the cause of their illness and how long they anticipate suffering from this illness. Ideas about the likely consequences of this illness follow, along with ideas of how if possible they will overcome their illness.

Analysis of the individual interviews of those attending Youthspace highlighted the following themes:

Interviewees had a mean age of nineteen, six males and five females were interviewed. An example of an interview transcript can be seen in Appendix E.

Theme 1, when to seek help: help is usually sought following encouragement from a friend or family member, often a parent. Help is sought independently when the issues facing the individual begin to impact upon everyday life. Frustration at being unable to do things may trigger a want for change, as well as seeing the effects illness may be having on those around them. For example:

"When it got to like three years of dealing with it., and it's starting to affect my college work."

Theme 2, where to seek help: the GP is often the first point of help seeking, however experiences are often bad due to the GPs lack of knowledge about mental health. The experience with the GP depends very much on the individual characteristics of the GP, such as their willingness to commit additional time and approach when talking to the individual.

Theme 3, timeline and procedure: when seeking help from the GP, the individual is often referred to several different services before finding one they find beneficial. For example:

"They kept sending me to counsellors, and this and the other and they were just no good."

There is a delay in referral time, waiting lists and therapy programmes of up to months. However this can be different depending on the persistence of individual GP. Some GPs may offer additional services throughout the waiting time however others may not.

There is often a delay in seeking help due to waiting for issues to subside or believing their feelings and behaviour is as a result of 'hormones' or is 'normal teenage behaviour'. This delay can be as much as years, and is likely to be at least 1 year.

Theme 4, support: individuals have found that friends can be unsupportive, and that there is a negative perception of mental health problems by some. There can be stigma and generalised ideas. For example:

"I just fit that instant oh he's an emo, self harmer guy…"

This affects how open individuals are about their mental health and also contributes to feelings of sadness.

Theme 5, treatment: Drugs is a common form of treatment however adherence is problematic, several individuals reported to take themselves off their medication and reported a preference for therapy based treatment. For example:

".. youthspace guy was talking through everything that was gonna happen and they all offered treatment.. cbt.. I'm taking so many drugs for getting better.. and depression I don't wanna start more."

Theme 6, information seeking: interviewees reported that information is sought from friends or family who have also experienced mental health problems. The internet is also used as a source of information. For example:

"For a few weeks before I was like googling different things like depression and just being a teenager and all the different types of things you can get from puberty."

Focus Groups identified:

Forty eight students took part in eight different focus groups. Thirty five females and thirteen males took part, with an age range of sixteen to eighteen.

Theme 1, control: An example of a focus group transcript can be seen in Appendix C. A defining feature of mental illness is a lack of control over ones behaviour. Students believe that ultimately the effect that having a mental illness has on oneself is that behaviour is less controlled than it should be. For example:

"You probably have more control when you just have a bad mood than you actually do when you have a mental illness."

Theme 2, delay in recognition: Students were not sure of whether this was a conscious lack of control. Rather than stating that an individual with a mental illness tries but cannot control their own behaviour, students stated more that behaviour was out of their control in that they were not acting freely. Control was highlighted in all 8 focus group sessions, a defining feature that distinguishes mentally healthy from unhealthy was that within society behaviour must be controlled in order to 'fit in' and act in accordance with social norms. Students stated that those with mental illness are unable to do so.

Students stated that someone with a mental illness would be able hide or conceal their illness in order to 'appear normal' however eventually the build-up becomes so much that a change must occur. For example:

"Not if you don't show it really so people try and sort it out themselves."

Students reported that individuals, who try to hide their concerns would either be in denial, not recognise their concerns are serious enough to warrant attention or be afraid of negative judgement.

Theme 3, recognition: It was felt that recognition of a mental illness in someone else would be easier than in oneself. In oneself, changes may occur very slowly allowing your perception of your normal self to change. For example:

"I think it'd be because you're too used to yourself like because it would like progress slowly you just got used to being just slightly different."

"Also, I don't think you'd like, especially being students, you could just say oh I'm stressed because I've got an exam next week and after that it'll be okay."

It was felt that self-recognition would only occur if recognition was made by an outsider or if a serious incident occurred to trigger concern. Students felt that it would be some time, possibly 6 months or longer before self-recognition of a mental illness would occur, and even then concerns may be downplayed, denied or a period would go by where individuals would wait for concerns to subside. Participants stated that it is easier to recognise mental illness in people you know well due to a change in behaviour, without displaying out of the ordinary behaviours identifying mental illness in the wider population is difficult. It is often only extremes of mental illness that are noticed and even then it is the behaviour that is noticed not a cause or knowledge as to why someone may be displaying such behaviours.

Theme 4, help-seeking: When deciding to seek help for mental illness, participants thought that either the internet or GP would be the first step. For example:

"Internet. Searching online. Finding symptoms and thinking that you have the same symptoms as that and then yeah.. reading up on things."

Participants stated that the internet was more likely to be used independently without encouragement and more so out of ease. If encouraged by family or friends the GP would usually be the first place help was sought. For example:

"Yeah like encouragement really, like if all your mates realise like well you not the same as you have been something's like going on here, to help make them realise that you're better off going to get help than just letting it progress in case there is something wrong."

Students did state that the GP may not be used for help seeking due to feelings of not being 'bad enough' or being a 'burden'. Through the internet individuals may seek help through charities or look for other organisations outside of the NHS as they may feel this is a more friendly and non-judgemental environment.

Theme 5, knowledge: Within this sample, participants felt that outside of school lessons, not much would be known about where to seek information about mental health. For example:

"Psychology, Stuff we've learnt in psychology."

There is some knowledge of things that are available such as charities and helplines but no solid ideas of how to access these. Participants reported that if they were not psychology students and had not experienced mental health through friends or family that they would have little knowledge about recognition, cause, consequences and treatment options.

The media was reported as being a major source of mental health knowledge but all participants felt that it exaggerates mental health and only shows extreme or unusual cases. Participants stated that there is a scale of mental health and there may be many people at different points on this scale however without being at the extreme end mental health may go unnoticed. Participants felt that the differing levels of severity within mental health affect recognition as well as decisions about help seeking. It may also affect first aid help given to someone with a mental illness as more extreme cases may require more extreme treatment.

Summary

When comparing these analyses against each other help seeking can be seen to appear consistently throughout. Recognition of when a mental illness is developing seems problematic as

knowledge amongst GP's is not specific to mental health, and when making recognition outside of

the GP this is made based on comparisons with previous behaviour. Both interviews and focus

groups identified delays in seeking help. Self-help knowledge mostly revolved around changes in

perception.

The below table highlights and summarises the themes identified through the three

different approaches.

	LITERATURE REVIEW	INTERVIEW DATA	FOCUS GROUPS
Help seeking	X	X	X
Sex differences	X		
Treatment	X	X	X
Timeline	X	X	X
Treatment procedure		X	X
Support	X	X	X
Information seeking		X	X
Control		X	X
Delay	X	X	X
Recognition	X	X	X
Knowledge	X	X	X

As can be seen, the identified themes remain fairly consistent across each source of data. It

is possible that lack of data was as a result of research aims and conversation topic in interviews and

focus groups. The literature review was the only data source that revealed differences in knowledge

amongst sexes. Females were identified as being more likely to experience mental illness (Jorm et

al., 1997) however this was not mentioned in alternative sources. Lack of control could not have

been identified in previous research as often participants were given a description of someone

rather than having to use descriptive words themselves (Jorm et al., 1997). Failure to report further

consistencies could be due to the use of closed questions as opposed to the open question style of

both interviews and focus groups.

Based on this analysis a total of 135 items were generated (see Appendix D). Each theme

that had been identified from each source of data was compiled into a table. Along with this, every

statement identified through transcriptions were added. Verbatim statements were adjusted to

enable agreeableness to be decided in a questionnaire format. All items were categorised as a

statements about behaviour, perception, emotion, cause, knowledge or consequence. Items were

then grouped into 6 key topics around mental health literacy so that when a questionnaire is

developed questions can be arranged consistently in order of topic.

Discussion

Through the analysis of 3 sources of data; previous research, interviews and focus groups, clear overlaps can be seen within different populations.

Analysis of previous research suggested that knowledge was heavily based on previous experience of mental health. This was corroborated by both sixth form students through focus groups and individuals with mental health problems through interview data. All three sources suggested that knowing someone who has experienced mental health either directly or indirectly has increased their knowledge of help seeking and treatment. Students stated that their knowledge came primarily from education in school and without this they would either rely on the media or information provided by others. All focus groups stated however that the media is not always accurate in their portrayal of mental health therefore it is important to provide other sources of information outside of both this and direct contact.

The delay in recognition, help seeking and treatment highlighted by previous research was also apparent when interviewing service users and sixth form students. Students however were not aware of the extent to which there can be a delay. Research demonstrated that if a disorder is not recognised within the first year of onset, it can be up to fourteen years before actual recognition is made (Marshall et al., 2005). This delay is not acceptable given the poorer outcomes for treatment the longer the duration of untreated illness (Marshall et al., 2005).

However, interviews from mental health service users suggested that even after seeking help from the GP, there can be a delay of many months before treatment actually begins and further delay whilst determining which treatment method proves the most effective. It is therefore not just a case of improving Mental Health Literacy within the wider population but within the health care system as well. Especially as this is often the first point of contact for individuals needing help.

Research identified those aged fifteen to twenty four to be less knowledgeable about mental health however given the increased risk of development here it seems necessary that these ages be

targeted most strongly, along with those of an older age to provide first aid when individuals come seeking help (Jorm, 2012).

Implications of this work have given an indication of both the detrimental effects of knowledge currently available and also the need for far greater resources. It was a consistent finding throughout the 3 sources of data that informal sources of help such as asking friends or online research are perhaps sought initially as an alternative to professional. The next step is the GP. If this is the case then more effort should be put into making sure information available through the media and on the internet is accurate and that encouragement is made not to use this help as a substitute.

The negative perception of professional treatments such as drugs and psychiatric help (Priest et al., 1996) could perhaps be combatted by making their successes more readily available but also not shying away from the fact that treatment is very individualised and that drugs may not work for everyone. Research shows that when severity increases so does the likelihood of professional interventions (Jorm, 2012). By encouraging people to seek help for even the slightest concern interventions could occur sooner with greater success. A common theme within the focus groups and Youthspace interviews was that delay in seeking help may occur out of fear of 'overreacting' or becoming a burden. If seeking help is normalised it may reduce this worry.

A great concern is perhaps the tendency to use self-help as an alternative rather than alongside professional help. If this is to continue, member of one's community need to be aware of how they can assist and provide support to the individual and their social network.

It is clear that mental health literacy could be improved as without education and direct contact with mental health, information may only be sought on a need to know basis. If mental health knowledge were more widely distributed it may be that the detrimental effects of mental illness could be somewhat reduced. For example, research has shown that delay in treatment can lead to remission and hospitalisation (de Haan et al., 2003). Greater knowledge may aid and accelerate help seeking, alleviating the negative effects of delay.

19

This research has enabled the development of a good understanding of mental health literacy which can aid in the development of a questionnaire hoped to educate and draw attention to the need for greater mental health knowledge for both personal and general uses. This questionnaire has the potential to be used as an intervention measure whereby interventions to improve mental health literacy can be evaluated. Poor mental health literacy can have major impact on individuals with a mental illness and those around them. By challenging what we do not know, hopefully a great improvement of knowledge can be made.

Future directions for this work would be for the items generated from this data to be reviewed by healthcare professionals and compiled into a four point scale questionnaire to be distributed to professionals, families and individuals with mental health disorders. The statement list will first be given to Health Care Professionals for feedback on the appropriateness of such questions. Where appropriate, wording and order may be modified based on feedback.

Psychometric properties of the measure will be modified to ensure the greatest validity. It can already been seen through categorisation that within the cognitive framework of illness perception, most items focus on recognition and risk factors, with some knowledge of professional help. It may be that additional items are needed to target all categories. However, these items have been developed within the framework of illness perceptions, when in actuality it is a measure of mental health literacy. Therefore modification may be needed within the current list of items to ensure validity.

In summary, knowledge about mental health is available, however secondary sources of knowledge are often not as sought or credible than first hand experiences. Those affected by mental illness often reach some sort of delay, whether this be in the recognition or treatment of their illness. Participants felt that support from informal sources of help like family and friends are equally as important in terms of encouragement and management as professional help as often this support is all that is available for long periods of inactivity from professionals. The items generated can be

used to aid the development of a measure of mental health literacy, and from this interventions can

be formulated to improve mental health literacy and the care of individuals with mental health

illness as a result.

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<u>Appendix A</u>

Focus Group Introduction Script

Introduction:

We're going to run a focus group. We're running the group as we are in the process of developing a questionnaire about mental health and so we want to find out what different groups of people think about mental health, including mental health professionals, people who have experienced mental illnesses, and young people such as yourself.

We are running the group in order to help us develop a questionnaire, rather than as a piece of research in and of itself. As it's not a piece of research we are not asking you to fill out consent forms. Obviously if it was a piece of research we would be asking you to do this.

If you don't want to answer a question or to talk about a particular subject then that's perfectly ok; you don't need to talk about anything you don't want to. If you would rather not take part in the focus group at all then that's also ok, just let me know and you can observe the group rather than take part.

Anything that is spoken about in the focus group will be kept private and confidential by me. You should also not discuss what other people say during the focus group with people who are not taking part, for example others in a different class. However, please don't discuss anything with this group which you would feel uncomfortable with others outside the group finding out about.

We have a number of questions which we would like you to discuss as a group which revolve around mental health. There are no right or wrong answers to these questions, and there may be multiple answers to each of them. You don't need to all agree with each other, or to reach a consensus as a group, it's fine if different people have conflicting opinions. Please don't feel worried about voicing your opinion if it is different from others in the group and please respect other people's opinions even if they are different from your own.

Appendix B

Focus Group Topic Guide

Section 1: What do you think mental health is?

Can you describe someone with a mental illness? What about someone without a mental illness?

Section 2: Help-seeking

At what point should someone help seek?

Section 3: Causes and risk

What do you think causes mental illness?

Section 4: Timeline

How do you perceive the time line of a mental illness?

Section 5: Consequences

What are the consequences of having a mental illness?

Section 6: Support

What would you do if a close friend developed a mental illness?

<u>Appendix C</u>

Focus Group Transcript

- ***Sample Demographics***: *3 males, 4 females. 6 aged 17, 1 aged 18. 6 white British, 1 White other and 1 Asian other. None had been diagnosed with a mental health disorder.2 knew someone with schizophrenia, 3 knew someone with depression and 1 knew someone with anxiety disorder.*

I: **So, first question. What do you think Mental Health is?**

BG: *The health of your brain, not your brain but, mind..*

TG: *the way you think whether it's like an adaptive way of thinking or maladaptive way of thinking and you've got like a disproportionate view of certain situations.*

GB: *Like, if you have it, it helps you to function normally but without it you struggle.*

FG: *It's probably a different way of thinking than the social norm.*

I: **So, can you describe to me someone with a Mental Illness?**

SB: *'Crazy'*

TG*: Someone with like depression might have a very negative erm, view of the world. Anything that happens, like anything bad that happens they think it's 'cause like their fault. Anything good that happens is out of their control; it's not likely to be repeated. Things like that. Erm, success is like a fluke not because of their actions.*

GB*: They might struggle to like do everyday tasks, that, yeah..*

FG*: And schizophrenia like seeing things.*

SB*: Yeah.*

BG*: Hallucinations like paranoia they might think everyone's out to get them.*

I: **And where do you think your ideas come from?**

Group*: Psychology, stuff we've learnt in psychology.*

SB*: AS level psychology.*

I: **Anywhere else?**

CG: *I have friends with it.*

SB*: Er..*

BG*: Reading things.*

SB*: TV and stuff, films. There's a lot of, you see a lot of like there's loads of films about erm, what are they called? The asylums and what not.*

TG*: The news.*

SB*: Like horror films.*

TG*: News and documentaries. Things like that. I think it's becoming more of a spoken about topic so not so hush hush type thing.*

I: **So how do you think media describes people with mental illness?**

SB: *Not brilliantly. Like they're kind of weird in a way.*

FG*: Sort of n outsider isn't it. Like they're kind of from different social norms.*

TG: *I think it's becoming less of a taboo. Like, I think people are becoming more open about it 'cause like in the old days no one used to speak about it but I think we hear about it a lot more often.*

I: **So, do you think that what you see in the media is accurate?**

GB: *No not always.*

BG*: I think fairly.*

FG*: It depends on perception doesn't it so it's different from the author. Makes it different from reality sometimes.*

TG*: It's sometimes exaggerated for dramatic effect like so you don't always know if you can trust things you see in the news or media.*

GB*: Mmm.*

SB*: Well I've never seen first-hand people with severe mental illness so I cannot really comment.*

I: **So what do you think might be inaccurate about what the media shows you?**

BG: *Like the level of it like I think they overdo it I think.*

GB: *A lot of what the media portrays are people who have done something because of their like poor mental health when they don't, not everyone with mental health actually causes disruption.*

BG: *Like extreme cases.*

GB: *But the media does seem to portray the people that do.*

FG: *It often portrays in a really bad way like they don't really belong to the society when it should be the opposite.*

I: **erm what, what are your ideas about kind of normal Mental Health?**

FG: *I think the main idea is like the majority isn't it like the average Mental Health is like everyone else, well majority of society.*

SB: *I suppose it's being able to get on and do things as the majority does. I suppose.*

I: **Erm, what do you think the difference is between sort of having a bad mood and like an actual mental illness, where's the line?**

TG: *You could have a bad mood for maybe like one or two days but like a disorder would go on for a longer period of time.*

SB: *Yeah.*

FG*: If it's like affecting your everyday life maybe and if you can't function.*

BG*: You probably have more control when you just have a bad mood than you actually do when you have a mental illness.*

TG*: A bad mood doesn't really need like medical attention whereas a disorder you'd think you need some help because something's not adapting like functioning as it should. And it's not going to return to normal without specific help whereas a bad mood you wake up and it's kind of gone.*

I: **So, do you guys think that you'd be able to say recognise if your friend had a Mental Illness?**

BG: *No.*

SB: *It depends really.*

FG: *Not if you don't show it really so people try and hide it and sort it out themselves.*

SB: *Yeah, well..*

TG: *I think a lot of people wouldn't want to erm, like, feel like they're making a fuss so they wouldn't want to say like "oh I think I've got a disorder" they'd prefer to say "oh I'm just having a bad day or I'm having a bad couple of days" because they wouldn't want to like make an example out of themselves. Or could be worried of being embarrassed people will take the mick out of them or something.*

SB: *Yeah.*

I: **And what about in yourself if you were developing a Mental Illness do you think that would recognise that?**

BG: *No.*

CG: *I think you would.*

SB: *I'd like to think so but then again I don't think it happens. I'd want to..*

BG: *I think it'd be because you're too used to yourself like because it would like progress slowly you just got used to being just slightly different.*

CG: *Yeah but at some point you'd be like "this isn't right this is what I was a few weeks back".*

BG: *Yeah but if you've got a Mental Illness you wouldn't be like really like thinking about like how you were.*

CG: *You could be in denial.*

TG: *Also, I don't think you'd be like, especially being students, you could just say "oh I'm stressed because I've got an exam next week and after that It'll be okay". And then kind of coul try and make sense of it by pin pointing it to an event to kind of reassure yourself or kind of delude yourself you don't have a problem. 'Cause I suppose a lot of people like alcoholics will say "oh I don't have a problem I drink because of this". It could be the same with like a Mental Illness.*

I: **So at what point do you think someone should start to seek help?**

SB: *If it's consistently happening like, if it's just, you feel really bad for a few days but then you ee it start to get better or if it's, or if you like have a bad day but then keep having bad days consistently and if you start to know this isn't quite right.*

BG: *When it like has an impact on your actual functioning your normal day routine.*

TG: *Yeah, when it stops you being able to do things you used to do. Things like that. I dunno I think a lot of the time I presume it'd take someone else looking in rather than yourself like recognising your problem.*

I: **So what experiences do you think somebody might have before they try and get help?**

BG: *Like if there's something they can't do.*

FG: *I don't think they want help all of the time necessarily, they don't want to admit that there's something wrong. Erm..*

TG: *And it might literally get to the point where say if someone's depressed, it might literally get to the point where they're starting to self-harm, things like that, where they actually like realise it's having a great impact, like something kind of big and a landmark has to happen. Because when you're kind of going on day to day, kind of yeah you can be feeling a bit bad than usual but you're kind of getting on with things but then like something substantial needs to happen to make you like realise you've got a problem.*

I: **What sort of things do you think make people more likely to get help?**

BG: *Other people influence you.*

SB: *Yeah like encouragement really, like if all your mates realise like well you're not the same as you have been something's like going on here, to help make them realise that you're better off going to get help than just letting it progress in case there is something wrong.*

GB: *Sometimes it could be like they might not be able to go to work so they can't get a steady income and that so they realise that they need that income that they're not going to work because they, because they're worrying or because they're paranoid about something, they realise that they need to go and get help so they can return.*

TG*: And I think if the help's there it's obviously like easier if people make it come across as not such a negative thing like if you take the taboo away I think people would be much more likely to go and get help because they wouldn't see it as like something to be ashamed of. Because I know in come cultures like in China they see like they don't recognise depression. They like see it as something else but if that taboo wasn't there then they'd be more likely to openly get help like before it got worse.*

FG: *Because we talked about social media and social media portrays it in such a negative way. We need to change the way of thinking and people portrayed in a completely different way so it's not such a taboo as T said.*

I: **And what makes somebody less likely to get help?**

TG: *Being on their own.*

SB: *Or if their friends like start to mock it in a way, start to have banter about it if they're like "oh you've been a bit of a freak lately" so that's like discouraging you from..*

BG: *Internet. Searching online. Finding symptoms and thinking that you have the same symptoms as that and then if yeah.. Reading up on things.*

TG: *Being like quite proud can prevent you from doing it as well. Like having a stubborn personality like not admitting that you have like a problem. That could prevent you from getting help.*

SB: *Or just being scared that you wanna, that you don't want to find out you like don't want to believe that something's happening. You just wanna hide away.*

I: **So what do you think might go through the mind of someone when they're getting help?**

SB: *Pretty worried to find out that they may potentially have a Mental Health problem.. Big thing.*

TG: *I think relieved as well, they say a problem shared is a problem halved. At least they know that they're getting like, going the right direction. They're getting help, it's going to get better. Because I*

suppose like when you feel depressed you might feel the problem's quite isolated to you and you're kind of like a freak. But if someone gets help they're kind of quite reassuring.

FG: *Because what they need is the attention isn't it. Because when you have depression they just need attention to make themselves feel better.*

I: **And where can you get help from?**

FG: *GP.*

BG: *Like those confidential helpline thingy's.*

TG: *through the school, you could have like a counsellor or a teacher or like even your friends to get help.*

BG: *Somebody else who's like recovered from or like is dealing with a Mental Illness.*

I: **Who might somebody go to for help?**

SB: *Probably initially family, mum or dad. That kind of thing or a close mate.*

BG: *Friends.*

SB: *Yeah. Someone you trust and know they're gonna, I dunno, not judge you or someone you know is gonna listen and help you.*

I: **And if you didn't know where to get help from, how might you find that out?**

BG*: Internet.*

SB: *Google.*

Group*: Internet.*

I: **Just the internet?**

GB: *There's some TV adverts for it like helplines and stuff like that.*

TG: *You could tell a friend like if you're gonna confide in someone you could kind of try and find..*

SB: *Yeah or if you knew someone. If you knew someone who's suffered. They'd know I presume.*

I: **And what do you think happens when someone seeks help?**

SB: *Erm, psychological tests to see if they have what they think they have or..*

BG: *Counselling, treatment from counselling, talking about your problems.*

CG: *Drugs.*

BG: *Like trained how to get back to normal functioning again.*

I: **So do you know about other sorts of help?**

SB: *Erm..*

BG: *I dunno.*

TG: *I guess you've got like therapy by yourself or you can have like group therapy or you could like drugs if you've got like a low serotonin level or what is it?..*

BG: *SSI's.*

TG & BG*: A diet.*

BG*: That electrode thingy.*

Group*: ECT.*

SB*: Yep.*

TG: *Or CBT, EBAT, RABT.*

Group: *Laughs.*

BG*: All our revision.*

I: **So what would be the optimal help what's ideal?**

BG: *A mixture.. of stuff.*

SB: *Well..*

BG: *CBT and drug treatment.*

FG: *Most common is antidepressants but they don't prove to work but obviously, well they don't always work but they're the most common ones.*

TG: *Probably just a change to what you're doing at   moment I, because if what you're doing at the moment is making you depressed because you kind of, through maladaptive thinking got into a routine that's bad for you. Probably changing that routine like you know being more socially active and maybe like changing your diet or exercise as well as doing the drugs, just like a change would help I think.*

I: **What do you think causes Mental Illness?**

BG*: Genetics.*

GB: *Environmental pressures, so like your job or..*

FG*: Stress.*

SB: *I suppose a bit of both, you might have a genetic predisposition but then there might be something in life like an experience that triggers it.*

TG: *It's not always something you can control.*

SB: *Yeah.*

TG: *Like, if you get fired because of like a situation that's not your fault that could cause you to be depressed or if you get divorced.*

BG: *If somebody dies..*

TG: *Because somebody cheated on you that's not your fault but it causes depression. If someone dies like. It's not always your own fault but I think a lot of people blame themselves about things that happen to them.*

I: **What about things other than depression is that the same causes?**

BG: *Like schizophrenia and like things like that?*

I: **Yeah any Mental Illness?**

TG: *I reckon like biological could be more.*

FG: *Age as well like what age it develops.*

BG: *Personality.*

I: **So what might make someone more susceptible to getting a Mental Illness?**

TG: *Lack of confidence.*

BG: *Yeah I think your personality has a major impact.*

TG: *Whether you allow certain events to affect you a certain way because like a lot of people in their lifetime are probably gonna get fired. Some people will take it as more of a positive thing where they'll move on from it whereas some people will sit and stew so I think it's just how you react to certain situations not just situations in themselves.*

SB: *Or things like drugs like marijuana has been linked to certain Mental Health things and..*

TG: *When you drink a lot as well like lifestyle.*

FG: *I think also like marijuana it's like an addiction, so it's like a different type of personality. So people who have a certain type of personality would take drugs. That's, that would also need to..*

I: So are there things people can d to make themselves less susceptible or less likely to get a Mental Illness?

BG*: Exercise and diet.*

TG: *I don't think you always have a lot of control when it comes to these things like. Like if it's biology like in schizophrenics or anyone with like any Mental Health I don't think you can particularly like make yourself act or like produce certain neurochemicals it's kind of like out of your control.*

FG: *Maybe childhood as well, like the way parents raise children. So maybe they could prevent it somewhere.*

SB: *Or I suppose like if you've got a family who's got a history of Mental Health disorders then and tou know you might be at risk of getting it then you're probably gonna do your research and go about looking at what life's like in a way and what you can do to try and prevent getting a..*

TG: *By surrounding yourself with like positive people could prevent other people with like a half half attitude like half empty.*

I: Do you think there are any like warning signs that somebody might be developing a Mental Illness?

SB: *Not well, it depends on what the Mental Illness is but it's not really probably that obvious to other people but to yourself like but if suddenly start seeing hallucinations you're obviously gonna think something's up.*

FG*: Probably like in depression a sad mood and you don't want to wake up so you sleep too long some days.*

TG*: Just a change in the way you're behaving really.*

I: And what's your perception of kind of like the timeline of Mental illness. So how long do you think somebody might have a Mental Illness for?

SB: *Quite a while I suppose.*

GB: *I think a long time.*

SB*: It's not just something that... You'll be fine one day, wake up one day and you're hallucinating left right and centre. But..*

BG: *I think it's probably always with you. I don't think you can get rid of it.*

GB: *Because there's quite a long time between identifying it and for yourself then finding help and then the whole help process until you get sort of thing so I think it takes quite a long time.*

TG: *I think 'cause like if you did develop a Mental Health issue, I think once you know it's there it'll kind of always be in the back of your mind so you want necessarily always be able to be like rid of it in a way. Well you might be able to act normally as well but it'd kind of always be there so I don't think once you get it it ever really leaves you. It's like alcoholics.*

BG: *You could like supress it I think you could supress it but I don't think you could totally eradicate it. It could always be with you somehow.*

> I: **And is it something that you're born with or does it develop?**

BG: *I think you're born with like a predisposition but then the environment like effects it. Triggers it.*

SB*: Yeah.*

TG: *Like, probably varies depending on like what mental issue you have.*

> I: **And what are the treatment options we touched upon it earlier but..**

BG: *There's like group discussions or like 1:1 talks with therapists.. Drugs.*

FG*: Cognitive therapy. I think it's very useful to change people's way of thinking but it doesn't always work like schizophrenia. I think it's more biological.*

SB: *ECT.*

TG: *Yeah a mixture of biological and psychological help. Like do what you can to fix it.*

I: **And how long do you think someone might go before their behaviour is noticed?**

SB: *Depends on their social situation. If they're one of these people who's grown up their whole life being like keeping to themselves being relatively lonely like then you might not, no one might pick up on it. But then if you're an extravert then er, it's much, it's a lot more likely that your friends or family will probably pick up of your behaviour is radically, well, starts to change and you start to not be yourself.*

TG: *It depends if you want help or if you're trying to hide it. 'cause obviously if like you start noticing changes you tell your friends straight away you'll notice it a lot quicker but if you're tryna hide it or supress it it'll take a lot longer 'till like you boil over and, and can't hide it anymore like that could be further down the line.*

I: **And how long do you think somebody might wait before they try and get help?**

FG & CG & BG: *A long time.*

FG: *About 6 months.*

BG: *No I think..*

SB: *It sort of depends, well.*

FG: *Usually it depends on the culture as well because in the culture of England people like to hide their feelings so in England it probably would take longer to notice and say something about it.*

BG: *I think you have to like accept it yourself before you can admit that you need help. And that's probably going to take a long time.*

SB: *Sort of depends on personality because if you're one of those people who worry all the time about all, loads of things and then you realise something's going wrong then you might want to get it checked out quickly to make sure you're alright but if you're one of them people who tend to try and ignore or hide and just get on with things then they could just be like trying to push it away "oh I dunno it'll be, it'll go away" that kind of thing. It could go on like that for ages and not got help for a while.*

I: **And what do you think are the consequences of having a Mental Illness?**

SB: *Could be extreme, could..*

BG*: Major impact on life and daily routine, the people around you, your friends, your family.*

FG*: Yeah I think it affects how people think of you and like how they talk to you so it could like be really effective with like your social situation.*

TG*: I think if you see it as kind of like a negative thing I think it'd make it feel like worse for yourself but if you kind of try and give a positive side to it like "yeah I do have a Mental Health but I'm now getting help and I'm doing this for myself I think it could have less of an effect if you don't make it such, like an extreme thing. Like if you make it more sort of socially acceptable, like as it is becoming then I don't think it will have as big an impact on your life.*

SB: *But still like if you've got voices in your head 24/7 like saying they're going to kill you and stud and you just petrified and you don't wanna leave the house then it completely can take over your life. You can't, there's not much you can do about it I suppose.*

TG*: The thing is it varies with like what you've got obviously 'cause like..*

SB*: Yeah completely yeah.*

TG: *Very very extreme. It will vary with how extreme your Mental Health Illness is.*

I: **And what sort of different symptoms might people experience?**

SB: *Hallucinations, just, er..*

TG: *A change in the way you think.*

SB: *Yeah.*

TG: *A change in the way you feel.*

SB*: Eating.*

GB*: Fear of like going outside or going to work.*

BG*: Extreme changes.*

FG*: And people often isolate themselves, they don't want to go out, they don't want to see people.*

I: **How might someone try and manage their symptoms?**

BG: *Ignore it.*

SB: *Just try and hide it away.*

CG: *Deny it.*

GB: *Some people might try and, might try and tackle it themselves head on so might try and say, they might just kind of isolate themselves and not put themselves in a situation they're scared of to try and..*

I: **And what kind of impact can it have on lifestyle?**

FG*: Enormous.*

SB*: Potentially huge, or potentially very insignificant. Like, like I said before if you've got crazy voices in your head al the time and you're just too scared to leave the house then you could just en up being totally housebound and not do anything in your life because you're just like constantly in fear of just if you're, obviously that's extreme case but it can be much milder case of Mental Health which could*

barely impact you at all and you could live a totally relatively normal lifestyle and not be too bothered by it.

I: **And how do you think people with Mental Illess and treated by other people?**

FG: *People often see it as negative and basically the western cultures like positive people so they see negative people as a bad thing.*

SB*: They're often patronised as well and treated as lesser because..*

TG: *But then I think at the moment they are trying to tackle that certain stereotype and taboo. Like I think it's definitely better than what it used to be. I mean it's not like perfect I know. You're not gonna get everyone accepting it you're still gonna get people patronising you treating you differently but I don't think, I think it is getting better and it's like going towards the right direction because I think it is getting a lot more common so you don't think that your illness is like isolated to yourself, don't feel on your own. Like you're in a group, like a lot of people have Mental Illness'. So I think a lot less people can be judgemental 'cause like a lot of people know someone with it or themselves suffer with a Mental Illness so they're less likely to judge because you know like people are more educated about it. I think when more people are educated about it the less they're likely to like make quibs about it and like treat it as a joke.*

I: **And what sort of impact do you think Mental Illness can have on people other than the person with a Mental Illness?**

GB: *You mean sort of like family and friends have maybe got to care for them depending on how bad their Mental Health is. So it can affect their lives and maybe stop them going to work or they have to become part time or yeah..*

TG: *I think people can start to blame themselves for something that happens like so.. if your son or daughter gets schizophrenia and you think it's because of like your parenting skills, they could feel*

guilty about that. Or like if you broke up with someone and they maybe developed depression you could blame yourself for the action that triggered it.

I: **Okay last question. Do you think you're currently provided with enough information on Mental Health?**

SB: *Erm, well if I didn't do psychology no.*

Group: Yeah.

SB: *I mean you see the vague advert about dementia on TV but..*

CG: *Yeah the information is there if you want to find it, it's just I don't think people actively look.*

FG: *they don't ask where to find it. They often wait for someone to find it because they need attention.*

TG: *I don't think people.. I think 'cause a lot, because of the media and things like, it's seen as like a bit extreme so if you're only reporting about extreme cases you think that's what depression is so if you've got anything less than that you may not think that you have a Mental Illness.*

Appendix D

Focus Groups Item generation

KEY
A: Recognition of specific disorders.
B: How to seek information about Mental Health
C: Risk factors and knowledge of self-treatment or professional help.
D: Attitudes to promote self-recognition and promote help seeking.
E: Impact of Mental Health on coping.
F: Attitudes towards Mental Health.

No.	CATEGORY	STATEMENT	WHERE THIS WOULD FIT
1	BEHAVIOUR	A person with a Mental Health Illness would behave differently to the majority.	A
2	BEHAVIOUR	A person with a Mental Heal Illness would react differently in difficult situations.	A
3	BEHAVIOUR	A person with a Mental Health Illness would find day to day life more difficult.	E
4	BEHAVIOUR	A person with a Mental Health Illness would be more likely to seek help following encouragement.	D
5	BEHAVIOUR	A person with a Mental Health Illness would ask someone to seek help for them.	D
6	BEHAVIOUR	A person with a Mental Health Illness would stop taking prescribed medication.	E
7	BEHAVIOUR	A person with a Mental Health Illness would let problems build up until they come to a head.	E
8	BEHAVIOUR	A person with a Mental Health Illness would try to normalise their behaviour.	F
9	BEHAVIOUR	A person with a Mental Health Illness would have had problems since childhood.	F
10	BEHAVIOUR	A person with a Mental Health Illness may be unable to work.	A
11	BEHAVIOUR	A person with a Mental Health Illness seeks attention.	A
12	BEHAVIOUR	A person with a Mental Health Illness would seek help from a GP.	C
13	BEHAVIOUR	A person with a Mental Health Illness would seek help through their school.	C
14	BEHAVIOUR	A person with a Mental Health Illness would take illegal substances.	A
15	BEHAVIOUR	A person with a Mental Health Illness would not find help for some time.	D
16	BEHAVIOUR	A person with a Mental Health Illness would change their diet.	E
17	BEHAVIOUR	A person with a Mental Health Illness would seek help from family and friends.	C
18	BEHAVIOUR	A person with a Mental Health Illness may not act in socially acceptable ways.	A
19	BEHAVIOUR	A person with a Mental Health Illness may lack control over their actions and thoughts.	A
20	BEHAVIOUR	A person with a Mental Health Illness would seek help from the internet.	C
21	BEHAVIOUR	A person with a Mental Health Illness would seek help from a	C

		charity.	
22	BEHAVIOUR	A person with a Mental Health Illness would be a danger to others.	A
23	BEHAVIOUR	A person with a Mental Health Illness would be a danger to themselves.	A
24	BEHAVIOUR	A person with a Mental Health Illness would demonstrate odd behaviour.	A
25	BEHAVIOUR	A person with a Mental Health Illness would have a compulsion to behave in certain ways.	A
26	BEHAVIOUR	A person with a Mental Health Illness would demonstrate behaviour that makes them stand out.	A
27	BEHAVIOUR	A person with a Mental Health Illness would take longer than 6 months before seeking help.	D
28	BEHAVIOUR	A person with a Mental Health Illness would have to make sacrifices to accommodate their illness.	A
29	BEHAVIOUR	A person with a Mental Health Illness may not seek help and try to deal with things themselves.	C
30	BEHAVIOUR	A person with a Mental Health Illness would use the Internet for self-diagnosis.	C
31	BEHAVIOUR	A person with a Mental Health Illness would cause disruption.	A
32	BEHVIOUR	A person with a Mental Illness would try to hide it.	E
33	BEHAVIOUR	A person with a Mental Health Illness would wait for problems to subside.	D
34	PERCEPTION	A person with a Mental Health Illness would only be recognised if their illness was severe.	D
35	PERCEPTION	A person with a Mental Health Illness would not blend in in a social situation.	A
36	PERCEPTION	A person with a Mental Health Illness would perceive situations differently.	A
37	PERCEPTION	Media only portrays abnormal cases of Mental Health Illness.	F
38	PERCEPTION	A person with a Mental Health Illness would not recognise there was a problem.	D
39	PERCEPTION	A person with a Mental Health Illness would justify changes in behaviour.	D
40	PERCEPTION	A person with a Mental Health Illness would believe they are not 'bad' enough to need help.	D
41	PERCEPTION	A person with a Mental Health Illness would not be taken seriously until they were an adolescent.	F
42	PERCEPTION	A person with a Mental Health Illness would be more easily recognised by friends or family.	D
43	PERCEPTION	Media only portrays unusual cases of Mental Health Illness.	F
44	PERCEPTION	Some Mental Health Illness' are more well-known than others.	A
45	PERCEPTION	Some Mental Health Illness' are more common than others.	F
46	PERCEPTION	Depression is the most common Mental Health Illness.	F
47	PERCEPTION	A person with a Mental Health Illness would think differently.	A
48	PERCEPTION	A person with a Mental Heal Illness would think negatively.	A
49	PERCEPTION	A person with a Mental Health Illness would see things that aren't there.	A
50	PERCEPTION	A person with a Mental Health Illness would seek help if they see their illness as a problem.	D
51	PERCEPTION	A person with a Mental Health Illness would seek help later if they're not a danger.	D

52	PERCEPTION	The type of Mental Health Illness affects how long it takes to seek help.	D
53	PERCEPTION	A person's social situation would affect how long it takes them to seek help.	D
54	PEERCEPTION	Personal outlook affects the decision to get help.	D
55	PERCEPTION	The internet is a reliable source of information.	B
56	PERCEPTION	A person with a Mental Health Illness would seek help from the Internet rather than GP due to ease.	B
57	PERCEPTION	Media depicts people with Mental Health Illness as irrational.	F
58	PERCEPTION	Media depicts people with Mental Health Illness as dangerous.	F
59	PERCEPTION	Media depicts extreme aspects of Mental Health.	F
60	PERCEPTION	There are different levels of Mental Health Illness.	A
61	PERCEPTION	Anxiety and depression affect people at a similar level.	A
62	PERCEPTION	Everyone will experience aspects of Mental Health Illness to some extent.	A
63	PERCEPTION	The best form of treatment for Mental Health Illness is a mixture.	C
64	PERCEPTION	Antidepressants are the most common form of treatment.	C
65	PERCEPTION	A person with a Mental Health Illness may not get better on antidepressants.	C
66	PERCEPTION	There is a delay in receiving successful treatment.	C
67	PERCEPTION	GP's are able to help people with Mental Health Illness.	C
68	PERCEPTION	A person with a Mental Health Illness will never completely recover.	F
69	PERCEPTION	A person with a Mental Health Illness would be treated like an outsider.	F
70	PERCEPTION	A person with a Mental Health Illness would be recognised.	A
71	PERCEPTION	Perception of Mental Health Illness is affected by culture.	F
72	PERCEPTION	A person with a Mental Health Illness should surround themselves with positive people.	C
73	PERCEPTION	A person with a Mental Health Illness would be patronised.	F
74	PERCEPTION	There is a negative stereotype attached to Mental Health Illness.	F
75	PERCEPTION	Knowledge about Mental Health Illness could improve public perception.	F
76	PERCEPTION	A person with a Mental Health Illness would not identify it for some time.	D
77	PERCEPTION	A person with a Mental Health Illness would get better through changing their thinking and behaviour.	C
78	PERCEPTION	The process of treatment for a Mental Health Illness would take some time.	C
79	PERCEPTION	Mental Health Illness develops over a period of time.	A
80	PERCEPTION	Social situations can affect behaviour and emotion.	C
81	EMOTION	People describe themselves as being depressed without diagnosis.	A
82	EMOTION	A person with a Mental Health Illness would feel down for a longer period of time than someone without.	A
83	EMOTION	A person with a Mental Health Illness would contemplate suicide.	A
84	EMOTION	A person with a Mental Health Illness would struggle to come out of bad moods.	A
85	EMOTION	A person with a Mental Health Illness would blame themselves.	A
86	EMOTION	A person with a Mental Health Illness would feel frustrated.	A
87	EMOTION	A person with a Mental Health Illness would display extreme emotion.	A
88	EMOTION	A person with a Mental Health Illness would be able to control their	E

		emotion and appear as *normal*.	
89	EMOTION	A person with a Mental Health Illness may feel that they cannot manage their illness themselves.	E
90	EMOTION	A with a Mental Health Illness would not want to admit they have a problem.	D
91	EMOTION	A person with a Mental Health Illness would be worried.	A
92	EMOTION	A person with a Mental Health Illness would be relieved.	A
93	EMOTION	A person with a Mental Health Illness would afraid of being categorised.	A
94	EMOTION	A person with a Mental Health Illness would feel ashamed.	F
95	EMOTION	A person with a Mental Health Illness would feel like a burden.	F
96	EMOTION	A person with a Mental Health Illness would be afraid of going to the doctors.	E
97	EMOTION	A person with a Mental Health Illness would want to hurt themselves.	A
98	EMOTION	The success of therapy depends on the relationship with the therapist.	C
99	EMOTION	A person with a Mental Health Illness would feel alone.	E
100	EMOTION	A person with a Mental Health Illness needs to want to help themselves.	D
101	CAUSE	A person with a Mental Health Illness' behaviour is affected by upbringing.	C
102	CAUSE	A person with a Mental Health Illness would display behaviours depending on personality.	A
103	CAUSE	People are born with Mental Health Illness.	C
104	CAUSE	A person with a Mental Health Illness would have a different brain system.	C
105	CAUSE	Mental Heal Illness is caused by things in the environment.	C
106	CAUSE	A person with a Mental Health Illness would have a family history of Mental Health.	C
107	CAUSE	Mental Health Illness is caused by genetics.	C
108	CAUSE	Mental Health Illness is caused by traumatic events.	C
109	CAUSE	Mental Health Illness is caused by both the environment and genetics.	C
110	CAUSE	Mental Health Illness develops at a certain age.	C
111	CAUSE	Mental Health Illness is triggered.	C
112	KNOWLEDGE	Knowledge about Mental Health comes from the media.	B
113	KNOWLEDGE	Knowledge about Mental Health comes from people with Mental Health Illness.	B
114	KNOWLEDGE	Knowledge about Mental Health mostly comes from school.	B
115	KNOWLEDGE	Information about Mental Health Illness is available.	B
116	KNOWLEDGE	Information about Mental Health Illness is not sought out.	B
117	CONSEQUENCE	A person with a Mental Illness would not get better without help.	E
118	CONSEQUENCE	The family of a person with a Mental Health Illness would have to take on different responsibilities.	E
119	CONSEQUENCE	A person with a Mental Health Illness would have psychological tests.	C
120	CONSEQUENCE	A person with a Mental Health Illness would have counselling treatment.	C
121	CONSEQUENCE	A person with a Mental Health Illness would have drug treatment.	C
122	CONSEQUENCE	A person with a Mental Health Illness would receive Electro	C

		Convulsive Therapy.	
123	CONSEQUENCE	A person with a Mental Health Illness would receive Cognitive Behaviour Therapy.	C
125	CONSEQUENCE	A person with a Mental Health Illness would attend group discussions.	C
126	CONSEQUENCE	A person with a Mental Health Illness would have 1:1 discussions.	C
127	CONSEQUENCE	A person with a Mental Health Illness would be treated differently from the majority.	A
128	CONSEQUENCE	A mental Health Illness would completely take over a person's life.	E
129	CONSEQUENCE	A person with a Mental Health Illness would be housebound.	A
130	CONSEQUENCE	A Health Illness would not impact a person's lifestyle.	
131	CONSEQUENCE	A person with a Mental Health Illness would need to be cared for by friends and family.	E
132	CONSEQUENCE	The family and friends of a person with Mental Health Illness would blame themselves.	E
133	CONSEQUENCE	A person with a Mental Health Illness would see more than one counsellor.	C
134	CONSEQUENCE	The family of a person with a Mental Health Illness would try to manage the illness at home.	C
135	CONSEQUENCE	A person with a Mental Health Illness is put on a waiting list when seeking help.	C

Appendix E

Interview Transcript

I:when did you first start having concerns.. about.. what was going on

P: Its been a few years, but like ive been able to deal with things myself, its been the past about a year or so, just under a year that things were getting too bad

I: so what kind of things were happening?

P: It's mostly family problems and that,obviously what I went through with the brain surgery and not being able to do what I wanted to do in life…

I:uh huh

P: and being where I wanted to be by this age

I:yeh

P: it just gets me down, like coz all me dreams and ambitions and goals were just taken away from me

I: yeh course, so you say like the brain surgery, when was that?

P: when I was 17

I: ahh ok, and so then after that did you develop symptoms for…

P: I developed epilepsy , and when I had the brain surgery and had a mini stroke aswell..

I: Ok, yeh so you had a lot to go through!

P: I've been through a lot yeh (laughs)

I: Did you feel like that was… you could cope with that at the beginning?.. but then

P: yeh, until I found out that I couldnt do like anything that I wanted to do.. erm main dream was to join the army, and obviously once I developed the epilepsy that was a no go.. But then I found out I can still go but I have to be fit free for a ten years, so like I got nine years to wait now.

I:How did that affect you..

P: it destroyed me, I didn't have any back up plan, you know I thought to myself the army you don't need any qaulifacations, you don't need nothing.. you can just go there, they'll tell you everything, teach you everything and then you're in.

I: so what kind of stuff were you doing, you say it destroyed you?

P: well I was working and living in a pub when I got a (..) on the brain, and that urm, coz before the brain surgery I was always working, literally I had about four jobs, and after the surgery and stroke I just couldn't do anything, you know I'm quite an active person, n not being able to do anything is just.. drives me up the wall

I: yeh sure, but you said that you were able to manage it, what kind of things did you do?

P: help others…

I: is that what you did, take your mind off it?

P:It distracts me from me own problems.. but then coz your not dealing with your own problems, your bottling it up, n then when you've got nothing to do, your sort of thinking about them, n then once that bottles open it all starts coming out, and then umm.. helping people my mind will just block off my problems n the bottle will get full n once it starts over filling that's when it explodes. N that's when you get really down

I: mm, yeh, so then is that, at what point did you think that you needed to seek help, then

P: well I blocked everything out, I dunno was just getting too much for me n like even going out n trying to help people you know n cheer them up just wasn't working

I: yeh, so did you speak to anyone, before you got help.. or did you straight

P: I kept going to the doctors

I: ok, was that by yourself?

P: yeh

I: ok, so then what happened from the doctors? Were they supportive

P: yeah he was quite, fairly supportive, but he kept sending me to different coucillors and this that the other, and they were just no good. Like they were rubbish (laughs) like I think the one he sent me to was fairbridge or fairgate in town, and it's a youth one from 16 to 25, n I walked in there n there were just a load of kids running around, n I was like what the.. yknow. Them don't even seem like they need any..yknow they're running about like theyre on a school playground.

I:yeh

P: and then they were telling me the things, like how they do things, n they were like what we do is we don't just jump straight into the counciling… we take you out to do activities like rock climbing or water rafting and this that the other n we get to know yer, n then we decide how we can help… n im like it all sounds good goin ut for free days out n that but its not what I needed, coz im quite an active person anyway.

I: yeh., so you just wanted the help

P: yeh I told them I know roughly what my problems are.. I just need someone to sit with n tell them my problems n get some sort of advice on how to deal with them.. you know what I mean.. its got to a point where I cant.. so I need someone to help me get past it

I: so then how did you then get to youthspace?

P: well I been trying to get councilling for 7-8 months n my doctor refer me to all different places.. n then I kept sayin to him look.. I ve been there its rubbish, ive been there its rubbish.

I: so did you try all the ones he referred you to?

P: Yeh,… I did… I was willing to try anything, you know what I mean? N you know once he said I'll refer you to the psychologist… look counsillor.. psychologist… whatever.. just get me some bloody help

I: yeh.. so by then you didn't need anyone else to tell you to get help you were one who wanted it.

P: I got referred to the yewcroft a couple of years ago.. but I didn't seek the help.. so it was like I don't really need this..

I:yeh?

P: I walked out

I: was it the doctor that told you to go there?

P: yeh

I: so have your famly been supportive of it? Do they know?

P: errr… sort of.. a bit… but not really.. I don't really speak to them that much about it coz im one of these ones where I don't liketo burden other people with my problems when they've got their own problems. You know what I mean?

I: so do you feel now then,, so far your problms have been listened to? And concerns.. not just at youthspace.. like throughout

P: errrr partly… but not as fuly as id want them to at the moment.. but obviously like the youth space that was my first appointment… n obviously with the questions they were asking… it's the usual typical you know: how does that make you feel n all that n what do you want us to do for you…

I: yeh

P:well if I knew that I wouldn't be sat here.. coz I'd be doin it myself

I: so have you found that people have been quite receptive towards you or do you find there can be a lot of stigma

P: normal average general public… not really coz I don't talk to them much about my problems I just like to help them with theirs… but with doctors and that they've been fairly helpful so far

I: ok … so can you think of anything that wou;d make helpseeking easier? You say you've been to a lot of places.. banded around a lot

P: yeh I think there should be more counsillors and psychologists that focus on people that's not to do with drink aornd drugs.. coz there a lot a lot alot out there for the drink and drug related cousilling but if its just normal councilling its so hard to find.. so I really think there should be more out there for our average joe

I: so do you think sort of there is too much focus on..from what you'veseen, been sent to..

P: well not too much because there are a lot of problems in the world related to drink n drugs

I: yeh.. but related to you.. were there other things if you didn't need that

P: its like my doctor referred me to aquarius.. which is a drug n alcohol counsillors…n ii went there n I wastalking to them,, n they were like do you drink how much do you drink a day?.. I was like I don't really drink… they were like: drugs? I was like not really no…. so like we cant help you, we're drink n drugs…. I was like well my doctor referred me here.. so im here.. you know what I meanIts not my fault.. its not your fault but!

I: that's a good point, so what about the actual process after seeing your doctor?

P: well I do think my doctor waited too long before he actually started to refer me to places. But I can understand why they do that coz some people will be like ahh I feel depressed this that the other then the next week theyre fine.. theyre just trying to blag it. And err So it must have been

about 5-6months before he even referred me to anywhere. N I kept goin every like week or two weeks saying look I need some help, so obviously like I can see wny he did that. So you

I: that is a long time though.. especially as you were saying you only really told your doctor. Do you think it would've helped telling others? Or know people going through a similar thing?

Y: erm… I dunno because like people who are going through a similar thing like theyre are in the same boat as me.. n alls we gonna be doin is talkin about our problems n not how to resolve them coz we don't know coz obviously we both looking for that same thing… you know what I mean?... it could help its good to talk n that. But I dunno being like talking to someone with the same sort of problems like I say finding the answers to your problems is not gonna happen. You know what I mean

I: ok thank you, I think that's all my questions, im just having a little look… thank you you've been very helpful, talked about a lot of things

P: oh that's me, I can talk for England

I: (laughs)

I: so I just wanna talk a little bit about after the brain surgery, and how that affected like your relationships and how did it affect your role…

P: I just felt worthless, nothing I could do.. I like to be helpful like I say, n with not being able to do anything why am I still here

I: ok what about roles in terms of working, I know you said you wanted to go into the army have you been able to do other things or has the way you've felt hindered that?

P: well its not hindered it.. but to an extent it has coz I get the feeling I mean I've applied for jobs before, I got kicked out of school I got no gcse's n obviously with the epilepsy aswell you know its

safety in the workplace n all that. I know people do get jobs with the epilepsy but its having the

qualifications aswell… im not a stupid person but im not exactly the brightest

I: so do you put that on your application forms? Or do you try and not

P:im completely honest with them

I:ok so in terms of the stigma attached and negative attitude do you think people who are

potentially employing you hold those attitudes?

P: probably, coz they're gonna want someone who's more confident n got the right kind of attitude

I: is that how you feel now, or how it was…

P: well now I've kinda given up on working for other people..

I: yeh..

P: n just thought, sod it I'll do my own thing [writing novel and t-shirt business]

I: ok, I really am finished now thank you for your time!

Reflective Summary

This semester I have been introduced to the term "Mental Health literacy" and the implications surrounding it. Before completing this placement I was not aware of the extent to which mental health knowledge is lacking, most likely through naively studying it for many years. Even myself after studying psychology and working within mental health I was not aware of certain processes involved in the recognition and treatment of mental health disorders. Frequently you become aware that individuals may have a mental illness and that they are in some form of treatment for this. However, what happens in the middle is left widely to the knowledge of health care professionals and close family.

Since the beginning of this placement I have read up on the research surrounding Mental Health Literacy and have read detailed individual accounts from individuals within mental health services with regard to their experiences. I read a number of interviews with individuals attending Youthspace for treatment of mood and anxiety disorders, which enlightened me as to their thought processes, the help seeking process and the timeline of such processes.

After acquiring such knowledge I then conducted 8 separate focus groups with AS level psychology students to gather their ideas about mental health based on themes I'd picked up from my own reading. I found these students to be in a similar position to myself, in that they were knowledgeable of the facts and things they had been taught in school but the real life experiences and empathetic understanding of mental illness is left widely to speculation if no direct contact has been experienced.

Following this data collection I went through each source again and picked out every statement made, re-writing these into easily readable statements to be used as questions. A total of 135 statements were compiled and split into 6 sections which can be used in a draft Mental Health Literacy Questionnaire. This questionnaire will be given to healthcare professionals to be reviewed and modifications will be made based on feedback. Once finalised this question can then be

preliminarily administered; to individuals with mental illnesses, professionals, family and the wider population.

The implications of this are that if effective in determining knowledgeableness, this questionnaire could be used more widely within mainstream systems as a preventative measure. By highlighting areas where knowledge is lacking, efforts can be made to improve such knowledge and ultimately improve the wellbeing of all those affected by mental health.

Throughout this placement I have learnt about qualitative data analysis, coordinating transcripts into themes and conducting focus groups. I have learnt how to generate items for focus group discussions based on previous research and how to control group dynamics within such data collection. I have developed my understanding of mental health as well as the perception of mental health by the wider population.

I have learnt that the process of help-seeking can sometimes be detrimental through increased waiting and lack of understanding by some, and I can see where negative perceptions of mental health services may become construed.

Throughout my placement I have worked with two researchers who have wide knowledge of mental health literacy and they have supported me with transferring research and opinions into measurable statements. I have assisted my supervisor with the data collection processed and they have overseen my development of items to be used on a questionnaire.

During my next placement I will finalise this measure and begin data collection using it. This data will then be factor and thematically analysed. My progression is evident not only in the work I have produced but also in my confidence to complete my next placement more independently. Throughout this placement I have used the supervision of the researcher to develop my understanding of research processes and how to utilise such understanding to benefit myself and my work.

CHAPTER 2

A LITERATURE REVIEW ON SOCIAL RECOVERY IN PSYCHOSIS

Introduction

Slide 1
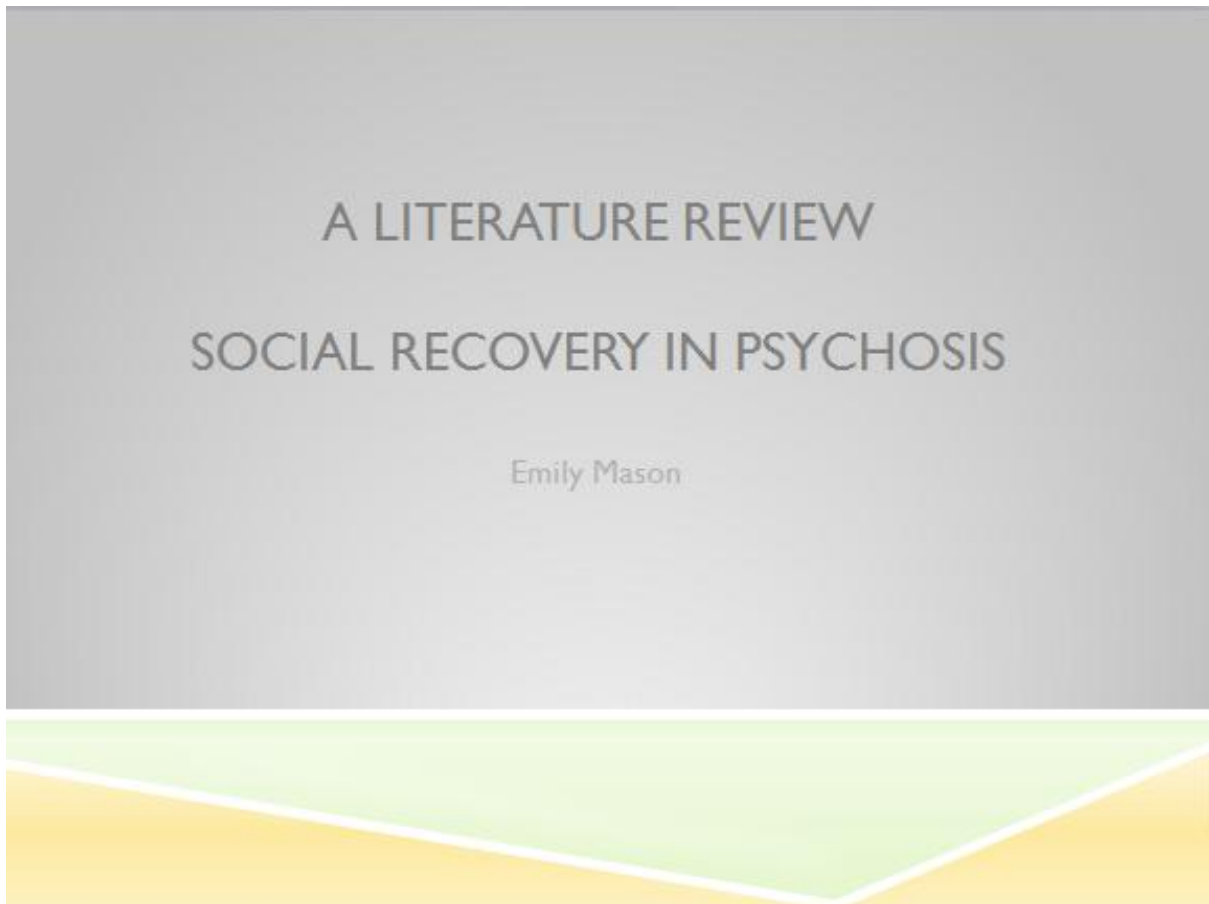
This semester I have been working with the Early Intervention Service (EIS) for Psychosis to complete a comprehensive literature review on the social aspects of recovery in Psychosis.

Rationale

Slide 2

When beginning my placement, Dr Chris Jackson summarised the rationale behind this

review.

Slide 3

As taken from their website, the EIS target young adults experiencing an early episode of untreated psychosis. This service aims to provide support during a period to reduce debilitation, ultimately decreasing hospitalisation and symptoms; improving function in all aspects of life.

Slide 4
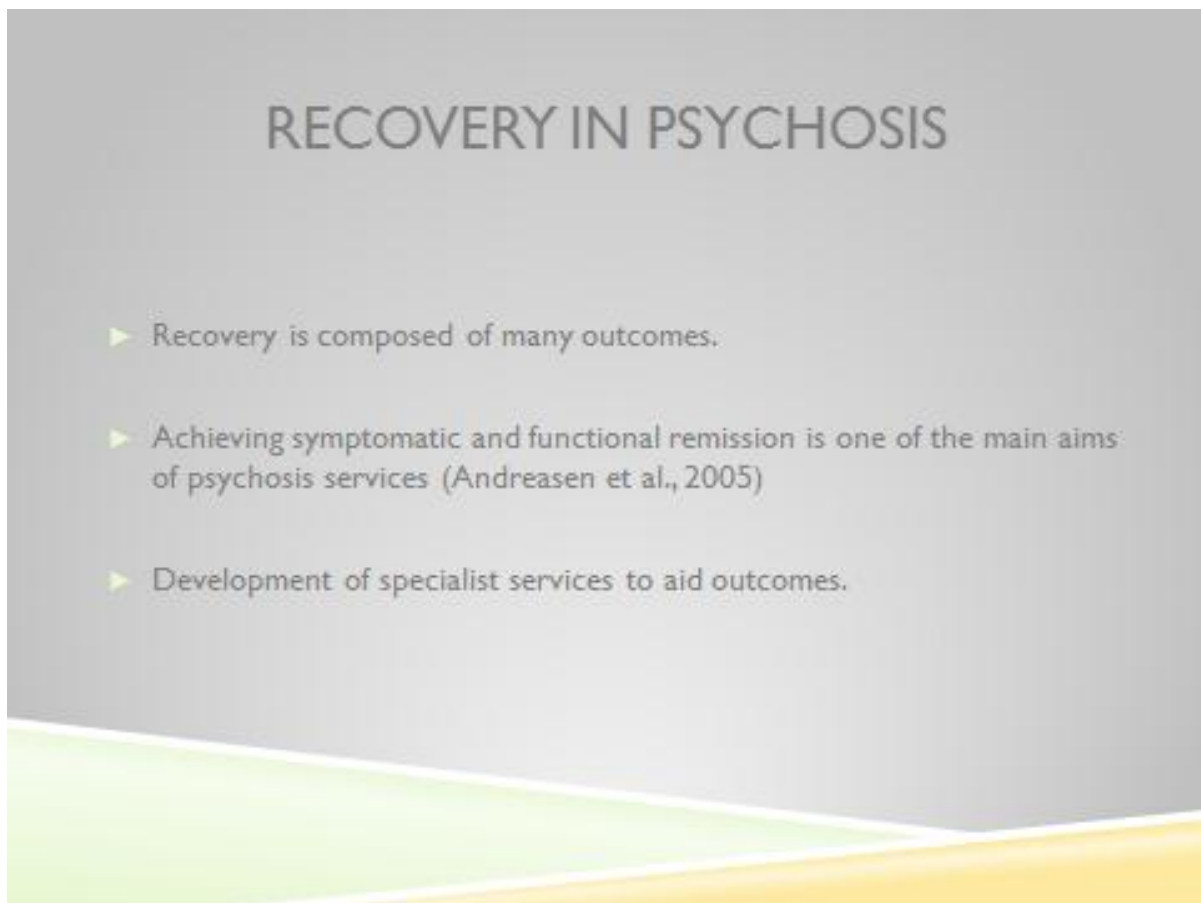
Recovery in psychosis is a broad term. Achieving symptomatic and functional remission is one of the main aims of psychosis services (Andreasen et al., 2005).

With the development of specialist and EIS it is necessary to pinpoint when and what is the best action to take. By identifying factors associated with favourable outcomes, interventions can be tailored.

Slide 5
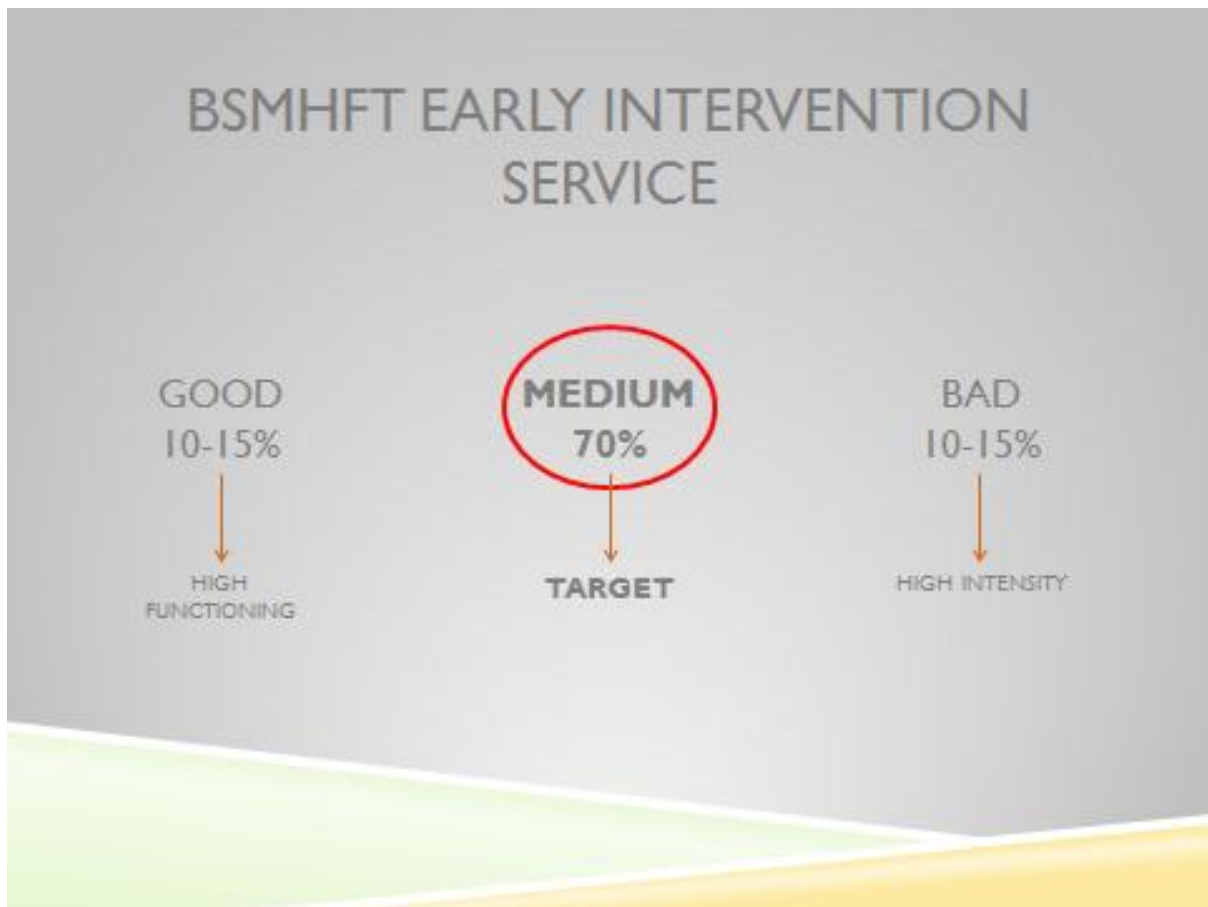
Dr Chris Jackson explained to me the general course of psychosis they see at their EIS. One group consists of individuals who maintain a high level of functioning and another group have very poor functioning requiring high intensity intervention. The main 70% of referrals however fall into a group in between. These individuals are not functioning poorly enough to require intense intervention, but also not adequately enough to maintain a good quality of life. Often, these individuals fail to function adequately socially and vocationally.

Without necessitating high intensity intervention, this group could be overlooked and not receive interventions enabling the best quality of life following remission.

Slide 6
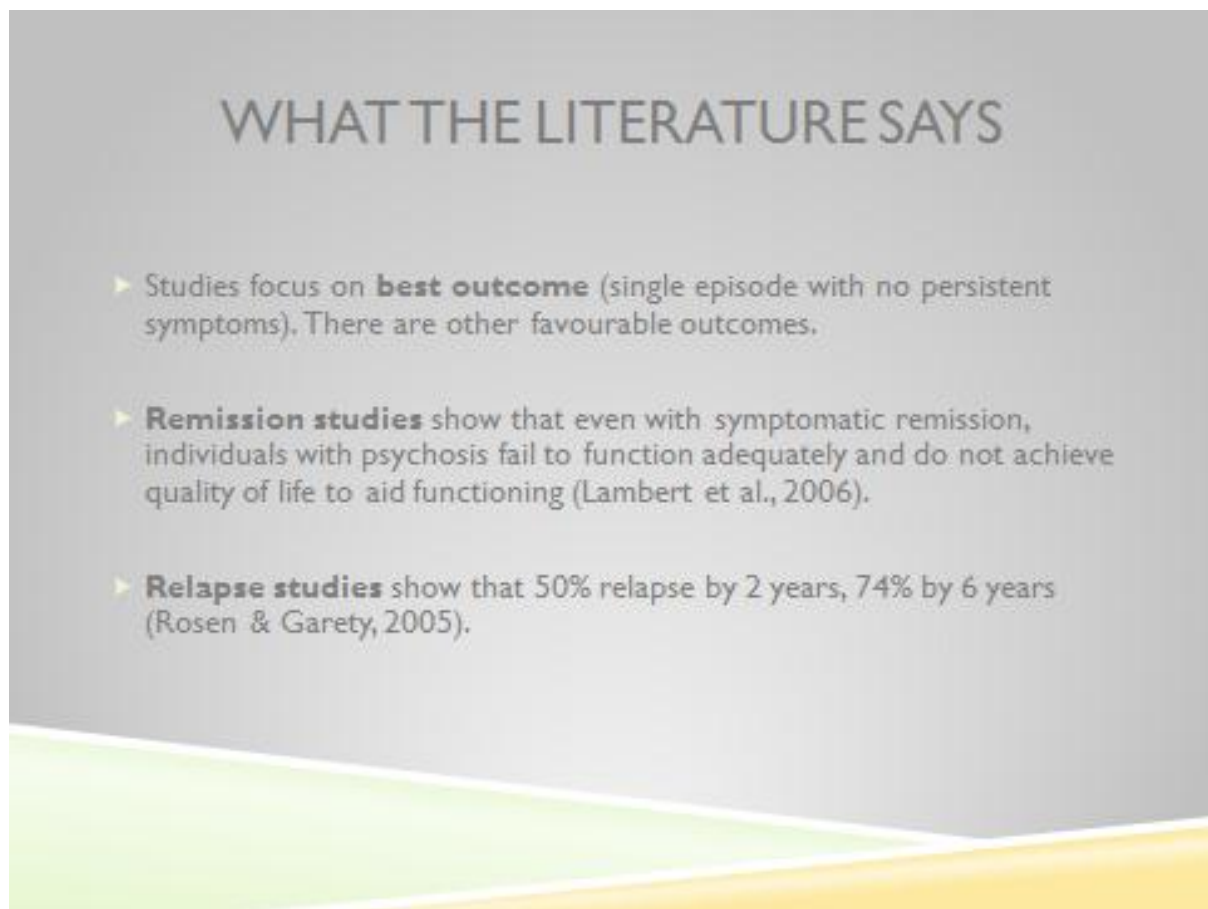
If we look at whether this theory is supported by current literature:

Rosen & Garety (2005) identified a focus on the best possible outcome of single episodes with no persistent symptoms, neglecting to explore other favourable outcomes.

Previously, Shepard, Watt, Falloon & Smeeton (1989) identified 4 patterns of illness:

1.   16% single episode with no persistent symptoms (best outcome)

2.   35% multiple episodes with no persistent symptoms (second best outcome)

3.   31% multiple episodes with persistent symptoms and no return to normality (worst)

4.   7% single episode with persistent symptoms and no return to normality (worst)

Lambert et al., (2006) explored symptomatic and functional remission, alongside subjective wellbeing in 2960 schizophrenic patients. Half the sample achieved symptomatic remission, 40%

subjective well-bring and less than 30% functional remission. When symptomatic and functional domains were combined only 17% achieved remission, when subjective quality of life was included this percentage decreased even further.

These results show clearly that even with symptomatic remission, individuals with psychosis still fail to function adequately and do not achieve a quality of life that aids such functioning.

In determining when to act given these variable patterns of illness, Rosen and Garety reviewed notes from 436, finding 50% had relapsed by a 2 year follow up, 74% by 6yr follow up. This suggests steps towards recovery will be evident by 2 years. Recovery may still occur until 6 years however less likely, beyond this time period little improvement will be made.

Slide 7

Wunderink, Sytema, Nienhuis & Wiersma (2009) demonstrated disparity between recovery outcomes. Results suggest symptomatic remission is more attainable than functional remission, and attaining both simultaneously comes with greater difficulty. Two thirds of those in symptomatic remission did not function adequately, however almost all of those in functional recovery were also in symptom free. Functional improvements are seen in the absence of symptom improvements. This demonstrates the protective nature of adequate functioning and perhaps suggests that only with functional remission can full recovery be achieved.

Similarly, Diaz et al., (2013) found 38% of a remitted group had some functional disability, demonstrating symptom remission is insufficient.

Slide 8

Early outcome studies suggest that social factors are more powerful in predicting long term outcomes. Poor social relationships, duration of hospitalisation and unemployment are defining characteristics of unfavourable outcomes (Strauss & Carpenter, 1974).

Flyckt et al., (2006) also demonstrated long term outcomes are better predicted by social functioning than psychotic symptoms, demonstrating aspects of recovery outside of that managed by medication should be addressed.

It is clear that despite symptomatic remission, functional recovery remains poor (Lambert et al., 2006), therefore symptomatic recovery alone cannot ensure full recovery.

Slide 9
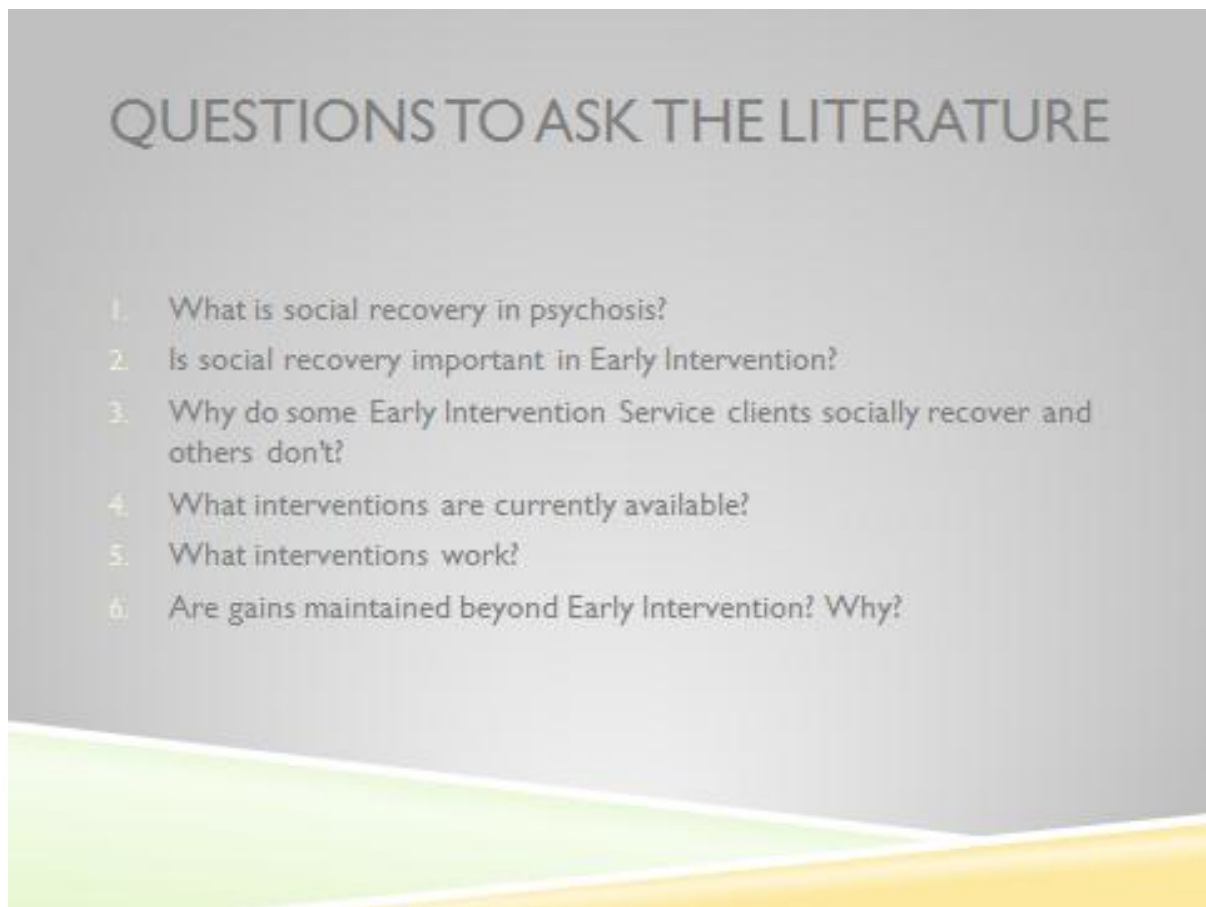
As with any research question, in order to gain answers the literature must be looked at in terms of a number of questions, the answers of which give a holistic picture.

Method

Slide 10

To gain the articles used within this literature review, a systematic search was conducted.

Slide 11

DATABASE SEARCH

Database search:

Psychinfo, Medline, Web of Science, ScienceDirect

Key terms:

[psychosis OR early psychosis OR first episode psychosis] AND
[social recovery OR social inclusion OR social function] AND
[intervention]

Removal of duplicates: N= 117

Review abstracts

Excluded unsuitable studies: N= 21

Not published in English language
Not relevant to topic
Published before 1990

Obtain full text of relevant articles: N = 5

BSMHFT Search:

N = 11

Organic backward and forward citation search through 16 full text articles

26 studies identified as relevant

18 studies used within this review

To begin with online databases were selected with the key terms [psychosis OR early psychosis OR first episode psychosis] AND [social recovery OR social function OR social inclusion] AND [intervention].

After removing duplicates 117 articles remained, abstracts were reviewed to leave 21 articles. Limits were then applied leaving only 5 articles, possibly due to the inconsistent use of the term 'social recovery'. As this was an insufficient number of articles to conduct a comprehensive review, I contacted the EIS for advice, who provided 11 relevant articles.

An organic forward and backward citation search was conducted for all 16 articles; 26 articles were identified as relevant to the topic however only 18 were used within the review.

Results

Slide 12

If we look at the results of this review in terms of the questions initially asked of the

literature..

Slide 13

The first question asked of the literature was "What is social recovery in psychosis?"

Alvearez-Jimenez et al (2012) highlights an increased emphasis on fully functional recovery, rather

just symptomatic. The researchers tested the symptom remission model and fully functional

recovery model over 7.5 years, concluding fully functional recovery consists of 4 parts:

1. Interpersonal relationships outside of the family

2. Vocational functioning

3. Success in fulfilling a particular role

4. Regular participation in basic living tasks

Slide 14

The second question was "Is social recovery important in early Intervention?"

Yes. Flyckt et al., (2006) demonstrated long term outcomes are predicted by early social functioning.

Alvearez-Jimenez et al., (2012) demonstrated at 7.5 year follow up only 26% met the criteria for fully functional recovery. Remission at 8 months predicted fully functional recovery at 14 months. Early symptom remission facilitates early functional recovery but functional recovery is critical for attaining long term full recovery.

Treatment delay also indicates a protective force of social recovery. De Haan et al., (2003) found delay in treating with medication (DUP) was associated with mild relapse but delay in providing intensive psychosocial treatment (DIPT) was associated with hospitalisation.

Slide 15

QUESTIONS ASKED OF THE LITERATURE

3. Why do some Early Intervention Service clients socially recover and others don't?

UNFAVOURABLE PROGNISIS	FAVOURABLE PROGNOSIS
Poor pre-morbid functioning	Better pre-morbid functioning
Male gender	Females
Single	Married
Longer DUP	Shorter DUP
Lover education levels	Better education
Negative Symptoms	Less negative symptoms
Higher baseline psychopathology	Lower baseline psychopathology
Lower baseline functioning	Better baseline functioning
Persistent substance misuse	Little substance misuse
Lower medication adherence	Medication adherence
Lower early symptom resolution – longer time to response	Higher early symptom resolution - early time to treatment response
Lack of symptom remission	Early symptom remission
Difficulty making use of psychological therapy due to poor emotional awareness, poor emotional regulation, poor insight)	Better social support, psychological mindedness, emotional regulation, ability to make use of therapy, better insight.
Fully functional recovery is less likely by 14 months and therefore longer term recovery less likely	**Symptom remission is translated into functional recovery by 14 months and therefore there is greater chance of longer term recovery.**

Our third question was "why do some early intervention clients socially recover and others don't?"

The below table summarises variables that characterise favourable and unfavourable prognosis.

In terms of streamlining interventions, the best practice is perhaps to identify those who will do poorly and make efforts to change this through streamlining into high, medium and low intensity groups.

Slide 16

Fourth, we looked at what interventions are currently available.

Current interventions have been built on cognitive footings. Fowler et al., (2009) evaluated

the 3 stages of SRCBT:

1. Developing a formulation.

2. Working towards medium to long term goals.

3. Actively promoting social activity.

Slide 17

Another new intervention strategy focuses on helping find supported employment. The individual placement and support program (IPS) promotes functioning within normal work. IPS rests on several principles (Bond, Mueser, Drake & Becker., 1997):

1. Competitive employment

2. Rapid job search

3. Integration of mental health rehabilitation

4. Client preferences

5. Continuous assessment

6. Time-unlimited support

IPS supports social recovery by providing greater opportunities for building and sustaining social relationships, developing interpersonal skills and encouraging engagement in social activity.

Slide 18

Integrated treatment programmes (Valencia, Juarez & Ortega., 2012) include the following interventions:

1. Psychosocial treatment: focussing on treatment management, social and family relations.

2. Psychoeducation: family members receive information.

3. Pharmacological treatment: medication management consultations.

Similarly, combining both CBT with supportive counselling or routine care demonstrated that lower rates of relapse (Wittkowski, 2000).

The effective integration of CBT, family intervention, social skills and cognitive remediation has also been demonstrated (Patterson & Leeunwenkamp, 2008).

Slide 19

Our fifth question was of the interventions currently available, "what interventions work?"

Fowler et al., (2009) compared SRCBT with treatment as usual, demonstrating an average gain of 12 hours per week of structured activity for those receiving SRCBT. Results were associated with improvements of symptoms and feelings of hopelessness, supporting the cognitive basis, suggesting goals and activities mediate recovery. Promoting positive self-concept could be a key focus of interventions.

For IPS, Thomson, McCarthy & Olson., (1998) demonstrated that competitive employment rates rose from 0% to 44%. Also, Drake et al., (1996) demonstrated 76% clients attained at least one competitive job. More recently in a review Bond, Drake & Becker., (2008) found 11 studies in favour of IPS. Across these competitive employment rates were 61% for those with IPS compared to 23% for controls. IPS participants also obtained employment 10 weeks earlier.

This integrated approach demonstrated significant improvements in psychosocial functioning, symptomology, relapse and hospitalisation rates, medication adherence and therapeutic adherence (Valencia, Juarez & Ortega., 2012; Patterson & Lccumwenkamp., 2008; Wittkowski., 2000).

Slide 20

Lastly, we asked "Are gains maintained beyond early intervention and why?"

In determining when to act, Rosen and Garety found perhaps the early course of psychosis is the most malleable.

Albert et al., (2011) highlighted that recovery is not a stable process.

1. Early stable recovery (met recovery at follow ups year 1, 2 & 5)

2. Early unstable recovery (recovery was unstable at follow up at either year 1 or 2)

3. Late recovery (had not met recovery before 5)

This suggests that gains beyond early intervention are often not sustainable; however gains can be made in its wake. Perhaps for those who have met recovery at 1 and 2 year follow ups, greater efforts should be made to ensure these gains are sustained. Recovery at 5 years wasn't

always predicted by 2 years, suggesting even beyond EI treatment can foster recovery, suggesting

treatment should remain consistent rather than ease off.

Similarly, Alvarez-Jimenez et al., (2012) results demonstrated that at 7.5 year follow up only

26% met the criteria for fully functional recovery.

Conclusion

Slide 21

To conclude with a summary of what we've learnt from this review.

Slide 22

Looking at recovery in terms of just symptomatic remission is insufficient as even with symptomatic remission quality of life still suffers as a result of functional disability. Social factors serve as good predictors of functional recovery, these factors may also protect against relapse. Fully functional recovery includes both symptom remission and an improvement in social functioning. The first 2 years of psychosis are considered a critical period and holds predictive power. In light of this, interventions have begun incorporating symptomatic and functional treatments.

Research within this area is still somewhat scarce and often longitudinal in nature. Large scale replications should be conducted to keep up to date with progressive interventions.

Slide 23

Based on the research discussed, a potential protocol for EIS is at baseline, 3 or 6 month

clinical reviews, the presence of demographic and clinical variables associated with divergent

outcomes could be considered. Based on this, patients could be streamed accordingly, focussing on

symptom resolution with the view on moving on to functional recovery once remission is met and

patients are securely within the low intensity group. When securely within the low intensity group

possible early discharge to primary care could be discussed.

Resources can be maintained or reduced based on evidence and early discharges can be

evidence based. The accuracy of this protocol would however require testing prior to

implementation.

Reflective Summary

Slide 24

Slide 25

In reflecting back on this project, difficulties arose initially as the term social recovery is

relatively new. When conducting the initial literature search the term social recovery appeared very

infrequently, in light of this inferences were made through similar terminology, for example, social

functioning and social inclusion. Even with this extended use of terminology the initial literature

search failed to provide a wealth of research in this topic area. The EIS helped here by providing a

number of articles on predictive variables in psychosis. Much of the research included was not

specifically related to social recovery, however through a forward and backward citation search 18

end articles were found to be relevant to the topic area and were used within this review.

The most difficult part of this review was deciding what information was relevant to the

research question. When finalising the literature review a wealth of information regarding recovery

in psychosis, predictor variables, treatment options, relapse and remission were gained. In

condensing this review into a presentation format, much of this information was left not included. The struggle between wanting to show the work that had gone in to actually answering the research question and giving a clear cut presentation of exactly what the research entailed was trying. However, often in research the brief overview of surrounding literature does not represent the amount of reading around the topic that has actually taken place. Using six questions as a guide, useful but irrelevant information was removed leaving a condensed account of how the literature review was produced and what the main findings were.

This review has established that there does indeed seem to be a cut off point in psychosis, after which interventions may achieve limited success. Recovery is not solely defined in terms of remission of symptoms, in order to achieve fully functional recovery a return to social and vocational functioning is necessary. Baseline variables at the onset of psychosis allow predictions to be made about a particular course of psychosis, all courses however are variable. Based on this, the EIS have developed a protocol which could aid the treatment of psychosis within their services. Through the literature presented above, intervention work can begin to incorporate aspects of treatment that will aid all areas of functioning. Through streamlining, aspects of functioning can be targeted earlier and aid recovery as a whole through protective effects rather than debilitative ones.

Slide 26

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CHAPTER 3

AN INVESTIGATION EXPLORING THE BIOLOGICAL AND AFFECTIVE PATHWAYS TO PSYCHOSIS

Abstract

Background: Recently, studies have argued that the current approach to diagnosis is insufficient, given significant overlap between psychosis and neurodevelopmental disorders. The purpose of the current research was to explore two pathways into psychosis; biological and affective. *Method:* Participants from Early Intervention Services with early onset psychosis completed the Autism Spectrum Questionnaire (AQ), Childhood Trauma Questionnaire (CTQ) and detailed family history of autism and psychosis. It was hypothesised that the biological pathway would be demonstrated by participants with high autistic traits and family history but low childhood trauma. The affective pathway would be demonstrated by participants with high childhood trauma but low autistic traits and family history. Results clustered into two groups, representing either pathway. *Results:* Analysis demonstrated 47 participants clustered around affective factors (group 1). 5 participants clustered around biological factors (group 2), suggesting that within this sample the presence of childhood trauma was greater than autistic traits. This indicates a predominance of the affective pathway, wherein stressful life events rather than biological influences trigger psychosis. Family history did not influence group identification, and therefore neither pathway. *Conclusion:* Results supported the hypothesis that two groups would be characterised by traits representing separate pathways into psychosis. Only the AQ and CTQ produced significant differences between groups, other outcomes were not influential.

<u>Background</u>

Recently, studies have argued that the current approach to diagnosis is insufficient, given significant overlap between psychosis and neurodevelopmental disorders. Kraeplinian thinking distinguishes psychotic disorders from mood disorders; however evidence is demonstrating that this distinction is not so clear cut and often symptoms can be seen to varying degrees across disorders (Craddock & Owen, 2010). Historically, the DSM-II categorised autism as a childhood type of schizophrenia, characterized predominantly by withdrawn behaviour and inadequate development. Following this, work was done to distinguish the two in the DSM-II (Kolvin, Ounsted, Humphrey & McNay., 1971).

Despite their distinction, similarities remain between the two illnesses. For example, studies of childhood onset schizophrenia have demonstrates similar early symptomology to that seen in autism (Rapoport, Chavez, Greenstein, Addington & Gogtay., 2009). Language deficits are evident in both disorders; stereotyped, repetitive and concrete language seen in autism resemble symptoms of formal thought disorder, a positive feature of schizophrenia within diagnostic criteria (American Psychiatric Association, 2000). Similarly, deficits in social interaction, theory of mind and facial processing seen in autism (Couture et al., 2010) can represent social deficits observed in schizophrenia (Sprong, Schothorst, Vos, Hox, & van Engeland., 2007; Pinkham, Hopfinger, Pelphrey, Piven & Penn., 2008).

Diagnosis overlaps are the main evidence for the argument of a biological cause. However, as shown by secondary psychosis wherein psychotic symptoms are triggered by illness or substance abuse; classic symptoms can arise in the absence of a biological influence (Keshavan & Kaneko, 2013). Based on this, it has been possible to suggest two pathways into psychosis.

Biological Pathway

As stated previously, research has demonstrated diagnostic criteria are not clear cut. Recently, evidence has highlighted the biological overlap between autism and psychosis. These similarities can be understood in terms of symptom overlap and genetic susceptibility.

Symptom overlap

Deficits in social functioning, understanding the mental state of others and internal processing are prominent in both autism and schizophrenia. Verbal and high functioning individuals with autism are more likely to present with characteristics of schizophrenia; primarily comparable negative symptoms such as lack of interact and extreme activity levels (Konstantareas & Hewitt, 2001). Drug treatment research supports evidence demonstrating shared negative symptoms; antipsychotics have been demonstrated as effective in both disorders (Clarke, Littlejohns, Gorbett & Joseph., 1989).

Padgett, Miltsiou & Tiffin (2010) reviewed evidence for the prevalence of developmental disorders amongst those with psychosis. They found that features of both autism and schizophrenia-spectrum illnesses overlap; obsessive behaviour, flat affect, social withdrawal, poor speech and disorganised thinking are often observed in individuals affected by either disorder (Van der Gaag, Caplan, van Engeland, Loman & Buitelaar., 2005). Social functioning and neurocognitive deficits are also present in both disorders (Goldstein, Minshew, Allen & Seaton., 2002).

Genetic susceptibility

Research has demonstrated a 93% heritability rate for autism (Le Couteur, Phillips & Rutter, 1995). Autism and schizophrenia are often seen in the families of those with either disorder (Stahlberg, Soderstorn, Rastam & Gillberg., 2005) suggesting familial psychosis may be a risk factor for autism (Larsson, Eaton & Madsen., 2005). Genetic alterations have been demonstrated to be similar in both childhood autism and psychotic symptoms (Vorstman, Morcus & Duijff., 2006). Such chromosome deletions are also evident in families with siblings with mental retardation (Ghebranious, Giampietro, Wesbrook & Rezkalla., 2007).

94

There appears to be an overlap in genetic susceptibility in schizophrenia, bipolar disorder and autism. In a study of over 2 million families, first degree relatives of those with bipolar, schizophrenia or autism were more likely to experience one of these disorders as well. Similar results are seen in adopted away and half siblings, highlighting the genetic influence. Parents of children with developmental disorders are also more likely to have schizophrenia (Daniels et al., 2008).

The increased prevalence of developmental disorders amongst psychosis is in keeping with theories of a neurodevelopmental underpinning to schizophrenia (Padgett, Miltsiou & Tiffin, 2010). These developmental abnormalities may act as a risk for the later development of psychosis, with baseline deficits creating an underlying susceptibility. Imaging studies demonstrate similar brain anomalies in both disorders (Stanley, 2002) such as a reduction in neural activation within networks associated with social cognition (Pinkham et al., 2007). It is possible that given the early presentation of autism in comparison to psychosis (Padgett, Miltsiou & Tiffin, 2010), brain anomalies give rise to neuroanatomical lesions that then trigger a predisposition to psychosis. For example, anatomical differences seen in autism may require only subtle changes in areas associated with sensory and emotional responses to develop psychotic delusions and hallucinations.

Deficits resulting from developmental disorders, such as impaired sensory and emotional processing, may predispose individuals to symptoms of psychosis, such as perceptual or ideational disturbances. For example, experiencing a particular event as more distressing or arousing due to sensory or emotional abnormalities may alter the perception or interpretation of a particular event, which may in turn lead to a delusion or hallucination based on beliefs and interpretation.

The overlap of both disorders suggests shared risk factors in terms of genetics. Anomalies with Copy Number Variants are displayed in the aetiology of both disorders (Glessner et al., 2009). Neurotransmitter or receptor anomalies that predispose individuals to both disorders may also arise from genetic anomalies. For example, evidence suggests 5-HT and dopamine dysregulation are

influential in either disorder. As well as this, antipsychotic treatments have also been shown to have

a beneficial effect on those with developmental disorders (Buitelaar & Willemsen-Swinkels, 2000).

Together, this research suggests that biological influences, whether they be through

genetics, brain anatomy or neurochemical imbalance, create an underlying vulnerability leaving

those with such vulnerabilities susceptible to developing psychosis.

Autism

It is assumed that developmental disorders came about through the functional

disintegration of psychotic illness. Bleuler first coined the term autism in 1911 to describe the social

and emotional withdrawal those with schizophrenia displayed (Khun, 2004). However, in 1972,

Rutter reviewed evidence to conclude the two were separate entities. Despite this, there is

significant overlap.

Padgett, Miltsiou & Tiffin (2010) reviewed literature systematically to determine the co-

occurrence of developmental disorders and non-affective psychosis. Estimates varied dramatically

but the authors provided several conclusions: the two conditions were the same disorder expressed

differently, either may predispose the other, coincidence, expression of the same disorder at a

different stage in its timeline or these disorders were separate entities but remained related through

shared risk factors. The research reviewed thus far seems to support the conclusion that the

increased incidence of developmental disorders in early onset psychosis could indicate one disorder

may predispose the other.

It has been suggested that autism may serve as a risk factor for developing psychosis.

Comorbidity studies have demonstrated high rates of those with autism also have either bipolar with

psychotic features or schizophrenia (Matson & Nebel-Schwalm, 2007; Stahlberg, Soderstrom,

Rastam & Gillberg., 2004). This evidence highlights autism as a risk factor for psychosis.

Toal et al., (2009) found that a diagnosis of schizophrenia in autism was not associated with anatomical differences. Rather, it was associated with differences in brain regions shown to be implicated in studies of those with psychosis susceptibility. This therefore suggests the anatomical features of autism could also increase susceptibility. For example, participants with psychosis were observed to have reductions in grey matter volume within both the frontal and occipital lobes. Those with both autism and psychosis had a reduction of grey matter within the cerebellum, insular cortex, occipital lobe and lingual gyrus. These participants also had levels of reduced white matter.

This may represent a pathway whereby autism acts as an entry point through anatomical susceptibility. Only subtle additional abnormalities may lead to the development of psychosis. Additionally, those with autism have been found to have similar neurochemical differences also implicated in psychosis, such as the serotonergic, glutamergic and gaba-ergic systems (Page et al., 2006; Murphy et al., 2006; Yip, Soghomonian & Blatt, 2007). Together, the combination of neurochemical and anatomical differences may reduce additional abnormalities required for those with autism to develop psychosis.

In light of this, it is possible to suggest that developmental disorders may be a risk factor for schizophrenia-like psychosis (Stahlberg, Soderstrom, Rastam & Gillberg., 2004). However not all those with psychosis also have autism. For those with psychosis without autism, an alternative pathway has been suggested, wherein life stressors may trigger and determine psychosis onset (Myin-Germeys & van Os., 2007).

Affective Pathway

Alongside biological influences, it is also acknowledged that stress plays an important role in psychosis development in terms of underlying vulnerability (Katschnig, 1991). Myin-Germeys and van Os., (2007) first suggested that sensitivity to stress constitutes a separate pathway to psychosis, independent of cognitive or biological impairment.

Evidence to support this can be understood in terms of the vulnerability-stress model which states that when a stress threshold exceeds an individual's level of vulnerability, psychiatric symptoms emerge (Katschnig, 1991). Research has suggested that individuals with disorders such as schizophrenia may be more sensitive to stress, therefore when a significant life event arises, it is experienced as more stressful This is important given that life events have been demonstrated to affect the course of psychotic disorders (Bebbington et al., 1993).

Environmental influences can contribute to stress. Research has demonstrated that living within an inner city environment produces stresses positioning individuals at risk for developing psychosis. This is especially prevalent in those already vulnerable to psychosis (Krabbendam & van Os, 2005).

As well as living environment, victimization and childhood trauma have also been shown to predispose to psychosis (Bebbington et al., 2004). Epidemiological studies have demonstrated greater childhood trauma increases the risk of psychotic symptoms. For example, Cotter & Pariante (2002) found changes within the hypothalamus pituitary adrenal axis of the brain in those with a history of childhood trauma, an area involved in stress responses.

In a review of research on the relationship between childhood trauma and psychosis (Read, Os, Morrison & Ross, 2005) it was found that positive symptoms of psychosis such as hallucinations, particularly of auditory nature, were strongly related to abuse and neglect during childhood. A causal relationship implied a dose-effect, with those with a more extensive history of childhood trauma more likely to develop psychosis and to a greater degree.

Experience sampling has shown, those with a history of childhood trauma demonstrate greater emotional reactivity and negative effects, effects which seem to be enduring (Myin-Germeys et al., 2001). The role of trauma in the affective pathway may lie in its effect on sensitivity to stressful daily events.

Although it is clear stress plays a role in the aetiology of psychosis, the way through which stress impacts a vulnerable individual is less clear. The stress-vulnerability model proposes an interactional relationship whereby both an underlying vulnerability and stressful trigger are necessary to develop a disorder (Katsching, 1991).

Reactivity to stress has been measured through emotional sensitivity in experimental conditions. Generally, those with psychosis have higher affective reactivity under stressful conditions (Cohan & Docherty, 2004). Patients with psychosis demonstrated greater arousibility under stressful conditions, a trait which has been suggested to be associated with maladaptive coping (Dinzeo, Cohen, Nienow & Docherty, 2004).

Evidence suggests that those with psychosis are generally less able to handle daily stress. In a 12 month longitudinal study of patients with a recent onset of schizophrenia, although less stressful life events were experienced, they were reported to be poorly handled and uncontrollable.

It is possible life events act via increasing vulnerability through repeated exposure. Life events have been found to moderate emotional reactivity through increasing psychophysiological responses (Myin-Germeys, Peeters, Havermans, Nicolson, DeVries, Delespaul & Van Os., 2003).

Research has generally supported the hypothesis that stress sensitivity constitutes a vulnerability leaving an individual susceptible to developing psychosis (Bebbington et al., 1993). Theories behind stress sensitivity suggest that the decreased ability to handle stressful situations may be attributable to cognitive deficits, implicating cognitive deficits in the causal pathway. However, there is also the suggestion that neurodevelopment and altered stress sensitivity operate through independent pathways. If this stress vulnerability were of biological nature, one would expect greater biological impairments to increase the reactivity to stress and therefore increase the likelihood of developing psychosis. Without biological vulnerability, it would be the stress alone that increases susceptibility for developing psychosis.

Research thus far suggests that cognitive impairments such as those found in autism and stress sensitivity operate through different causal pathways; biological and affective. The pathways through which these underlying causes may lead to psychosis are understandable in terms of their manifestation as symptoms. Autistic traits such as impaired social functioning and cognitive impairments such as the ability to process internal and external stimuli are more likely associated with negative symptoms of psychosis; such as flat affect and social withdrawal. Positive symptoms of psychosis are likely to be manifestations of sensitivity to stress, for example, experiencing a hallucination leading to delusional beliefs following bereavement or drug misuse. Based on this, one would expect an individual with greater negative symptoms to show greater cognitive impairments in terms of autistic traits. Individuals displaying greater positive symptoms would be expected to have experienced greater stress.

Based on these pathways, one would presume that lack of or a smaller biological component would indicate greater likelihood of increased stress, leading to the development of psychosis. On the other hand, those who have a larger biological component would be expected to have experienced less stress.

If underlying sensitivity to stress independently creates vulnerability, it would be expected that life events are experienced differently depending on the level of cognitive impairment, greater impairment would necessitate decreased impact of life events on stress sensitivity (Liddle, 1987). This suggests life events may play a particular role in those with preserved functioning.

However, the problem with this theory is that individuals with Autism or other forms of developmental disorder have an independent correlation with stressors such as abuse. There is a growing body of research that the incidence of physical and sexual abuse is more prevalent amongst children with mental or developmental impairment (Westcolt & Jones, 1999). This makes it difficult to separate pathways.

Administrative records show 31% of children receiving special education had experienced maltreatment. As well as this, hospitalised children also appear to be at increased risk of abuse and neglect (Sullivan et al., 1997).

It has been proposed that the vulnerability lies in the inability to communicate or understand, and this may also lead to a misrepresentation of figures (Coles, 1990). Other reasons for increased risk may include greater dependency in caregivers, lack of knowledge and communication deficits.

Howlin and Clements (1995) described children with autism as a group particularly at risk of abuse due to their social isolation and communication deficits. Again, figures may be misrepresented as most research comes from case studies or institutionalised samples, whereas most children with autism receive treatment in the community (Mandell et al., 2005). Research of abuse in the community settings is lacking.

Mandell, Walrath, Manteuffel, Sgro & Pinto-Martin., (2005) found that in a sample of children receiving community mental health care, nearly 1 in 5 children with autism or Asperger's syndrome had experienced physical abuse, whilst 1 in 6 had experienced sexual abuse. Children who had been abused displayed more sexual acting out, ran away more frequently and were more likely to commit suicide. This research demonstrates that psychosocial history of children with disabilities such as autism should be considered when receiving care.

The prevalence of abuse is generally determined through information provided by the abused. In 1984, Ryerson found that in a study of mentally disabled children and adults, more than 700 were sexually abused. Abuse often started aged 2-4 and continued for 5-15 years. When comparing this to the general population the rate of abuse was 4 times greater for the mentally disabled.

It is of great importance to protect those vulnerable to abuse from any offending in order to prevent later psychiatric change.

Is abuse disclosed?

Balogh et l., (2001) reviewed retrospective case notes and found that for a quarter of inpatients reports of sexual abuse was not identified until after admission. Fifty percent of victims were abused by a family member, and mostly during adolescence. Female inpatients were likely to be the victim of rape or incest. Occasionally, victims with intellectual disability were abused by a perpetrator who also had an intellectual disability; however, the incidence of victimisation was twice as likely as perpetration. Researchers have stressed however that figures should always be treated with caution due to non-disclosure, underreporting and the impact of definition variation on inclusion (Kvam, 2000).

A study of sexual abuse and developmental disabilities showed the abused do not understand what has happened to them (Mansell & Sobsey 1994). In a review, Browne and Finkeehr (1986) identified the long term effects of child sex abuse as depression and revictimisation, substance abuse, self-destructive behaviour and isolation. This is preceded by fear and anxiety. It is difficult here however to tease apart the influence of underlying biological abnormalities and the effect of stress due to abuse on the development of these psychosis like symptoms.

Which Pathway?

The research here has demonstrated evidence of both biological and stress induced vulnerabilities in the onset and aetiology of psychosis. Not all those with psychosis have diagnosable autism, similarly not all those with psychosis have experienced stress. It has been noted that symptom overlap occurs between the two disorders, however often not to the degree meeting the criteria of a diagnosis. Also, research has also been presented to demonstrate the difficulty in teasing apart the influence either cause due to co-occurrence in some cases. Those with autism may be more susceptible to experiencing abuse (Balogh et al., 2001) and it is therefore difficult to say whether without either their autism diagnosis or experience of abuse these individuals would ever develop psychosis.

The purpose of the current work is to explore susceptibility to developing psychosis through the presentation of autistic like traits amongst individuals with psychosis. Autistic traits are characteristics or symptoms that are like those possessed by individuals with autism, for example, social withdrawal, obsessions or compulsions and flat affect. Through this, it will be possible to determine whether it is the actual traits or the diagnosis of autism causing underlying vulnerability (stress) or fundamentally biological mechanisms. It is possible to explore the biological and affective pathway to psychosis through the presence or absence of autistic traits and family history, as well as experience of childhood trauma. If autistic traits are seen in the absence of stress, it is likely psychosis has taken its course down the biological pathway. Psychosis in the absence of autistic traits would suggest an affective course.

It was hypothesised that in reflecting both the biological and affective pathway to psychosis, amongst those experiencing first episode psychosis two groups would be prevalent and defined by differential outcomes.

Hypothesis 1: Individuals with high autistic traits and a high incidence of family history for autism or psychosis will have experienced less childhood trauma.

Hypothesis 2: Individuals with low autistic traits and a low incidence of family history for autism or psychosis will have experienced high levels of childhood trauma.

Hypothesis 3: Individuals with a high level of autistic traits will demonstrate a greater number of negative psychotic symptoms, whereas those with low levels of autistic traits will display more positive symptoms.

Hypothesis 4: Individuals with a high level of autistic traits will demonstrate worse premorbid functioning, whereas those with low levels of autistic traits will display better premorbid functioning.

If the biological pathway exists it was expected that hypothesis 1 would be supported this research. However, if the affective pathway is more prominent it is expected that findings would support hypothesis 2. Findings supporting hypotheses 3 and 4 would support the distinction between pathways through differing presentation of symptoms depending on underlying influence.

Method

Sampling

Participants were recruited through the Early Intervention Service (EIS) for psychosis, this service forms part of the Birmingham and Solihull Mental Health NHS Foundation Trust. Participants presented with first episode psychosis and data used within this research was taken from a larger research study looking at autism and psychosis. The exclusion criterion for this research was any participant unable to provide full informed consent through lack of capacity or language understanding, as well as language barriers for participating in the interviews.

Procedure

A cross sectional interview design was implemented. The study from which the data was taken used 8 different measures (reported elsewhere), along with basic demographic data collection. For the purpose of this research only measures were used to assess the degree of autistic traits presented by the participant, the levels of experienced stressful events and biological influence through the assessment of family history. A further 2 measures were used to explore the effect of functioning on presentation.

Measures

Childhood Trauma Questionnaire

This questionnaire is a 28 item retrospective self-report measure used to assess experience and understanding of 6 early traumatic experiences; sexual abuse, illness, death, divorce, violence or other. Responses are recorded on a 5 point likert scale ranging from 'never true' to 'very often true'. To determine the effect of stressful life events, the Brief Childhood Trauma (CTQ) will determine the presence of abuse and neglect. This measure is of a sensitive nature and has been demonstrated to have good validity and reliability. Bernstein et al., (1994) established Cronbach's alpha for abuse and neglect ranged from 0.79 to 0.94, showing high internal consistency. Good test-retest reliability over

a 2 to 6 month period was indicated as well as through convergence with the Childhood Trauma Interview.

Autism Spectrum Quotient

This questionnaire consists of 50 items assessing five different domains: attention to detail and attention switching, social skills, communication and imagination. Participants must choose to 'definitely agree', 'slightly agree', or 'definitely disagree' with each of the 50 statements. This measure assesses autism traits across a wider spectrum, enabling traits outside of diagnosed autism to be indicated. This is important given that we are interested in the overlap of autistic like traits, outside of diagnostic criterions. Research has demonstrated it's validity in screening traits alongside varying function (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen., 2005).

Family History

Demographic data will indicate the incidence of autism spectrum disorders and mental health disorder amongst parental and sibling relatives. This will give an indication of genetic influences.

Premorbid Adjustment Scale

This scale assesses premorbid functioning through developmental periods; childhood, early adolescence, late adolescence and early adulthood. It consists of 26 items including social isolation, peer relationships, functioning outside of the family, social-sexual development and school. Items within each section are scored from 0-6. The '0' end of the scale represents the supposed 'healthy' end. The participant must select the number that matches the nearest descriptive phrase. Research has demonstrated its validity (Brill, Reichenberg, Weiser & Rabinowitz., 2008). Data will be used to determine its effect upon group identity outside of autistic traits and childhood trauma.

Positive and Negative Symptom Scale

This is an interviewer rated measure assessing the level of psychotic symptoms within the subtypes; positive, negative and disorganised symptoms, and a global symptom score. The interview lasts around 45 minutes. Participants are rated from 1-7 on 30 symptoms. Ratings are based on a both the interview and reports from family/care providers. Both the positive and negative scale consists of 7 items with a minimum score of 7 and maximum score of 49. The general psychopathology scale consists of 16 items with a minimum score of 16 and a maximum score of 112. This measure's validity has been demonstrated (Kay, Opler & Lindenmayer, 1988) and will enable the indication of associations between autism traits and psychotic symptoms.

Analysis

Based on the hypothesis that there are two pathways to psychosis, a cluster analysis was deemed appropriate due to its ability to group cases that possess similar traits but maintain their differences. Based on the three measures, it was possible to cluster participants into subgroups that have either high or low levels of autistic traits, childhood trauma and incidence of family history. Based on the research, there were two predetermined clusters representing both hypothesis and pathways to psychosis. Cluster 1 was expected to contain individuals with high autistic traits and family history, with low childhood trauma. Cluster 2 was expected to contain individuals with low autistic traits and family history, with high childhood trauma.

To determine whether these variables were significant in differentiating cases within either cluster, an independent t-test was carried out for each measure. Descriptive statistics summarized the categorisation of each participant to each cluster. A series of independent t-tests were also run to explore the significance of other outcome measures on the assignment of each case to either cluster, these included the Positive and Negative Symptoms Scale (PANSS) and the Premorbid Adjustment Scale.

Results

Participants had a mean age of 25, the youngest being 17 and the oldest being 36. A mixture of 37 males and 18 females were interviewed. Participants were predominantly self labelled as being white British (34) however white other (4), Asian (9), mixed black and white (5), mixed white and Asian (2) and mixed other (1) also participated. 24 participants had a diagnosis of psychosis, 11 schizophrenia, 6 bipolar and 14 other. A total of 39 participants reported to be cannabis users. 43 participants were single, 2 in a short term relationship, 6 in a long term relationship, 3 were married and 1 divorced. Participants predominantly lived with parents (30), only 13 lived alone, 11 with a housemate or partner and 1 in boarding. Most participants were not in education or employment (30). 5 had no qualifications, 21 achieved GCSEs, 14 A-levels and only 6 had an undergraduate degree, with 3 a postgraduate degree.

A cluster analysis was run on 55 cases, 3 of which were excluded due to missing data. Cases responded to the AQ, CTQ and family history. A hierarchical cluster analysis using Ward's method produced two clusters, between which the variables AQ and CTQ were significantly different. The first cluster (Group 1) was predominant containing 47 cases and was characterized by lower AQ scores (M=19.20, SD=7.30) and higher CTQ scores (M=43.13, SD=14.34). The second cluster (Group 2) contained 5 cases and was characterized by higher AQ scores (M=33.40, SD=5.17) and lower CTQ scores (28.40, SD=2.19). Family history demonstrated little difference for cluster one (M=1.94, SD=0.25) and cluster 2 (M=2.00, SD=0.001)

An independent-samples t-test was run to compare the level of autistic traits, childhood trauma and family history between groups. There was a significant difference between groups for AQ scores, $t(50)=-4.22$, $p<.05$, and for CTQ scores $t(44)=6.38$, $p<.05$. No significant difference was found for family history, $t(50)=-0.57$, $p<.05$.

An independent-samples t-test was run to compare scores from outcome measures outside of those included in the cluster analysis. These included the Positive and Negative Symptoms Scale

(PANSS) and the Premorbid Adjustment Scale (PAS). No significant difference was found between

groups for the PAS total ($t(49)=-0.85$, $p<.05$) nor the PANSS negative subscale ($t(50)=-0.39$, $p<.05$),

the PANSS positive subscale ($t(50)=-0.69$, $p<.05$) and the PANNS general ($t(50)=-0.27$, $p<.05$).

Discussion

The results from this research support the hypothesis that of the two groups, one would be characterized by greater biological influence and one group would be characterized by greater influence of stress. As group 1 demonstrated fewer autistic traits and greater childhood trauma, this would represent the affective pathway to psychosis. As group 2 demonstrated greater autistic traits and less childhood trauma, this would represent the biological pathway. Family history does not influence group identification, and therefore neither pathway.

The predominance of group 1 suggests that within this sample, participants experience greater influence of childhood trauma and less influence of autistic traits. This suggests that of the hypothesised pathways to psychosis, the majority of this sample fall within the affective pathway, wherein stressful life events rather than biological influences trigger psychosis.

Previous research identified a difference in symptom presentation depending on comorbidity; those with autism demonstrated more negative symptoms (Stahlberg, Soderstrom, Rastam & Gillberg., 2004) whereas those with greater childhood trauma demonstrated more positive symptoms (McClellan et al., 2003). Research had also identified that that poorer premorbid functioning is associated with a greater level of psychotic symptoms, predominantly negative (Brill, Reichenberg, Weiser & Rabinowitz., 2008). However, analysis of both the PAS and the PANSS did not reveal significant results in differentiating groups. This would suggest within this sample the level of premorbid functioning and presence of both positive and negative symptoms of psychosis did not influence group identity. Given the small nature of this study, these results would need to be replicated on a much larger scale to give weight to this finding.

Genetic susceptibility to both autism and psychosis has previously been demonstrated amongst family relations (Stahlberg et al., 2005), implicating a biological pathway. Within the analysis only diagnosed illnesses were included as a family history of mental illness, however many participants reported psychosis like symptoms in parents. This could perhaps suggest that the lack of

110

genetic influence found in this study may be due to the strict criteria of diagnosis and if the scope for inclusion was extended, more of an effect would be found.

The lack of diagnosed family history does not however rule out the possibility of a biological pathway. This research hypothesised that a higher level of autistic traits would indicate a biological pathway independent of environment. The reported psychosis like symptoms however indicate that siblings may possess some traits similar to that of the participant, either in terms of psychotic symptoms or autistic features. Perhaps if traits rather than formal diagnosis were studied amongst family members greater clarity on the influence of biology would be achieved.

Further study however would be necessary to untangle any biological-environment interaction, as research has previously shown that not only similar genetics but a shared environment can be implicated in cases where siblings also have a diagnosis of schizophrenia or related mental health illness (Van Os, Rutten & Poulton, 2008).

This research explored the prospect of two separate pathways to psychosis. Previous research had demonstrated that a biological pathway existed, as evidenced by symptoms between autism and psychosis, suggesting one may trigger the other. Deficits in social functioning, understanding the mental state of others and internal processing are prominent in both disorders (Konstantareas & Hewitt, 2001).

These results are consistent with research demonstrating the effect of both autistic traits and affective trauma. Less support was found for a biological pathway where genetic susceptibility is evidenced through familial prevalence of either disorder.

Due to the small sample used within this study, it is possible that the results found would be different if replicated on a larger scale. The second group was identified through cluster analysis to contain only 5 cases, therefore further analysis run on this group has reduced predictive power. The appearance of one group larger than the other is however expected given what is suggested in previous literature (Miller, Byrne, Hodges, Lawrie & Johnstone., 2002). Corcoran et al., (2003)

demonstrated that within a small sample, individuals clinically at risk for developing psychosis were identified as falling into two groups. One group was characterized by relatively normal development prior to the onset of psychotic symptoms; the other group were described to have had a somewhat abnormal development. Similarly to results found within the current research, the group of individuals who had abnormal development and later developed psychosis was much smaller than those with normal development. In the current research, those who possessed autistic traits were in the subdominant group.

The implications of this research highlight the inadequacy of current diagnostic tools. Traits and similarities can be seen across and within disorders; categorising individuals with strict criteria overlooks the parallels between them. As evidenced through research in favour of the biological pathway, these parallels extend far beyond symptom overlap. For example, brain anomalies can be seen across both autism and schizophrenia (Toal et al., 2009) however focussing on symptom presentation ignores the likelihood of an individual going on to develop a mental illness. Categorising based on diagnostic criteria also give implications for treatment, however an individual with psychosis may also have autistic traits that would benefit from alternative interventions not deemed effective for psychosis.

With this, treatment methods could be combined to target aspects of illness affecting functioning outside of that required for an official diagnosis. Research has already demonstrated effective pharmacological treatment sharing between autism and psychosis. Antipsychotic medication is both effective in reducing psychotic symptoms and challenging behaviour seen in autism (Beutelaar & Willemsen-Swinkles., 2000). Could interventions aimed at targeting aspects of autism seen in psychosis such as theory of mind deficit, be used within those who possess only traits in the hope that this may defer the onset of psychosis?

It is important that future work investigates the implications for those who display autistic traits but do not yet have a diagnosis of psychosis. Could a screening procedure be implemented

whereby those referred to community health services for difficulties that appear similar to autistic traits be considered at risk for developing psychosis. Likewise, a marker should be put on individuals within this category who have experienced trauma, as either pathway may lead to psychosis onset. This research would need to be completed on a much larger scale to add validity and generalizability to results.

This research clearly demonstrated the prevalence of an affective pathway, however it is not clear how this compares to biological contributions outside of this sample. Larger samples in future studies could explore this further. If, as this research would suggest, affective influence dominates, future research could focus more directly on the course of psychosis along the affective pathway to address unanswered questions. What are the differences between those who do and do not develop psychosis following trauma? What are the most effective treatment options? Could treatment begin prior to onset? Is psychosis preventable in the absence of a biological cause?

What is clear is that it may be beneficial for the appropriate psychosocial treatments to be made available prior to pharmacological input becoming necessary for symptom management. If there is a delay in treatment it may be that psychosocial influences exacerbate psychotic symptoms, which in turn may prolong the effect of psychosocial influences.

Alongside this, when considering directions for future research, the influence of anatomical structures could also be explored to perhaps add weight the underpinnings of a biological pathway. Research has demonstrated overlap between psychosis and autism, however exploring the anatomical features of those with high autistic traits may give an indication of whether traits themselves act as a precursor for psychosis or an underlying cause of trait presentation.

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