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QUALITATIVE EXPLORATION OF RECOVERY FOLLOWING FIRST EPISODE PSYCHOSIS: A GROUNDED THEORY APPROACH &CLINICAL RESEARCH PORTFOLIO

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CHAPTER 1

SYSTEMATIC REVIEW

Experiences of First-Episode Psychosis:

A meta-synthesis of emerging themes from qualitative studies.

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Abstract

Aim: The experiences of those with First Episode Psychosis (FEP) have been well documented in a growing body of qualitative literature (Boydell et al., 2010). The identified themes emerging from these studies attempt to understand people's subjective experiences. This review aimed at identifying and exploring the predominant experiences of young people and their families following a recent First Episode of Psychosis through the review of key findings of the qualitative literature in this area.

Method: Methodological critique of the included papers was conducted using a tool developed specifically for evaluating qualitative studies. Meta-synthesis of the findings emerging from individual studies was completed, resulting in the development of several key themes.

Results: The methodological evaluation suggested that most studies demonstrated strengths in commitment, transparency and clinical impact of findings. However, some studies lacked clarity around data analysis, validation of findings and the description of ethical considerations. The outcome of the meta-synthesis produced several key themes: i) Experience, ii) Emotional Impact, iii) Relationships, iv) Meaning Making and v) Coping & Adaptation.

Conclusions: The impact of experiences on emotions and relationships was a predominant feature for young people and their families/carers. In response to these experiences, participants undertook a process of meaning making which seemed to be a key component of coping and adaptation following the FEP. The theoretical and clinical implications of these themes were also discussed.

Key words: First Episode Psychosis, Early Intervention, Qualitative, Recovery

Background

The importance of understanding the subjective experiences of those with mental health difficulties has been well documented in recent years, with Scottish government initiatives such as, 'Delivering for Mental Health' (2006), highlighting the need to obtain service-user perspectives of mental health services. A recent report on recovery in mental health (Scottish Recovery Network, 2007) explored service-users' perspectives on what helped and what hindered recovery from long-term mental health problems. This report emphasised the importance of valuing the fact that service-users' recovery is about '*personal growth following (and in spite of) mental health problems*' (2007, p.157). There is increased recognition that these perspectives are best sought through the use of qualitative studies, with findings from qualitative research contributing to service development and influencing service provision. In particular, the exploration of First Episode Psychosis (FEP) has seen a growing body of qualitative research which seeks to understand these experiences in the context of the individual and those people close to them (e.g., family members). This qualitative research provides a valuable contribution to our understanding of the processes, experiences and nature of FEP, and the clinical implications for service development.

First Episode Psychosis

There has been an abundance of studies on FEP over the last decade, most of which have addressed quantitative research questions regarding the outcome of FEP patients (Killackey & Yung, 2007). Most quantitative studies seek to demonstrate these outcomes in terms of reduction in hospital admissions, reduction in reported

symptoms and medication prescribed. Typically, these outcomes are measured by Early Intervention (E.I.) services which seek to demonstrate the effectiveness of their model of service provision which includes early detection and phase-specific treatment.

In their review of outcome studies, Marshall et al. (2005) considered seven studies involving participants who had received care from E.I. services for people experiencing first episode psychosis. The studies included trials of phase-specific interventions in the early phase, as well as randomised controlled trials designed to either prevent transition to psychosis in an at-risk group or improve outcomes for people with first episode psychosis. The studies measured outcomes such as the number of participants who made transition to psychosis; the outcomes from phase-specific interventions such as CBT or anti-psychotic medication; hospital re-admission rates and changes in symptoms. The authors concluded that there were insufficient trials from which to draw any definite conclusions, and that further studies needed to be conducted to address unanswered questions about the efficacy of E.I. services.

Although useful, these outcome measures fail to provide a picture of what the person with FEP and their family subjectively experience in the context of recovery. This has been addressed by an increasing number of qualitative studies. For a service-user perspective, qualitative studies have proven more useful in exploring the personal narratives about the journey of recovery following an FEP. Whilst there have been published systematic reviews of quantitative studies on FEP (e.g.,

Marshall et al., 2005), to date there has only been one which seeks to review qualitative research papers. In their descriptive review of qualitative studies of FEP, Boydell et al. (2010) identified 27 discrete studies reporting research involving young people with FEP, their families or carers and service providers. They included all studies which used any qualitative methodology, using many varied groups of participants, with the aim of providing a descriptive review of the emerging themes. The authors identified key themes in relation to: the subjective experience of psychosis; views on early intervention services; the subjective experience of help-seeking; gaining and maintaining employment and the importance of peers. In an attempt to organise these findings, the authors used a predefined theoretical framework developed from ethnographic principles. Boydell et al. used the framework of Generic Social Processes (GSPs; Prus, 1987) to conceptualise the themes that emerged from their review. Generic Social Processes refer to the activities involved in human social interaction; the processes of being an agent actively involved in group activities and experiences. The authors suggest that GSPs '*highlight the emergent, interpretive features of association, focussing on the activities involved in the 'doing' or accomplishing of group life*' (2010, p. 8). Boydell et al. felt that four of these GSPs were particularly relevant to the experience of FEP, and findings from the reviewed studies were organised into the processes of i) achieving identity; ii) acquiring perspectives; iii) doing activity and iv) developing relationships. Through organising the findings of qualitative studies on FEP, Boydell et al. developed an understanding of the subjective experiences of people with FEP, their families and the service providers, and highlighted how these experiences can be used to inform service design and delivery.

The authors' attempt at this challenging review conceptualises the themes from the studies using a predefined theoretical framework. This framework has been developed from a different philosophical background to many of the research methodologies used in the reviewed studies. By imposing such a framework on the emerging themes, it is difficult to consider a 'bottom up' process of creating an understanding rooted in the data (i.e., the emerging themes). The review included any study which considered the perspectives of young people, carers, siblings and service providers. The research areas covered help-seeking behaviours, engagement with services, the impact of FEP on social relationships and many more. Such a varied range of included papers, from so many perspectives, presented difficulties when attempting to create an overall understanding of subjective experiences.

Meta Synthesis

Given this variety of qualitative studies there is a need to review and synthesise the findings in order to develop a more coherent understanding of the topic. As Ring et al. (2011) point out, the findings from one qualitative study may be difficult to generalise. Therefore, a synthesis of all the relevant qualitative studies on the same topic will identify any common themes as well as divergent views. The current review aimed at undertaking a more focused stance when considering the qualitative literature on FEP. By focusing on studies which only considered participants with a recent FEP, who had been involved with E.I. services or their families/carers, it was hoped a more detailed and coherent understanding of this group of service-users could be explored. Studies which considered the perspective of both service-users and their families/carers were included as this reflected the model of E.I. service

provision. This review aimed at exploring the subjective experiences of those involved with E.I. services, therefore it did not consider studies from the service-provider perspective.

The objectives for this review were:

- To identify and explore predominant experiences of young people and their families/carers following a recent first episode of psychosis.
- To consider the quality and key findings of the qualitative literature in this area.
- To synthesise and discuss emerging themes from the qualitative literature on young people and their families/carers' experiences of first episode psychosis.

Methodology

This review was conducted in several stages. The process of identifying studies suitable for inclusion involved formulating selection criteria and developing a search strategy. Once studies were identified, analysis of the quality of each study was conducted, and a synthesis of emerging themes was undertaken. These themes were checked against first-person accounts of the experience of FEP to ensure validity.

Search Strategy

There were several phases to the search strategy. An initial search string was derived using search terms including 'qualitative research', 'grounded theory', 'first episode

psychosis' and 'early intervention'. These terms were piloted and further refined to ensure sufficient scope for the search. Studies were included if they had been published in peer-reviewed journals, used qualitative research methods and explored individuals' subjective experiences of first episode psychosis, or their family/carers of individuals. The final search terms are shown in Table 1.

Table 1 – Final Search Terms

#	Search Terms
1	Qualitative
2	Qualitative Research
3	Grounded Theory or GT or IPA or Interpretative Phenomenological Analysis
4	Early Intervention or First Episode adj1 Psychosis or Psychotic or schizophr$

The search terms were combined with the Boolean operator 'AND' and duplicates were removed. The search was limited to English Language papers only, published after 1996 and where abstracts were available. Studies were included from after 1996 as this date reflects the beginning of the E.I. movement within FEP. Studies were excluded if they were not published in peer-reviewed scientific journals (e.g., conference abstracts and dissertations).

Electronic Searches

The search was conducted using seven databases: Ovid Medline (1996 – 2011), EMBASE (1996 – 2011), PsycINFO (1987 – 2011), EBM Reviews – the Cochrane Database of Systematic Reviews (2005 – December 2010), PsyARTICLES, Psychology and Behavioural Sciences Collection and Social Policy and Practice.

The search was completed in March 2011. This electronic search produced 59 studies, with 25 being excluded on the basis of their title. The abstracts of the remaining 34 papers were read, resulting in a further 12 being excluded. The remaining 22 papers were read in full, resulting in 12 studies being excluded (Moller &Husby, 2000; Moller, 2000; Gerson et al., 2009; Bergner et al., 2008; Corcoran et al., 2007; Franz et al,. 2009; Judge et al,. 2008; Dilks et al., 2010; Hardy et al., 2009; Yung & McGorry, 1996; Larsen, 2007; Pitt et al., 2009). These were excluded on the basis that they were focussed on the subjective experiences of individuals out-with the scope of this review. For example, the majority considered pathways to care, the experiences of help-seeking or were focussed on a person's experience of historic FEP (i.e., not recent). The aim of the current review was to consider only those experiences after someone had been in contact with E.I. services for a recent first episode psychosis, from either the perspective of the individual or a family member/carer.

Manual Searching

In order to ensure the sensitivity of the search, the reference section of each identified paper was read for further potentially relevant studies. On the basis of their titles a further 2 studies were read in full but did not meet inclusion criteria. Another qualitative researcher and expert in the field was consulted to ensure that no key studies had been overlooked. A total of 10 papers were included in this review (Hirschfeld et al., 2005; Kilkku et al., 2003; McCann et al., 2011; MacDonald et al., 2005; Mackrell & Lavender, 2004; Newton, et al., 2007; O'Toole et al., 2004; Perry et al., 2007; Sin et al., 2005; Sin et al., 2008). These studies are summarised in Table 2.

Table 2 - Study Characteristics

Author & Year	Aims	Sample	Method	Summary of Findings	Strengths	Weaknesses
Hirschfeld, R. 2005	Explore subjective experiences of psychosis	6 male service users	Grounded Theory	4 themes: 'experience of psychosis', 'immediate expression of psychotic experiences', 'personal & interpersonal changes', 'personal explanations'	Commitment and rigour: demonstration of theoretical sampling, triangulation and validation of coding frameworks. Good demonstration of reflexivity.	Recognition of potential researcher bias.
Kilkku, N. 2003	The meaning of information-giving to people with FEP	7 service users	Phenomenological approach	6 themes: 'The experience of psychosis', 'information from the experience of psychosis', 'Relief', 'Worthlessness', 'Confusions', 'Coping & confidence'	Demonstration of saturation, theoretical sampling. Good description of ethical considerations.	Transparency and coherence: data collection and analysis procedures unclear. No demonstration of reflexivity. No validation or cross checking of findings.
McCann, T. 2011	Understand the experience of care-givers of those with FEP	17 care-givers	IPA	6 themes: 'Burdensome Responsibility', 'Roller-Coaster & unpredictable experience', 'Feeling responsible', 'Coming to terms with change', 'Becoming closer', 'Maintaining hope'	Commitment and rigour: demonstration of theoretical sampling, validation, saturation. Impact on service development.	Reflexivity not mentioned.
MacDonald, E. 2005	Explore Social Relationships during recovery from FEP	6 service users	Phenomenological approach	5 themes: 'Being with people I like & understand me', 'Valuing families & other supports', 'Spending less time with old friends', 'Something happened to me – being different now', 'Building new relationships'	Commitment and rigour: good descriptions of data analysis, development of coding and validation of emergent themes. Good demonstration of reflexivity.	No details given of saturation/completeness of data collection. No use of triangulation.

Author & Year	Aims	Sample	Method	Summary of Findings	Strengths	Weaknesses
Mackrell, L. 2004	Explore Peer relationships in adolescents with FEP	12 service users	Grounded Theory	Increasing isolation from peers: Across adolescence – inequity in peer relationships (early); instability in peer relationships (middle); isolation (late).	Evidence of theoretical sampling, validation of emerging themes. Mention of reflexivity. Transparent & coherent data analysis and category creation.	No discussion of methodological background.
Newton, E. 2007	Explore experience of group CBT for young people with auditory hallucinations	8 service users	IPA	2 themes: 'accounts of the group', '4 key factors: content of voices, explanations for and responses to voices, ability to cope with voices'	Commitment and rigour: evidence of triangulation, validation and commitment to methodology.	No mention of reflexivity. Potential researcher bias not discussed.
O'Toole, M. 2004	Explore experiences of Early Intervention Service for FEP	12 service users	IPA	3 themes from focus groups: 'A very different experience', 'therapeutic nature of recovery', outcomes – increased confidence and independence'	Sensitivity to context: review of local service provision.	Commitment and rigour: no mention of saturation/theoretical sampling. No validation of codes. No mention of ethical considerations or reflexivity.
Perry, B. 2007	Explore experiences of FEP & feelings of hope	5 service users	IPA	3 themes: 'What's it all about?', 'Banged up', 'Belonging versus alone'	Commitment and rigour: clear research design and good data analysis. Codes checked by independent researcher. Recognition of reflexivity.	Unclear re: saturation/ data collection completed. Lack of coherence with narratives.
Sin, J. 2005	Exploring needs of carers of young adults with FEP	11 carers	Phenomenologic al Approach	7 themes: 'Living together', 'Caring extensively and intensively', 'Knowing and caring', 'Search for normalising activities', 'Support in caring', 'Adjusting to role'	Sensitivity to context: research into local service development.	Reflexivity not discussed. No mention of ethical considerations. Data analysis unclear, no theoretical sampling or validation.

Author & Year	Aims	Sample	Method	Summary of Findings	Strengths	Weaknesses
Sin, J. 2008	Understanding siblings' experiences of FEP	10 siblings of people with FEP	Phenomenological Approach	5 themes: 'Emotional Impact', 'Relationships in the family', 'Roles and coping patterns', 'Positives out of negatives', 'Useful resources for siblings'	Impact & Importance: highlighting area overlooked in research.	Poor transparency over method, analysis and coding. No mention of reflexivity. Poor methodological rigour: no demonstration of validation or description of analysis.

Evaluation of studies

The quality of any review of research will depend on the quality of the included studies. Therefore, prior to the synthesis of research findings, a methodological evaluation of included studies was conducted. Within the literature there is considerable debate about what constitutes high-quality qualitative study. There are over one hundred quality appraisal tools for qualitative studies (Noyes et al., 2010), highlighting the lack of consensus over how 'quality' should be measured. Some authors raise concerns about the risks of reducing qualitative research to a list of technical procedures (Barbour, 2001), and that using all-encompassing appraisal checklists might not be appropriate or possible. Within this review, the included studies used a range of different methodologies, making it difficult to impose a strict checklist or set of criteria against which to measure quality. Therefore, a tool for reviewing qualitative research papers developed in a previous study (Boyd & Gumley, 2005) was used to appraise the included studies. This guide is a flexible, non-prescriptive method to enable the review of qualitative studies, and was developed from a number of qualitative guidelines (Barbour, 2001; CASP, 2002; Mays & Pope, 1995; Yardley, 2000). See Appendix 1.3 for example. The methodological strengths and weaknesses of the included studies are also displayed in Appendix 1.2.

Sensitivity to Context

All reviewed papers demonstrated good sensitivity to context through the review of relevant literature and presentation of links between previous studies and the study being conducted. All papers used purposive sampling and some demonstrated their

use of theoretical sampling to expand on emerging themes (notably Mackrell & Lavender, 2004).Most studies described their use of open-ended questions during semi-structured interviews, and some demonstrated sensitivity to the socio-cultural setting of the research (Newton et al., 2007; Mackrell & Lavender, 2004). McCann et al. (2011) showed particular strengths in sensitivity to the context of their research, demonstrating both appropriate theoretical sampling and sensitivity to the socio-cultural setting and participants' perspectives. Similarly, MacDonald et al. (2005) demonstrated sensitivity to the cultural context and the importance of establishing rapport with participants prior to conducting interviews.

Ethical Issues

Half of the studies (Kilkku et al., 2003; Hirschfeld et al., 2005; MacDonald et al., 2005; Sin et al., 2008; McCann et al., 2011) described obtaining ethical approval from the relevant research ethics boards. All studies used transcribed interviews, but only four outlined their procedure for keeping data anonymous and confidential. Not all the studies were clear in their procedures for obtaining informed consent, allowing the participant time to consider taking part or how details of the study were provided to participants.

Commitment and Rigour

The majority of studies demonstrated commitment to the chosen research method through descriptions of data collection, analysis and validation of emerging themes. Most provided detailed, in-depth description of the particular research method used,

and the procedure of data collection was clearly described. All studies used interviews which were recorded and transcribed for analysis. Of particular strength was McCann et al.'s study (2011) which used the 'Responsive Reader' method of Interpretive Phenomenological Analysis (IPA). They demonstrated rigour in the data collection through explicit details of saturation and theoretical sampling procedures, as well as conducting an independent audit of the data in order to validate emerging themes. Newton et al. (2007) mentioned using data triangulation to improve internal validity, and Hirschfeld et al. (2005) checked the emerging themes from data analysis with participants. The majority of the studies employed an independent researcher to cross-check and refine coding strategies. MacDonald et al. (2005) enhanced validity by undertaking peer examination of the proposed themes.

Transparency and Coherence

Most studies showed a transparent and coherent approach to data collection and analysis through the explicit descriptions of methods and the development of coding frameworks. All studies produced a coherent and strong narrative from the data, establishing clear themes and novel insights in the research topics. The majority of studies explicitly demonstrated the method of data collection and process of analysis. Notably, Mackrell and Lavender (2004) described the process for the development of categories, subcategories and related codes for each stage of development, displaying examples of quotes which led to the development of some codes and subcategories. Four papers (Perry et al., 2007; Mackrell & Lavender, 2004; Hirschfeld, et al., 2005; MacDonald et al., 2005) evidenced reflexivity and acknowledged potential impact of

researcher bias and influence. Some studies also detailed how research diaries or memos were kept, and how these were incorporated into data analysis.

Impact and Importance

All the reviewed studies produced novel insights and perspectives on the area of research, and all presented emerging themes generated from the data analysis. Of the Grounded Theory studies, none provided an explicit theory from the data, but all demonstrated the emergence of a model for the identified themes. Hirschfeld et al. (2005) suggested that their themes offered the beginnings of a grounded theory into the meaning of psychosis for their participants. The majority of studies discussed the wider socio-cultural impact of their findings, and all demonstrated evidence of research-to-practice links through the discussion of clinical implications of the findings. Two studies specifically highlighted the ways in which the emerging themes could be considered for future development of services (Sin et al., 2005; O'Toole et al., 2004).

Meta Synthesis

Following the methodological review, individual themes were extracted from the findings of each study. In order to facilitate the synthesis of these individual findings, each was discussed with the research supervisor. Through a process of comparison within and between themes, and across studies, these were refined into five emergent themes: i) Experience; ii) Emotional Impact; iii) Relationships; iv)

Coping and Adaptation and v) Meaning Making. For clarity, quotes from participants in studies are in italics whilst quotes from authors are not.

Experience

Participants from seven of the studies discussed the experience of psychosis, either from their own perspective or that of being a carer (Hirschfeld et al., 2005; Kilkku et al., 2003; McCann et al., 2011; MacDonald et al., 2005; Newton et al., 2007; O'Toole et al., 2004; Perry et al., 2007). From the individual's perspective, the experience of psychosis appeared to be reported in relation to changes in feelings and behaviour, changes in interpersonal relationships and realisation that something had happened. Hirschfeld et al. (2005) found that the experience of psychosis for young men included feelings of depression and suicide, and was linked to difficulties in social roles, relationships and autonomy. Within their theme of 'Experience of Psychosis' the authors included the categories 'uniquely psychotic phenomena'; 'experiencing emotions' and 'thinking about dying' as the emerging experiences from their participants. They suggested that in response to these experiences, participants either avoided or expressed them, as a way of trying to cope with what they were going through.

Other experiences were described in the context of the person feeling they had changed; being somehow different as a result. MacDonald et al. (2005) described a theme of 'something happened to me – being different now' which captured their participant's beliefs about being perceived differently. This perhaps reflected the

stigma associated with the experiences, as one participant explained: *'it's just that they [former friends] view me differently now you know, because I've become psychotic they think that you are now a waste of life or something... they just think you're a loony or something like that which is not very good.'*(p. 137). Participants from O'Toole et al.'s study (2004) talked about having a 'very different experience' in the context of being involved in an E. I. service, as compared to care they had received elsewhere.

Kilkku et al. (2003) suggested that participants found their psychotic episode 'a very confusing and frightening situation', where they experienced a loss of control and a sense of not being present in their environment. This linked with McCann et al.'s (2011) theme of 'Roller Coaster and Unpredictable Experience' which was found from a sample of care-givers. Participants described the unpredictability of the person's experiences, and how this impacted on their ability to provide care. One carer reflected on changes in this over time: *'It's easier now than it was because ... [he is] healthier than he was a year ago... He's coping with everyday things a lot better, and that's easier.'* (p. 384).

Emotional Impact

The emotional impact of FEP was discussed by individuals, carers and siblings in several of the studies (Kilkku et al., 2003; McCann et al., 2011; Sin et al., 2008). From the individuals' perspectives, Kilkku et al. (2003) reported feelings of confusion, worthlessness and relief. Feelings of worthlessness were identified in

relation to participants lacking a clear understanding of what had happened to them. Kilkku et al. suggested this came from not receiving information from services, leading to participants feeling insignificant and not worthy of having their needs met. The experience of relief was associated with the commencement of care, when participants described a realisation that they could be helped, and they received information from services. One participant commented: *'I think that it is very important at the beginning of the care to be able to discuss and to get some advice. It is so frightening, it is important to get information about what had happened...'* (p. 61).

In Sin et al.'s study (2008) siblings reported emotional impact, describing feeling overwhelmed by the situation, along with feelings of shame, guilt and embarrassment in response to their sibling's experiences. One sibling described how she felt when her sister first became unwell: *'I couldn't sleep in the night... I would be crying day and night, I think because I used to go there [hospital] and the things she was saying... I had so many problems, I couldn't eat or sleep, and that just affected me badly'* (p. 35). For siblings, emotional impact was described in the context of how the events had impacted on their lives and how they felt about what was happening to their brother or sister. This was sometimes played out in feelings of resentment. One younger sister in Sin et al.'s (2008) sample commented: *'I don't feel that I need any attention or whatever; I am old enough to understand, but you still want a certain amount of attention from your parents. I don't see Mum that often, and I when I see her, its working around my brother'* (p. 36).

This contrasted with care-givers' emotional experiences, which were described in the context of feeling responsible and having to provide hope that things would improve in the future. McCann and colleagues (2011) reported that their participants described feelings of responsibility (particularly when they were parents) for the person having the experiences. This was demonstrated by one participant's comment: *'You feel responsible for everything that happens in your son's life. So you have all the weight on your shoulders...'* (p. 384). Emotional impact was also described in relation to maintaining hope; McCann et al. (2011) posited three overlapping sub-themes: hope in transition; fostering hope in the young person and developing hope as a caregiver.

Relationships

Emotional impact related closely to the theme of relationships, which emerged from the majority of studies (McCann et al. 2007; MacDonald et al. 2005; Mackrell & Lavender, 2004; O'Toole et al., 2004; Perry et al., 2007; Sin et al., 2005; Sin et al., 2008). From an individual's perspective, relationships were discussed in the context of receiving support, being with people and building new relationships following FEP. Mackrell and Lavender (2004) considered the impact of FEP on peer relationships throughout participants' adolescence. They suggested that, even before the onset of FEP, participants talked about inequity in peer relationships, in reference to categories such as family adversity (i.e., separation of parents), deprivation (i.e. limited financial resources) and hostility from friends. According to the authors, these negative experiences appeared to cause instability in peer relationships in early adolescence, resulting in experiences such as rejection by peers. The participants

described becoming increasingly isolated during adolescence, and following the onset of FEP further isolation and negativity in peer relationships was commonly reported.

MacDonald et al. (2005) described the importance of social interactions and activities, and the need to still engage in these despite the FEP. Participants in this study described spending less time with old friends (those from before the onset) and building new relationships following their experiences. One participant reflected on changes in their views on friendships: *'I am all the… wiser I suppose, in a certain sense, I am more wary. I don't openly hug every bloke and girl I see and count them as a life-long friend anymore. I have learnt how to sort of appropriately, I hate the word, but 'judge' people'* (p. 138). The value of families and peer support was key for many of Macdonald et al.'s participants, particularly in the sense of sticking by them through their experiences, as demonstrated by one participant: *'My mum, she has always stuck through me, all the trouble I have been in and that… They mean a lot to me, because some parents of friends, I know they kick their kids out when something happens to them. You know my family stuck with me and they have got confidence in me, more now that what they did'* (p. 135). This linked in with the themes identified by Sin et al. (2005) from the carers' perspectives. Their participants were all parents caring for a son with FEP, and their views reflected the other side of this relationship. The research team identified themes in relation to living together, supporting and caring for their son. Carers talked about providing a range of caring tasks, including practical and emotion support. They also talked about the toll this took on their own lives, as one mother described: *'the one thing I miss most is going away for a holiday which we haven't had for years… the longest*

time we [husband] were away in the last two years was to a relative's wedding in London. We left home just before lunch-time, and expected to be back before midnight after the banquet. It ended up that we have to come back without the meal as he got into a panic with us not being around' (p. 592). This reflected the level of involvement some carers had, and the way in which the person with FEP became dependent on this level of support. McCann et al. (2011) also found care-givers talked about becoming closer with the young person, through providing care and strengthening the existing relationship, although this was not always easily achieved. One carer explained: *'I guess it has given depth to the relationship. It's been pretty crap [difficult] sometimes. There's had to be a bit of honesty and recognition of each other as individuals, and honesty about how both our behaviours have affected the other person. So there's a closeness, but it's been hard going'* (p. 384).

Meaning Making

This theme emerged from the majority of studies involving the individuals with FEP (Hirschfeld et al., 2005; Kilkku et al., 2003; Newton et al., 2007; Perry et al., 2007) and one study with siblings (Sin et al., 2008). Meaning making appeared to be an important task for the individuals, providing a way of making sense of their experiences. Hirschfeld et al. (2005) found that participants created personal explanations for their experiences in the context of recreational drug use, changes in social relationships, social isolation and as a punishment for events in earlier life. The authors suggested that these personal explanations functioned to help participants make sense of their experiences, often by providing a link to their sense of themselves prior to the onset of their difficulties. This was echoed by participants

in Perry et al.'s (2007) study, whose theme 'What's it all about?' emerged from participants' struggle to make sense of their experiences. Their narratives featured explanations such as psychical and emotional stress, previous abuse and religion or faith. Participants in Newton et al.'s (2007) study of experiences of psychological therapy during FEP also described the importance of explanations for hearing voices for participants in making sense of their experiences.

For siblings, meaning making was described in the context of obtaining information about what their family member was experiencing. Sin and colleagues (2008) found that siblings wanted information that was tailored for families, was easily accessible and provided them with education on coping and communication skills.

Coping and Adaptation

The majority of studies with findings belonging to this theme were from the care-givers' and family members' perspectives (McCann et al., 2011; Sin et al., 2005; Sin et al., 2008). Studies by Kilkku et al. (2003) and O'Toole et al., (2004) considered the perspective of the individual and posited themes related to coping, confidence and increased independence. Participants in Kilkku et al.'s (2003) sample described how information given to them from E.I. services about psychosis helped them to integrate their experiences into their lives and increased a sense of coping and confidence about the future. Similarly, O'Toole et al. (2004) suggested that the outcomes of the experience of being involved with an E.I. service included feelings of increased confidence and independence.

In the context of studies on carers' and siblings' perspectives, the coping and adaptation theme is perhaps related to the *Meaning Making* theme discussed earlier. For individuals, meaning making referred to the process of making sense of their experiences. For family members, findings from the studies suggested that carers talked about adjusting to their role, searching for normalising activities and coping with negative experiences. Participants in Sin et al.'s (2005) study described adjusting to the caring role, along with needing support in caring to allow them to cope with some of the difficult experiences. McCann et al. (2011) described carers' experiences of coming to terms with the change in their circumstances. They posited two sub-themes: accepting the change and carers accepting their circumstances, by adjusting to their role as a carer as well as a parent. One participant described that process: *'The role changes because he's 23, he's an adult and so you can be a support person by being supportive, but your role changes in being the carer and a payer of all of his bills and doing all of those support things, to now just being on the edge again'* (p. 384). This participant reflected on the changes over time during the course of their son's experiences.

Siblings also described coping patterns and role changes within the family. Participants in Sin et al.'s (2008) study talked about their role in sharing the care-giving, helping to support their parents and monitoring their sibling in regard to their experiences. Siblings reported trying to keep their interactions with their brother or sister as normal as possible, involving them in social activities and fostering a sense of a conventional sibling relationship. Some siblings also described how their

relationships had changed after the experiences of their brother or sister, highlighting how they had to adapt to this but finding that this had eventually made the relationship closer.

Validation of results

In order to establish validity of the above themes, they were checked against thirteen first-person accounts published in the journal *Schizophrenia Bulletin*, (Anon, 2007; Anon, 2010; Ben-Dor, 2001; B.G.W., 2002; Coleman, 2003; Greek, 2010; MacPherson, 2009; Parker, 2001; Reina, 2010; Salsman, 2003; Scotti, 2009; Sundstrom, 2004; Weiner, 2003). These accounts came from individuals, carers and siblings who described their experiences of psychosis from their own unique perspective. The search was limited between the dates 2001 and 2011 and where full texts were available. Although not all accounts were specifically about FEP, all represented the person's experience of psychosis over a number of years.

The majority of the first person accounts described the experiences of psychosis and the associated emotional impact. It was apparent that the experiences described by the individuals were similar to those demonstrated in the reviewed studies. Many described changes in thoughts, behaviour and social interactions. There were detailed descriptions of the experiences that led the individuals into contact with mental health services, which linked with descriptions from the reviewed studies regarding loss of control, the unpredictability of the experiences and the frightening or confusing nature of them (Reina, 2010; Weiner, 2003). Scotti (2009) described

his relief of learning about his diagnosis, as it meant he had an understanding of what caused his experiences, helping him to realise it was not his fault. The emotional impact of psychosis was closely linked with the descriptions of the experiences, and was apparent throughout nearly all the narratives. Emotional impact was reflected in the individuals' descriptions of the experiences of psychosis, in the context being involved with hospitals or services and the impact on family members (Weiner, 2003; BGW, 2002). Ben-Dor (2001) poignantly recalled her son's experiences of psychosis and the emotional impact these had on her family.

Social relationships featured throughout many of the narratives, usually in the context of peer relationships and support from family. Parker (2001) described the difficulties she experienced in making and maintaining friendships in the context of her schizophrenia. Scotti (2009) described the '*steadfast support*' he received from members of his family. Reina (2010) talked about how his girlfriend had helped him through '*troubling times*'. Coleman (2003) recalled her experiences of living in a community for people with mental health difficulties, highlighting the '*support, camaraderie and friendship.*' From a sibling's perspective, Sundstrom (2004) described the experiences of his sister, and how these impacted on the family relationships.

Meaning making was apparent through several of the first person accounts, tying in with the theme emerging from the reviewed studies. MacPherson (2009) described her frustration with the management of her schizophrenia by services that she '*decided to make an attempt at finding my causes and solutions to my dilemma.*'

Through her therapeutic journal she developed her own understanding which aided her recovery. Greek (2009) highlighted the importance of meanings in his hallucinations, by placing them in a personal context he was better able to understand the meaning behind them and relieve anxiety caused by them.

Coping and adaptation were described by the individuals as part of the journey of recovery. Adapting to the experience of being in hospital, taking medication and adjusting to the role of carer were evident. Salsman (2003) emphasised the importance of personal adaptation following psychosis: '*I came to see the important truth that only I know what is best for me in my journey of recovery… Through trial and error, I have learned what works and what doesn't.*'

Discussion

Main Findings

This review aimed at appraising and integrating the research findings from studies which involved participants with a recent FEP, who had been involved with E.I. services or their families/carers. It was suggested that by using a more focused stance to consider the experiences of young people and their families/carers following a recent FEP, a more detailed and coherent understanding of this group of service-users could be explored. The meta-synthesis produced five interacting themes from the literature: i) Experience, ii) Emotional Impact, iii) Relationships, iv) Meaning Making and v) Coping and Adaptation. These themes are represented in Figure 1 below.

Figure 1: Emergent Themes
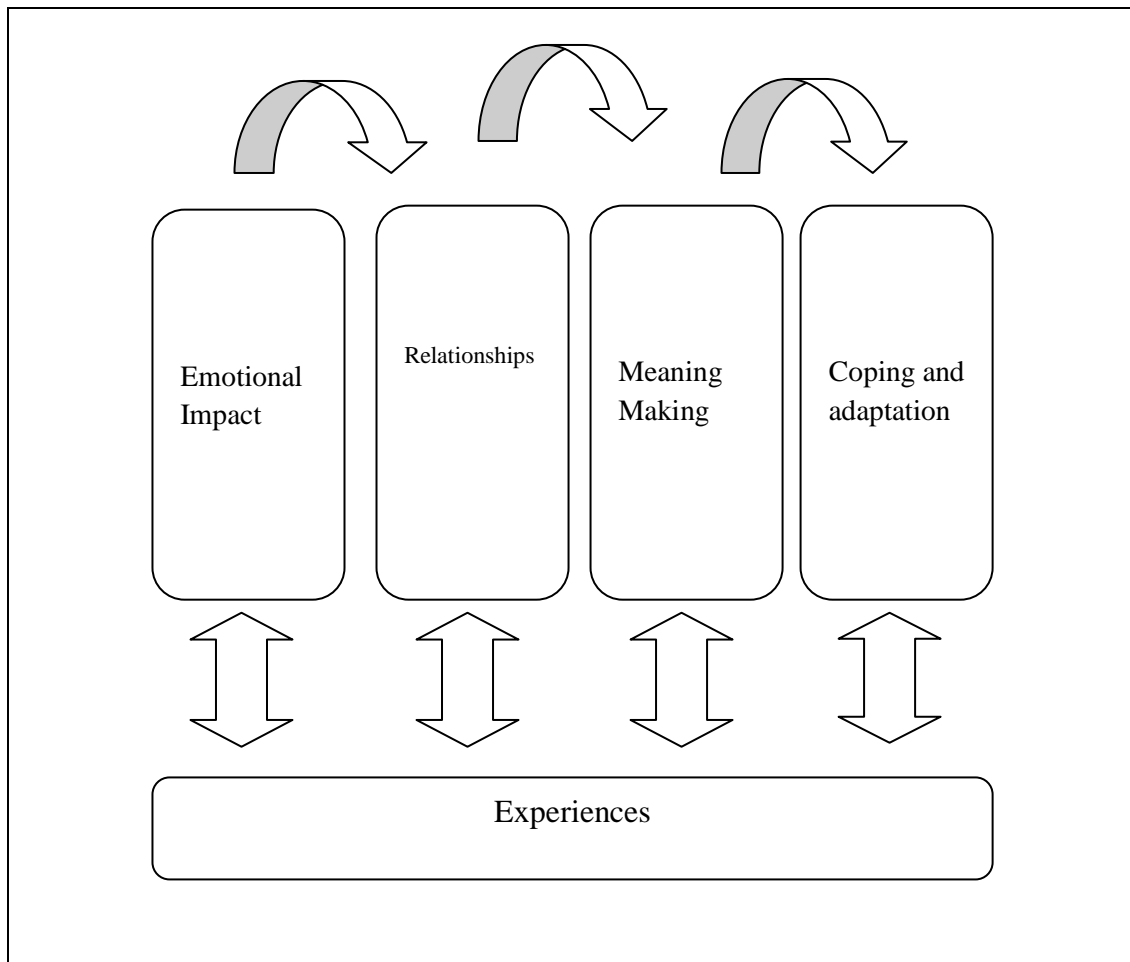
The experiences of psychosis were closely linked with the other emergent themes, at both a subjective level and as reported by families/carers. The emotional impact of FEP was reflected in the feelings individuals had about themselves, their experiences of events associated with their first episode and the impact of this on their families and peer relationships. Carers described the effects of looking after a child or sibling who was experiencing their first episode, and how this changed the roles and relationships.   Social interactions were a key feature, with individuals describing both positive and negative experiences. The importance of receiving support from family linked the narratives from both individual and carer perspectives, with both

viewing relationships as an integral part of recovery. Peer relationships were often the subject of negative experiences, with individuals describing rejection by peers, stigma and isolation during the FEP. Conversely, family relationships were often strengthened as a result of the experiences of the young person, with both parents and siblings reporting feeling closer, although this was not always an easy process.

The process of coping and adaptation overlapped with the themes of relationships and meaning making. For individuals, making sense of their experiences was a predominant theme, with young people emphasising the importance of receiving information about their experiences from services and having the opportunity to reflect on personal explanations for the causes of their experiences. Meaning making was linked with increasing feelings of confidence and coping in relation to individuals developing an understanding of what had happened to them. Through being involved with the E.I. service, young people seemed to be able to achieve all these tasks and develop a sense of hope about the future. Family members seemed to adapt to their roles in relation to the young person with FEP, allowing them to cope with the experiences they were having. Providing care, practical and emotional support and hope were all important parts of this role, as was the ability to reflect on the changes within the relationship. These findings were validated against first person accounts of experiences of psychosis, which echoed similarities across all emergent themes. In particular there appeared to be similarities in the way in which individuals' experiences were the foundation from which themes such as relationships, emotional impact and coping were developed.

Methodological Limitations of the Literature

The methodological evaluation suggested a number of strengths and limitations within the literature. The majority of the studies demonstrated strengths in methodology, particularly in transparency, rigour and impact on service development. There remained some doubt however about the use of 'technical fixes' (Barbour, 2001). Not all studies were explicit about coding processes, and not all described the process of data saturation. Some also failed to mention whether emerging themes were validated, and whether codes were cross-checked with independent researchers. Reflexivity was a concern in some studies, as was the validation of findings and clarity over the development of themes. Only four of the studies provided discussion on future directions for research, mostly through highlighting the limitations of small scale qualitative research and the need to conduct studies with wider scope. There was a lack of reporting of a detailed theoretical framework from the reviewed studies. Although there were tentative attempts at developing models from the emerging themes, there were no explicit theories, reflecting Boydell et al.'s (2010) concern that little theory is being empirically generated through qualitative studies. In relation to ethical standards, some failed to mention any details regarding ethical approval, explanation of research to participants, procedure for informed consent or ensuring confidentiality. In addition, few studies demonstrated the procedure for obtaining informed consent or how the research was explained to potential participants and none of the studies reported allowing the participants time to consider taking part. However, it is acknowledged that word limits imposed on published studies may have impeded the reporting of such details.

Limitations

The research papers included in this review were limited by the previously mentioned search parameters. This inevitably meant that studies not in the English language or those that were unpublished were not included, introducing the risk of publication bias where relevant studies may have been overlooked. There are only a relatively small numbers of studies in what is an emerging area of research interest. The studies employed a range of qualitative methodologies, of varying quality. Many of the studies demonstrated methodological weaknesses under evaluation, yet it was decided that studies would not be excluded due to methodological weaknesses but rather the emergent findings were considered in the context of the methodology employed by each study. Methodological critique was undertaken by only one reviewer, in consultation with the research supervisor. On reflection, this process might have been strengthened by employing several independent reviewers to rate the papers according to the methodological evaluation tool.

Clinical Implications

The findings have important implications clinically, in particular for the provision of E.I. services for young people and their families. The review demonstrated that E.I. services were involved in shaping the meaning making process, through the provision of information and therapeutic interventions. This then impacted on an individual's or carer/family member's coping and adaptation to the experiences of FEP. E.I. services seemed to provide a context for understanding the experiences, providing a sense of relief, the ability to cope and increased confidence about the future. The narratives of the participants demonstrated the emphasis on experiences

through the FEP, although these were not always in the context of symptoms which would typically be the focus of E.I. services. It would be important for services to tune into the subjective experiences of individuals, rather than emphasising the experiences which led them into contact with services. The themes from this review highlighted the importance of seeing the person as part of their wider system. Supporting the person in being an active agent (rather than a passive recipient of care), whilst involved with an E.I. service would facilitate their exploration and understanding of their experiences, promoting autonomy and recovery. The overlapping theme of relationships with coping and adaptation highlighted the importance of involving family, providing information and support to carers and siblings, so as to support the processes of adaptation within family life.

Conclusions

The emergent themes from this review demonstrated the predominant experiences of psychosis for individuals and their families/carers, the emotional impact of FEP and effects on interpersonal relationships. The emotional impact of FEP was felt by individuals and family members alike, which closely overlapped with the theme of relationships. It seemed that the continuing experiences of FEP shaped the processes of meaning making (both subjectively and by carers/families) as well as coping and adaptation. The process of adaptation was influenced by the meanings ascribed to the experiences of FEP, as well as adapting to life following FEP and the involvement of services. Future research might consider the impact of interventions on these predominant experiences. Given the overlapping nature of relationships and coping, it would be interesting to explore the involvement of family members in the

context of an E.I. service, finding out the level of involvement and the impact of involving families on the young person with FEP. The variety of qualitative studies conducted to date has enabled the exploration of the area of FEP. However, little empirical theory has been generated from the existing studies. In order for the findings of qualitative studies to be more seriously considered in terms of service and policy development, methodological strength would need to be improved.

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CHAPTER 2

MAJOR RESEARCH PROJECT

Qualitative Exploration of Recovery Following First Episode Psychosis:

A Grounded Theory Approach

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Lay Summary

Specialist Early Intervention (E.I.) services are becoming increasingly accepted as the most effective way of working with people experiencing first episode psychosis. Although there have been many studies looking at the clinical outcomes of E.I. services (such as symptoms, Hospital admissions etc), there remains relatively little research on the subjective experiences of people following their first episode of psychosis. Similarly, there are relatively few studies which look at recovery as defined by service-users. Therefore, this study aimed at exploring people's experiences using qualitative research methods, using Grounded Theory to build an understanding directly from the participants' narratives. Nine participants from a local E.I. service were interviewed about their experiences of recovery following their first episode. Seven themes emerged from these interviews: build up of experiences; awareness; acceptance; friends and family; shame; loss and re-building. The clinical implications of these findings were in relation to how E.I. services align themselves with the individuals' experiences, focusing on their needs rather than the symptom-based approach traditionally taken. The importance of viewing the individual as part of their wider social system was also highlighted, with family and friends being involved in many aspects of the person's journey.

Abstract

Aim: Specialist Early Intervention (E.I.) services are becoming increasingly accepted as the most effective way of working with people experiencing first episode psychosis. Although there have been a wealth of studies looking at the clinical outcomes of E.I. services, there remains relatively little research on the subjective experiences of recovery following a first episode of psychosis (FEP). This study explored the individual's experiences of recovery following a first episode of psychosis, in the context of a specialist E. I. Service.

Method: Grounded Theory methodology was employed to explore the individual experiences of people involved with an E.I. service. A total of 9 individuals selected from a group of E.I. service users approaching the end of their care were interviewed. Data from the transcribed interviews were analysed using Grounded Theory methodology, where themes emerged from the coding process.

Results: The study identified 7 key themes: Build Up of experiences, Awareness, Acceptance, Shame, Family and Friends, Loss and Re-building. Themes were often expressed as continuums and all appeared to overlap.

Conclusions: This study provided an initial understanding of the predominant experiences of recovery following FEP for E.I. service-users. Future research might consider the experiences of those in other service settings.

Key words: First Episode Psychosis, Early Intervention, Recovery, Grounded Theory, Qualitative

Early Intervention

In the last two decades the provision of Early Intervention (E.I.) services has become increasingly accepted as the most effective way of working with First Episode Psychosis (FEP), (McCrone et al. 2010; Gafoor et al., 2010). In general, specialist E.I. services operate from a model of early detection and phase-specific treatment, which differentiates them from standard mental health care. The early detection element focuses on identifying those people in need of treatment for a first episode of psychosis and reducing the Duration of Untreated Psychosis (DUP) or in some cases identifying those who are at ultra-high risk of developing FEP (Yung et al., 2004). It has been established that longer DUP is associated with increased severity of symptoms, poorer responses to treatment and increased relapses in future (McGorry et al., 1996; Larsen et al., 2001; McGlashan, 1999). In their meta-analysis, Marshall et al. (2005) concluded that a prolonged DUP had a negative effect on a person's recovery. It has also been suggested that the longer psychosis is untreated, the more the damage can be done to an individual's relationships, social networks and educational/career progression, especially given the typically young age at which first episode psychosis usually emerges. Phase-specific treatments can be defined as treatments (psychological, social or pharmacological) provided by E.I. teams for people in the early stages of psychosis (Miller & Mason, 1999).

However, there remains some controversy over the establishment of specialist teams for FEP (Pelosi & Birchwood, 2003). Pelosi (2003) argued that the setting up of specialist teams diverts resources (both staffing and funding) from generic, community psychiatric services on the basis of poor predictive value. He pointed out

that it is difficult to predict which of those young people experiencing clinical features of FEP will go on to develop a severe and enduring mental illness - effectively meaning that E.I. services are treating 'false positives'. He suggested instead that the focus should be given to providing high-quality care to all those experiencing mental illness, through local community psychiatric services and general practitioners. Arguing in support of the provision of specialist E.I. teams, Killackey and Yung (2007) cited a number of studies which have demonstrated that E.I. services offer improved clinical outcomes, reduced hospital admissions and cost effectiveness of treatment, compared to that of standard care in community mental health teams. Preliminary evidence from two randomised controlled trials of E.I. versus standard care suggested beneficial outcomes compared to standard care. The OPUS trial (Petersen et al., 2005) assessed the outcomes of patients from integrated treatment for first episode psychosis compared to standard treatment. The results of the trial at 1-year follow up showed the E.I. group having better symptomatic and social functioning. In the Lambeth Early Onset (LEO) Trial (Craig et al., 2004) participants receiving E.I. were less likely to relapse, had fewer hospital readmissions and were less likely to drop out of the study than the control group.

Marshall et al. (2005) reviewed seven studies with a total of 941 participants involved in E.I. services, and included all randomised controlled trials designed to either prevent transition to psychosis in an at-risk group or improve outcomes for people with FEP. These studies measured outcomes such as transition to psychosis, outcomes from phase-specific interventions such as CBT or anti-psychotic medication, hospital re-admission rates and changes in symptoms. The review suggested that of the seven trials included some reported positive outcomes with

regards to prevention of transition to psychosis or improved clinical outcomes, but many reported outcomes that were either not significant at follow up or failed to be maintained in the longer term. The review concluded that there were insufficient trials to draw any definite conclusions from, but that interest in E.I. is rapidly growing and further studies need to be conducted to address unanswered questions about the efficacy of E.I. services.

Typically, these randomised controlled trials were focused on measuring outcomes in terms of clinical recovery, which differs from service-user defined recovery. Within the literature on service-user involvement, recovery (as defined by the individual) is not based on clinical outcome measures (Andresen et al., 2010). Service-user definitions of recovery focus on changes in attitude to life and the illness, consider the role of hope, the establishment of a meaning and fulfilling life and developing a positive sense of identity (Andresen et al., 2003; Resnick et al., 2005; Leamy et al., 2011). Andresen et al. (2010) argued that through measuring symptoms, medication compliance and service utilisation, researchers risk excluding the intrapersonal processes of psychological recovery, and therefore are unable to truly reflect the service-user definition of recovery. A recent report from the Scottish Recovery Network (Narrative Investigation on Mental Health Recovery, 2007) set out to develop an understanding of recovery by collecting narrative accounts from service-users with long-term mental health problems. The report explored a number of factors that service-users found both helpful and unhelpful in their recovery. The findings suggested that there were internal (individual and self-controlled) elements and external (social or environmental) elements required to promote recovery (2007, p. 7). This document made the point that recovery was less

about the 'absence of symptoms' but rather about having the '*opportunity to live a satisfying and fulfilling life, in the presence or absence of symptoms*' (2007, p.6).

Outcome studies traditionally employed quantitative methods, collecting data on standardised measures of symptoms, assessments of overall functioning and quality of life. These methods are entirely appropriate when assessing the effects of E.I. services or interventions, but by their nature fail to include an individual's subjective experiences in the context of E.I. services. As discussed, the results from clinical outcome studies remain inconclusive, and there remains a lack of understanding about a person's experience of recovery from FEP in the context of E.I. services. Given this gap in knowledge, the past few years has seen a steady increase in the number of qualitative studies which specifically explore the subjective experiences of people with FEP and their wider social networks. Boydell et al. (2010) aimed at providing a descriptive review of the findings from these qualitative studies. They reviewed thirty-one studies which considered the perspectives of the individual with FEP, their families or carers and service providers, with studies employing varied methodologies. The studies covered wide ranging time scales, from early recognition of usual experiences, to help seeking behaviour, through to engagement with E.I. services and views on specific interventions. Boydell et al. identified key themes emerging from the findings of the reviewed studies in relation to the subjective experience of psychosis; views on early intervention services; the subjective experience of help-seeking; gaining and maintaining employment and the importance of peers. The authors attempted to conceptualise these findings according to a predefined theoretical framework developed from ethnographic principles. The authors organised the findings according to Generic Social Processes

(GSPs; Prus, 1987), which '*highlight the emergent, interpretive features of association, focussing on the activities involved in the 'doing' or accomplishing of group life'* (2010, p. 8). According to Prus (1987, p.274) these processes '*not only signify key elements of people's involvements in situations, but also define the essence of community life'*. Boydell et al. felt that four GSPs were particularly relevant to the emergent themes in relation to the experiences of FEP, as identified in the findings of the reviewed studies. The themes were organised into the following GSPs: i) achieving identity; ii) acquiring perspectives; iii) doing activity and iv) developing relationships.

The review demonstrated that a limited number of studies have been conducted into E.I. services (seven in total), and the authors concluded that in terms of E.I. services, further exploration is needed into the social and cultural aspects of service engagement. They pointed out that the weight of qualitative research focused on the subjective experience of illness, together with seeking and receiving help (2010, p. 22). The authors attempted to review a varied body of literature and organised the findings by applying a pre-defined theoretical framework to understand the data. However, this 'top-down' approach to interpretation meant the opportunity to generate an understanding directly from the data (in a 'bottom-up' way) was missed. Much of the language used within the review (and some of the included studies) suggested an understanding from the perspectives of service-providers, researchers and clinicians, for example, through labelling experiences as 'symptoms' or the use of medical terms such as 'prodromal'. This language appeared to have been imported from constructs as driven by E.I. services, rather than from the perspective of the individuals involved.

Recovery, as defined by the service-user has been overlooked in the qualitative literature, where the focus has been on the measurement of clinical recovery as defined in the context of mental health services. Therefore, the current study aimed at exploring the subjective journey through experiences and interactions with services, rather than measuring clinical recovery, in the context of an E.I. service. A realistic starting point was the exploration of how people who have experienced a FEP talk about the impact of this on their sense of identity. With this in mind the initial research questions focussed on i) how an individual's identity is expressed in relation to changes in the person's social and interpersonal context, following first episode psychosis; ii) how an individual's identity is expressed in relation to recovery in an E.I. service context and iii) are there any commonalities or divergences in how people express their experiences of recovery. Grounded theory has emerged as a popular qualitative research methodology due in part to the focus it places on the systematic yet flexible guidelines for collecting and analysing data to generate theories 'grounded' in the data themselves (Charmaz, 2006). Unlike other qualitative methodologies, grounded theory research methods use explicit guidelines where data collection and analysis are conducted together. This involves constant comparison of data gathered and coded, in order to shape future data collection in subsequent interviews. The principles of grounded theory fit well with the exploration of service-user defined recovery, where care needs to be taken to generate an understanding of individuals' experiences directly from the data, i.e., personal narratives. This avoids imposing a predefined theoretical framework onto these experiences, instead allowing for the development of a theoretical explanation derived from subjective accounts, using idiosyncratic language.

Method

Participants

The study recruited 9 people who had experienced FEP and had been patients attending an E. I. service in Glasgow. Participants were recruited from a purposive sample of patients within six months of their discharge or transfer of care from the E.I. service back to GPs or other secondary mental health services. The exclusion criteria were if the participant had a learning disability, or where English was not their first language. There were five male and four female participants; all were White; the median age was 26 years (range: 20 – 35 years). Three participants had returned to work, one had begun voluntary work, three were engaged in college or university studies whilst two were not working or in education. All but one of the participants lived independently, either alone or with their partner or child. The youngest participant had returned to live with his parents. All had experienced their first episode of psychosis for which they received intervention from the E.I. service and were now in recovery from their episode (i.e., not currently experiencing psychotic phenomenon). All participants had experienced at least one hospital admission for their experiences. Participant details are outlined in Table 1.

Table 1: Participant Details

Transcript No.	Pseudonym	Gender	Age	Employment Status	Living Circumstances
1	Christine	Female	24	Working	Lives with partner
2	Danny	Male	26	College	Live alone
3	James	Male	23	Voluntary Work	Lives alone
4	William	Male	24	Working	Lives with partner
5	Simon	Male	33	Not working	Lives with partner
6	Amy	Female	31	College	Lives alone
7	Debbie	Female	35	Not working	Lives with daughter
8	Lindsay	Female	29	Working	Lives alone
9	Joe	Male	20	University	Lives in parents' home

Research ethical approval was granted by the relevant NHS Ethics Committee, (Research Ethics Committee 3, Ref: 10/S0701/67; Appendix 2.2). Local NHS Management Approval was obtained (Ref: GN10CP389; Appendix 2.3) which approved study procedures for obtaining informed consent, protection of data and participant confidentiality.

Researcher

The researcher (first author) developed an interest in Early Intervention in Psychosis after working on previous research projects in the area. This work began her interest in how individuals experience E.I. services, and how the services impact on their experience of recovery from FEP. Throughout her involvement on previous research projects she developed close links with the local E.I. service and collaborated with clinicians regarding the development of this research idea.

Procedure

Participants were made aware of the study at their 18-month pre-discharge review. Service-users were given an information sheet (Appendix 2.4) by their key worker, and the opportunity to meet with the researcher to ask any questions they had before agreeing to participate. If interested, the service-user consented to their key worker providing the researcher with their contact number and arrangements for interviews were made by telephone. Following an explanation of the research area, each service-user was given the opportunity to ask questions, before providing informed consent to participate in the interview (Appendix 2.5). Each participant was interviewed once, with all interviews being conducted within the clinical base at the E.I. service. All interviews were digitally recorded using Sony ICD-UX300 Digital Voice Recorder for later transcription. The interview schedule (Appendix 2.5) included questions that were open-ended and flexible, acting to guide the interview and to encourage participants to talk openly about their experiences. The schedule was developed with a Clinical Psychologist with experience of working with FEP, and was refined in discussion with the researcher. The interview topic was introduced to participants by explanation that the researcher was keen to gain an understanding of their experiences of recovering from psychosis. Open-ended, broad questions were used to facilitate discussion around the topic, followed by more specific 'probe' questions, which aimed at eliciting more detailed examples of experiences from the individuals. The researcher listened empathically, using reflections and summarising what the participant had explained in order to confirm understanding and facilitate free-flowing conversation. The researcher remained alert to not introducing pre-conceived ideas or personal meanings into the interview.

By reflecting back and checking understandings with the participants, they were free to challenge and where necessary, correct any assumptions held by the researcher.

The interview schedule was organised into three parts, each considering different time frames and orienting the participant to think about their experiences of recovery during these times. The first section prompted participants to think about their experiences during first few months, including how they came into contact with services. This was followed by more specific questions encouraging the participant to reflect on those experiences (e.g., How did you feel about that? What were you thinking at the time?). The second part of the interview oriented participants to think about changes over time; for example, asking how their feelings had changed during their involvement with E.I. services, and what their main sources of support had been.   Care was taken to use the participant's own language to explore and reflect feelings and experiences, without introducing any of the researcher's own meanings or interpretations. The final section guided the discussion to 'here and now' and focused the participant on their current situation, enabling them to move away from reflecting on their past experiences. The participants were asked to consider whether they had learned anything from the experiences they had talked about, and whether there was anything they felt others (e.g., services, family, friends) could learn. These later questions were designed to assist the participant in closing and finishing the interview especially given the emotive nature of topics explored. The interviews lasted, on average, for an hour.

In line with grounded theory procedure (Strauss & Corbin, 1998), questions were developed after each interview as new themes emerged and these were then incorporated into subsequent interviews. After the first few interviews, early analysis produced several key topics in relation to the area of interest. In order to elaborate on these early topics the focus in subsequent interviews sought to ask participants more specifically about their experiences in relation to the topic. For example, early analysis suggested the area of 'family involvement' might be significant in some people's experiences of recovery. In order to expand on, refine and challenge this emerging theme, subsequent participants were asked about the support they had received from family and friends.

Data Analysis

In grounded theory methodology, data collection and data analysis inform each other, whereby emerging themes from data analysis will shape further data collection (Charmaz, 2006, p.42). Data analysis, therefore, cannot be separated from the data collection, and coding is seen as a crucial link between data collection and the development of a theory to explain the data. The initial phase of coding established 'segments' of data which were then used in more focused coding to identify and develop the most salient categories (Charmaz, 2006, p. 43). The interviews were initially transcribed by a clinical secretary, and then re-listened to by the researcher at least twice in order for researcher to become more familiar with each interview. This process also allowed the researcher to make corrections to the transcripts, for example correcting the length of time of pauses. After transcription, the interviews were coded on a line-by-line basis, following the content of the discussion,

summarising main activities and staying close to the language used by the participant. This process allowed the researcher to become familiar with the data, and notice more frequently emerging codes. The second phase of analysis involved more focussed coding to capture the more significant emerging categories from the initial codes. Through repeated comparison of individual codes (within the same interview and across different interviews), more general categories which subsumed these codes appeared. These were also compared with researcher field notes and memos to identify the emergence of more over-arching themes. This process continued until all data were accounted for by any given theme. An example of line by line coding can be seen in Figure 1.

Figure 1. Example of line by line coding (codes eventually subsumed by theme of 'Build Up')

Transcript Text	Line Codes
'emm. . . {3 secs} I was just I think it was stress	Feeling stressed
and things I was in my final year at uni and (hmm)	Recalling events from final year
and emm and I had my exams and my dissertation	Sitting exams; writing dissertation
and everything to do so I was really stressed with	Feeling stressed
that and then when it was all finished I was like . .	Remembering when uni finished
{2 secs} just totally, everything changed and I think	Feeling different
I just got a bit high (hmm hmm) emm. . {2 secs}	Trying to understand
but obviously I had never experienced it before so I	Unsure about experiences
didn't know what was happening and I didn't think	Assuming nothing was wrong
anything was wrong so it just got worse and worse	Gradual decline
and worse until emm . . {2 secs} my parents kind	Parents intervened
of. . {2 secs} emm. . {2 secs} thought there was	Realisation something was wrong
something wrong with me	

Transcript 1, Page 1, Line 29

Throughout the data analysis process there were several turning points in the development of emerging themes. These were recorded in the researcher's memos and reflective diary, and noted in the coding of transcripts. Following each reading of the interview transcripts the researcher made memos on any emerging areas of interest, along with any reflections, thoughts and feelings arising from reviewing the interview. For example, when developing the theme of 'social support' it became apparent that the participants' descriptions reflected opposite ends of the same spectrum. For some, social support from family and friends was seen as an important part of recovery, yet for others this was described as potentially detrimental to recovery in terms of fears about the stigma attached to their experiences.

Saturation

Grounded theory methodology employs *theoretical saturation* to guide sampling. The ambiguous meaning of 'saturation' creates a problem in knowing when enough data have been collected, which often relies on the researcher's assumptions about the data collected, presenting a risk that some data be overlooked. In order to overcome this ambiguity, Dey (1999) suggested that the term *'theoretical sufficiency'* is a more appropriate aim for grounded theory researchers. Theoretical sufficiency suggests that rather than establishing categories saturated by the data, there should be categories suggested by the data. Within this study, the principle of theoretical sufficiency better fits how the research was conducted, emphasising the need to be open to what was happening in the interviews (Charmaz, 2006) and not closing down categories without having explored all the data. For each of the

emerging themes the transcripts were analysed for data which could elaborate, develop or challenge the theme, resulting in theoretical sufficiency being achieved.

Ensuring Quality

The constructivist approach involves the researcher taking a reflexive approach to data collection and analysis, considering *how* the theories emerge, and recognising that their own assumptions, values and interpretations will affect the research. Throughout the data analysis process, memo writing was undertaken to enable reflection on the codes created, highlight areas of further data collection and the development ideas about the data. In order to ensure an open and responsive stance to the data was maintained, all emerging codes and subsequent themes were discussed with the research supervisor during regular supervision meetings. These meetings enabled the researcher to reflect on previous interviews, emerging areas of interest and allowed for the recognition and acknowledgement of any personal assumptions about the data.

Results

The study identified seven key themes: Build Up of experiences, Awareness, Acceptance, Shame, Family and Friends, Loss and Re-building. These themes are represented in diagram 1 below.

<u>Diagram 1 – Emergent Themes</u>
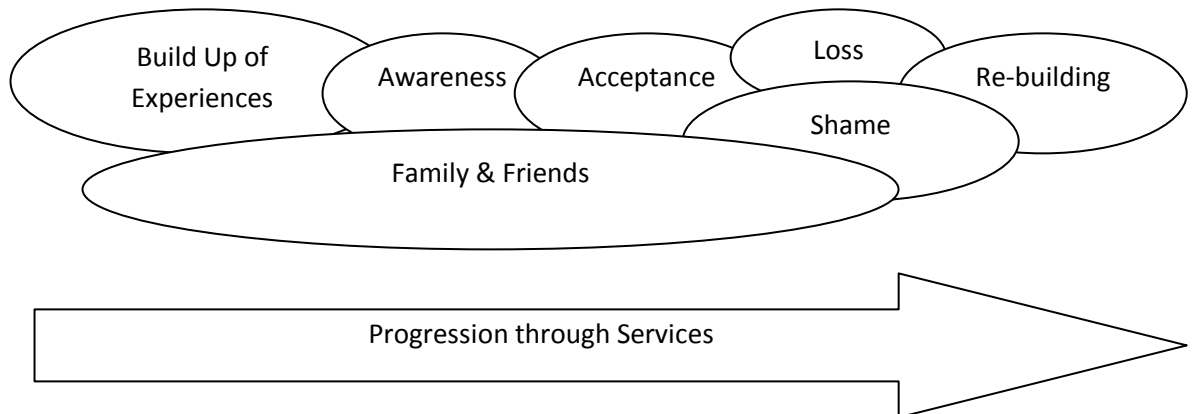
For clarity, participants' responses are verbatim, in italic and the researcher's responses are in parenthesis (e.g., *right, okay*). The researcher's speech is in bold. Some of the researcher's questions have been included to allow for the context of the discussion to be understood. Pauses in speech are indicated by dots, with one dot representing a one second pause. Participants' names have been changed to pseudonyms.

Build Up of Experiences

All participants used the interview to reflect on their experiences. They all began by describing the experiences which led them into contact with services, and they largely described these experiences as building up over a period of time. Nearly all participants talked about their problems framed in the context of ordinarily occurring events, for example describing being under stress at work, pressure of university work, problems with friends or partners; all except one who still struggled to resolve his understanding of the nature of experiences. This build-up of experiences is captured by this participant:

Joe: *'Erm .   . {2 secs} kind of like a collaboration of different things, so it would be, erm .   . {2 secs} stress was a major part of it I would say so, em, the I mean, the stress came from overworking (mhmm) eh I was doing college at the time, I'd moved in with my girlfriend and I was trying to like get a flat with her at the time (mhmm) there was conflict with ma friends as well (mhmm) eh there was a lot of partying you know, student obviously (mhmm) so erman just all that together really sort of stressed me out and I, I obviously on top of that I wasn't getting enough sleep or eating enough (mhmm) so that as well kinda led me down that path and the other kinda thing like that just kinda topped it off was the em there was street drugs involved so...'*

<div align="right">Transcript 8, Page 1, Line 36</div>

These experiences were framed in the context of salient events in Joe's life and were related to age-appropriate activities and events such as being at college. Throughout the narratives it was clear that this understanding about the build-up of ordinarily occurring events was echoed by nearly all the participants, as demonstrated by William's description:

William: *'emm it was just a number of factors and it's one of these things that are, you could probably try it a million times and it wouldn't actually, you wouldn't get the combination of events. There was a mixture of my education, emm hadn't gone like it went, my degree, basically I didn't get the results in my degree, emm it was at a time where the recession was starting to kick in and it was even harder to get. I think, I mean it's still the same now, the markets the way that it is (huh huh hmm hmm). So I was kind of a struggling to get work and emm things in my social life weren't going particularly well (hmm hmm) emm financially I was, I had actually accrued some debt from being through university (hmm hmm sure) basically there was a whole host of different things (hmm hmm) and emm I suppose it was a case of my mood had dropped to a certain point and then after things were still kind of a building up...'*

William's narrative indicated his perception of the unique combination of events at that specific time in his life. Many participants reflected on what was happening in their lives and tended not to attribute their experiences to becoming unwell, but rather saw them as part of the stress of daily life. For some, there was a gradual build-up of stress, resulting in them arranging an appointment with their GP, whilst for others there was a quicker build up resulting in contact with services that was out-with their control (e.g., being involved with the Police). Joe recalled having numerous experiences but did not frame them in the context of becoming unwell:

> **Joe:** *'I mean there's lots of experiences before that (yep) but they were very minor which is another reason why maybe I didn't realise that it was happening (right okay uhu) it was like a build-up of little things (mhmmmhmm) you think someone was saying something and then they'd go naw a didn't say that but that happens in life anyway (mhmm absolutely) so you wouldn't pick it out (right uhu).'*

It was apparent in the majority of narratives that there was no use of medical language during the descriptions about early experiences. Participants did not initially describe themselves as 'unwell' or having 'symptoms'. The descriptions reflected their understanding that their experiences were due to a combination of salient factors related to events happening in everyday life at that time.

Whilst reflecting on the build-up of their experiences, some participants recalled not thinking anything was wrong. Several explained that they had never experienced anything like it before, suggesting how they lacked a point of reference from which

to construct any understanding. For Christine, her understanding was in the context of 'University stress':

> **Christine: '***I was just I think it was stress and things I was in my final year at uni and (hmm) and emm and I had my exams and my dissertation and everything to do so I was really stressed with that and then when it was all finished I was like .   . {2 secs} just totally, everything changed and I think I just got a bit high (hmm hmm) emm.   . {2 secs} but obviously I had never experienced it before so I didn't know what was happening and I didn't think anything was wrong so it just got worse and worse and worse until emm .   . {2 secs} my parents kind of.   . {2 secs} emm.   . {2 secs} thought there was something wrong with me, so they were going to refer me to emm or get a doctor involved but I decided just to take myself down to A & E and then they decided cos I didn't think anything was wrong (hmm hmm) so they decided yes you need to emm .   . {2 secs} go in for observation and I ended up being there for like three weeks (right) four weeks (huh huh).'*

<div align="right">Transcript 1, Page 1, Line 29</div>

Christine's narrative demonstrated a feeling of resistance as she struggled with the suggestion that something could be wrong. She appeared ambivalent about being admitted to hospital, perhaps indicating her feelings about whether there was something wrong.   This struggle was a common category emerging from nearly all the narratives, and was used in the development of the theme awareness.

Awareness

The descriptions of build-up seemed to provide a platform for participants to talk about the process of becoming aware that what they were going through was more serious than they had realised. This was especially so for those who had sought help

initially from their GP, compared to those whose initial contact with services had been arranged out-with their control. They described seeking help for experiences that they had tried to understand in the context of everyday stress, with the result of being referred to a secondary mental health service or being admitted to hospital. For some this was an unanticipated consequence of help seeking, which they struggled to make sense of. William described using the context of being in hospital to construct an understanding that he was '*unwell*':

> William: '*I was quite good at describing what was wrong with me (hmm hmm) which I think helped (hmm hmm) which I understand, even from people that I met who were in hospital as well maybe aren't as articulate and there's even quite a lot of people that don't, they don't kind of recognise that they have illnesses, suppose it's something your brain, your brain doesn't have another brain (sure) to tell you that there's something going wrong with it (huh huhhuh huh) emm, whereas emm, I think {. . . 3 secs} I was already stepping back (huh huh) having a wee look and then basically I recognised that, well you're in a hospital why do people go to hospitals – it's for people who are sick (huh huh) so that kind of a thing enters your mind, emm so that was the kind of a first kind of steps in becoming unwell.*'

<div align="right">Transcript 4, Page 4, Line 122</div>

The majority of the participants sought help independently, either through their GP or by going to a hospital; however, there was limited use of a mental health context. Help seeking occurred in response to painful emotional experiences, such as feeling frightened by what was happening or feeling very depressed. Amy described how she felt about the experiences which led her into contact with services. She recalled that she went to hospital to seek help for hearing voices:

> **Researcher: '*And what was that like at the time, do you remember what it was like for you?***

> *Amy:* *'See at the time I was beside myself, I was frantic (hmm hmm) I just didnae know what was happening (hmm hmm) so it was like, it was like getting hit wae a, getting hit off a brick wall (hmm hmm) know what I mean? (yepyep hmm hmm) One minute you're awe right and the next minute you're no doolally, but you're changed (hmm hmm absolutely).'*

Transcript 6, Page 5, Line 154

Amy's description indicated that her awareness about her experiences changed quickly. This is in contrast to other participants (such as William), whose awareness seemed to develop over a longer period of time.

Being admitted to hospital seemed to provide a different context for some participants, prompting them to think about themselves as being 'unwell'. Several described how difficult they found their initial contact with services, and how fearful they were about what was happening to them. For many, becoming aware that their experiences were being framed in the context of a mental health problem presented a challenge. Most had an understanding in the context of everyday occurrences, using an explanation of 'stress' to make sense of their circumstances. Once in contact with services the context changed, providing an alternative and often contrasting framework. Some of the difficulties with initial contact could be explained by this contrast, where the two perspectives were at odds with each other.

Feelings about being admitted to hospital were apparent throughout some of the narratives in relation to the meaning admission and the first use of medical terms such as psychosis. The meaning participants attached to this change in

understanding indicated negative feelings about mental health problems, the involvement of hospitals and the intervention of mental health services. It was apparent through the narratives that early descriptions of experiences contained no medical terms or reference to psychosis. This contrasted with some of the language used as the interviews developed, as participants began to import terms from services, reflecting a change in awareness of their experiences. Danny explained how he had been feeling before he came into contact with the E.I. service:

> **Danny:** *'Emm, a little while before that I was becoming depressed, (yeah) and erm, things like that .   . {2 secs} so my GP referred me to the [Community Team 1] (right) but it was nothing like, psychosis, nothing psychotic (yep). It was just solely for depression (yeah).   . {2 secs} emm, and just over the time things just started kind of ah, kind of ah, spiralling out of control (yeah yeah).*

<div align="right">Transcript 2, Page 2, Line 41</div>

Acceptance

Following an increase in awareness, many participants described memories of being given an explanation that their experiences were due to psychosis. For some, this created a very different context about what they had been going through. William recalled:

> **William**: '*Oh well, I mean I remember, I remember when I got told. I mean when I initially got described as having psychosis (huh huh) well I think the term that was used at the time was that I was psychotic (huh huh) and obviously the negative connotations that go with emm being psychotic (absolutely) a kind of a psycho if you like (hmm hmm) it's something that's*

very difficult to kind of a take in emm it was something that emm I was a bit resentful of I guess (hmm hmm).

Some participants talked about their struggle with accepting the explanations they were given. The process of accepting a very different understanding was often difficult, painful and for some involved a degree of submission. Being given an explanation and assigned a label seemed to be the start of a difficult process of dealing with the reality that their experiences were part of psychosis. This was demonstrated by William:

> **William:** '*In the fact that you know, whilst you feel unwell and you feel a bit depressed I mean I thought at worse it would be depression, I had actually gone to my doctor (hmm hmm) emm, prior to that and said that I was feeling quite depressed, (hmm hmmm) emm but I would never have said that I had psychosis but I guess again even from my perspective it was a misunderstanding and I think it's a generally misunderstood term.*'

For some participants the explanation given by services contrasted sharply with their own understanding. It was apparent that some struggled to integrate this difference in explanation, as Christine recalled:

> **Christine:** '. . . *{3 secs} I think that I felt like it was her fault [Psychiatrist] that I was in there [hospital] (hmm hmm) and I blamed like also my parents and things but I didn't accept that anything was wrong with me for a while, like a long time so, emm, I was in, I was out, and then I went back in again (right) after I was out, I think I was out for a couple of weeks and then (right) emm I was back in, so the first and second times were quite different (right) emm.*'

Christine talked about not accepting anything was wrong with her, and blaming her psychiatrist and parents for being admitted to hospital. This struggle with acceptance appeared tied up with feelings of blame and denial which perhaps reflected the difficulties she felt in relation to accepting the alternative explanation of her experiences as provided by the E.I. service. This struggle also seemed to be played out in her repeated discharge and re-admission over several months. The process of acceptance had significant meanings attached to it. By accepting an explanation of psychosis for their experiences, participants accepted that something about themselves had changed; the meaning they had constructed about their difficulties changed from one of everyday stresses to one involving a mental health problem. One participant (Simon) struggled to resolve his experiences in the context of psychosis. His struggle to integrate the two perspectives (personal and service-based) was clear in his narrative:

> **Researcher:** *'Right okay, so looking back now, so how do you, how does that sit with you [diagnosis of psychosis]?'*
>
> **Simon:** *'. . . . . {5 secs} a dunno. . {2 secs} in some ways a still want to prove everybody wrong because a don't, I still feel the same way as a did then (mhmm) it's no like having the cold or anyhineh, ... {4 secs} it's kinda hard to put it intae words, (mhmm, mhmm, it's a tough one) mhmm, the, as far as being paranoid and aw that goes, a know that a wiznae right but am still sure a heard it aw, am still sure eh it, erm . . . {3 secs} when, when a think aboot it a could put up arguments like in ma own head (uhu) a do it aw the time for both sides (right) naw it couldnae a happened because, it did happen because this wiz said and how would anybody know, know'.*
>
> **Researcher:** *'And you can still see both sides (mhmm) uhu, when you look back?'*
>
> Simon: *'A probably always will.'*

It was clear that many participants struggled with the acceptance of an alternative explanation of their experiences. Exploration of this struggle often led to discussion about the participants' feelings in relation to this change in understanding from which emerged the following theme.

Shame

For most participants the process of acceptance appeared to involve feelings of denial, blame, anger and submission. The theme which emerged as common across all the narratives was that of shame. This was expressed as a continuum, where at one end some participants felt a deep sense of shame about what had happened, whilst others described how proud they felt for coping with what they had been through.

For some, shame was related to feelings that they had let others down. Simon poignantly described his feelings after accepting that he was '*unwell*':

> **Simon**: '*A wiz a bit disappointed in masel (right, uhu, how come?) [sighs]. . . {3 secs} It's as though a let it happen, (right) a know ye canny help it, if it's gonny happen it's gonny happen but a was really disappointed in maself (right uhuuhu).*'

> **Researcher: '*Tell me a bit more about that?*'**

> **Simon**: '*Em . . . . {4 secs} I've always like been the strong wan, (right) been the wan that people come to when they're upset (mhmm) an . . {2 secs} it was as though ad fallen in ma own estimations (right, okay, that's*

interesting, mhmmmhmm) a didnae like it (no, uhu) an a started to come roon tae awright am no well, that's when a got, a wiz really, a got dead dead dead depressed (right, uhu) because a felt as though a wiz letting everybody else doon, a wiz letting masel doon, gave up ma hoose, if there wiz anybody there then ad basically ran away fae it (right) an a wisnae happy wi that either (right).'

Transcript 5, Page 12, Line 433

For many, the acceptance of the explanation provided by the E.I. service was closely associated with feelings of shame. Accepting a change in the identity was challenging and perhaps linked to feelings of shame in relation to the meaning 'being unwell'. For Simon the meaning of being 'unwell' contrasted with his self-image of being the '*strong one*', resulting in him feeling a sense of disappointment in himself. This was not unique – many participants expressed shame in relation to changes in their identity and in the context of how others saw them. Many recalled not wanting other people to know that they had been given a diagnosis of psychosis; for example, Debbie talked about the '*embarrassment*' of people knowing she had been '*crazy*':

Debbie: '*Yeah you obviously change because you wouldnae wish it on anybody because it's quite a scary thing (hmm hmm) and then it's like an embarrassment as well (hmm hmmm) you know you don't want people to think, oh she's no right because she was cracked up you know? (huh huh) And another thing you feel as if like people treat you different when they know how like what's happened to you and stuff like that (right) so it's nice to meet somebody who doesn't know what happened to you because they don't judge you or anything like that (right) they don't, anything disnae come into their mind to think along the line of god you should have seen her you know, she's crazy (huh huh) emm.;*

Transcript 7, Page 13, Line 446

This highlighted the issue of stigma, which was mentioned by many participants. At one end of the spectrum sharing their experiences with others was associated with negative feelings, whilst for others it was a positive thing to do. Feelings of shame about what the individual had been going through linked with ideas about stigma, and the reactions participants received (or predicted they would receive) should they disclose their experiences to others. William talked about the stigma he felt in relation to talking about psychosis with his friends and family:

> **William:** *'I tried to just, I never really discussed any of my illness with any of my kind of social (hmm hmm) emm group I hang around with or, to be honest it's not really even discussed very much within my family (hmm hmm)[...]I suppose if you start mentioning things like, like I've got psychosis and things like that then that probably destabilises trying to build or repair or maintain relationships with other people (hmm hmm) emm, so from that aspect of things, it wasn't something that I kind of spread about (huh huh) because I think there is a lot of misunderstanding around the term, (huh huh) a lot of negative, yeah there is a lot of stigma around it so, it was never something I really discussed and it was preferable in that sense.'*

> Transcript 4, Page 12, Line 422

Non-disclosure to friends and family was a strategy some participants used, instead preferring to keep information about their experiences private. Those who engaged in this strategy were keen not to be seen as 'different' by their peers or family. This was apparent in Christine's narrative:

> **Christine:** *'I had a couple of emm.   .   . {3 secs} well one, like good supportive friend (hmm hmm) but.   . {2 secs} that was quite difficult talking to friends about it (huh huh) so.   . {2 secs} emm, I just tried to act normal (right) and pretend that nothing was wrong and stuff (huh huh).'*

> Transcript 1, Page 14, Line 479

At the other end of the spectrum, some felt proud of themselves for living through difficult experiences and felt that by telling others they were better able to cope. Joe talked about focusing on being proud of getting through things, rather than feeling ashamed:

> **Joe:** *'Em …… ... {3 secs} I think yeah. I think being proud of it in a way, just in a way I'm not (mmmm) totally proud of it (mhmm) but being more proud of it than ashamed of it is definitely better (mhmm) it's a lot better (mhmmmhmm, that's really interesting, it's very interesting).*
>
> **Researcher: 'What do you mean, I don't want to put words into your, I want to know when you say "you're proud of it"/**
>
> **Joe:** *'Nawnawnaw, that's just the term I was using (uhu) being (uhu no it's good) being proud of like getting through it, being proud of yourself instead of concentrating on things that you would be ashamed of like aw erm, you broke down and you couldn't handle the pressure and just be like well I've came back like, you just turn that straight around and say I've came back after a couple of months (uhu) and I'm absolutely fine (uhu) and to be able to cope with it for that length of time is a good thing (absolutely, absolutely, yeah).'*
>
> Transcript 9, Page 11, Line 389

For those who framed their experiences in a positive way, there seemed to be a different meaning attached to what they had been through. Joe talked about feeling proud to have 'come back' after a couple of months. Throughout his narrative it was apparent that he understood his experiences as part of a short-term, one –off event in the context of university stress, street drugs and too little sleep. This had quite a different meaning when compared to others who felt that being given a diagnosis of psychosis meant they had of a life-long chronic illness.

Family and Friends

The theme of shame was closely related to the theme of *family and friends,* in that much of the context for the shame was linked to social identity. Throughout all narratives family and friends was an obvious theme, although this was expressed quite distinctly from person to person and often differently even within the same narrative. As mentioned, some participants did not want friends to know about their experiences, perhaps an indicator of the shame and stigma that they felt. Conversely, some talked about wanting to actively involve family and friends in their experiences and there were descriptions of how valuable social supports had been.

Many participants recalled how family and friends had been involved in the early stages of their experiences when they were trying to make sense of what was happening. Simon explained that he told everyone about his experiences to see how they would respond, as a way of testing out his own construction of the meaning he had given to his difficulties:

> **Simon:** *'. . . . {5 secs} I wiz tellin everybody to see what their reaction would be (okay) to see whether they thought a wiz no well or it wiz somebody trying to noise me up (mhmm) and . . . . {4 secs} everybody bar one person said a need tae get ma heid seen tae (right okay) basically (uhu)'*

> **Researcher:** *'And how did you feel about that?'*

> **Simon:** *'Mmmm . . . . . {5 secs} a don't know (mhmm) a dunno very . . . {3 secs} alone (mhmm) it's as though everybody were aw saying that he's no right (right) an . . {2 secs} am gone it's fine, there's nuttin wrong wi ma heid (mhmm).'*

<p style="text-align:right">Transcript 5, Page 9, Line 327</p>

James also talked about his friends being the people who noticed his behaviour, resulting in them seeking help for him:

> **Researcher: '*Emm and these things had been happening for a wee while?'***
>
> **James: '***Aye, aye, it all just builded up kind of a thing (right, right, I see.) Just slowly, but then a couple of my friends, they hadn't experienced what I experienced, but they experienced a wee bit it just wasnae as bad, and they kind a noticed and they said to my brother cos it was the day I was out in the car, and I stopped at, you know [Named Park] the park? (huh huh) I stopped there and I think, they told me this after, like a while after it, like we had to go and get [Named Brother], that's my brother (huh huh) they had to go and get him to go and get me cos they told him that I wasnae right (right ok).'*

<div align="right">Transcript 3, Page 4, Line 112</div>

Even when family and friends had not been involved in early experiences, the majority of participants described the support they received once they had been in contact with services. The following quote from Joe illustrated the influence his girlfriend had on him:

> **Joe:** '*Em, yeah my mum and dad supported me quite well. (mhmm) My dad was there most times, my mum was there most times, the, the thing that really mattered to me was my girlfriend came up (right) and saw me every single day (mhmm) eh ...{1 sec} sh .. she was there every single lunchtime (mhmm) which was the most helpful thing (right uhu) I think to be honest. Eh . . . {3 secs} just for obvious reasons (yeah uhu).'*

<div align="right">Transcript 9, Page 9, Line 308</div>

It was sometimes difficult for participants to involve family and friends, particularly if they had been living independently at the time of coming into contact with services. For many, the E.I. service helped orchestrate meetings between individuals and families, with positive results, as described by Danny:

Researcher: *'In terms of your recovery would that be important part of it, telling your mum and dad?'*

Danny: *'Emm.   . {2 secs} yeah I think it, yeah, yeah, I think it was emm.   . {2 secs} because it felt different from the first time I was in hospital when it was just me (hmm hmm) I felt just so lonely.   . {2 secs} to the second time I was in hospital it felt, just.   .   .   . {4 secs} a big difference that I was going home to people, rather going home to.   . {2 secs} just my lie (yeah huh huh) emm, I had people there. Yeah, I think it was cause not only did I have the service there but I had.   . {2 secs} my mum, dad and family because the services close at whatever time (yes) but my folks were always there.*

<div align="right">Transcript 2, Page 11, Line 396</div>

In general, narratives reflected the positive involvement of family and friends, although there was recognition by some participants that this involvement had not always been easy.

Loss

The notion of loss was mentioned by all participants, often in several places throughout the narratives. Many talked about losing "chunks" of their lives, perhaps whilst in hospital. Others felt that they had lost a bit of the person they were before they had been unwell. The language used by nearly all participants reflected painful feelings associated with the process of acceptance, adjustment and changes in identity. The following excerpt from Amy highlighted this well:

Amy*:' I just felt as if like .   .   . { 3 secs} know how like, the original me was like standing there and the new me standing there and I'd look, know how how mentally, I would be looking at this, the way I used to be (hmm hmm) and lookin, I wouldnae have said that I wouldnae have acted like that*

and I wouldnae have done that you know what I mean, (huh huh) and see now it's just, see trying to, trying to find who I was to who I am now (hmm hmm) it's as if am grieving (right ok) it's as if I've got a lot of grief for the old me (right huh huh).'

Researcher: *'**That's a really powerful way of seeing it**. (hmm hmm). **So you feel like you've lost some of the old you?** (aye) **hmm hmm. Do feel like/***

Amy: *'It's as if the old me died, if you know what I mean? (**hmmmm hmm hmm**)*

Transcript 6, Page 14, Line 487

Christine also reflected on the changes she experienced as a result of being unwell. In her narrative it became apparent that she felt that she had lost opportunities, meaning she had to change her plans following her time in hospital:

Christine: *'Yeah, well before I went in I had all these plans. I had a job and I was going to move to London and emm . . . . {4 secs} and when I was in hospital I couldn't do that because it was supposed to be starting when I was there (right) so when I got out I felt like everything had just fallen apart and . . {2 secs} I had just left uni and all my friends, you know, kind of moved away (hmm hmm) so it was gone from being at uni to after that was a massive change and I thought I would never get back to . . {2 secs} you know, I felt like my whole life had . . {2 secs} just changed (hmm hmm) obviously it did but . . {2 secs} emm still now it was completely different to what it would have been like if I hadn't been ill but . . {2 secs} (hmm hmm) I was emm . . . {3 secs} am getting there (hmm hmm).*

Transcript 1, Page 16, Line 559

The way in which many participants talked about losses suggested a feeling of resentment about what had happened to them. Many felt that the timing of their difficulties had occurred at a point in their lives where they had many plans,

resulting in changes to future plans. William reflected on his resentment and regret at lost opportunities:

> **William:** '*I suppose, and it's a period of, it will still be a period of my life that to an extent lost I suppose, (hmm hmm) emm it's how you compensate I suppose, (hmm hmm) and whether you kind of, you can lose more time I suppose dwelling on it than if you just try and make the best of it (hmm hmm) you know? I won't say the time you have left cos that sounds very terminal, (no I know what you mean, I know what you mean) emm but obviously you've got the rest of your life to kind, to try and just be happy (huh huh) and you're as well going for that (absolutely) then I mean it is, I mean I was what I think I was I'm 24 now, emm so I think I became ill when I was 22 (right) so I'm still relatively very young and it was probably a year that I could probably have enjoyed, had all these different factors or I hadn't had maybe some undercurrents that led to it (yeah) emm, that's, you can't, there's no time machine or anything like that you know (huh huh) so it's just the case of well you can still just enjoy that (sure sure) emm, so I don't think I will ever be completely free of any kind of regret or maybe emm negative feelings towards it.*'

<div align="right">Transcript 4, Page 18, Line 628</div>

The discussions about loss usually led onto how the participants had managed to recover and re-build after their experiences. All talked about this process of 're-building' as a key component of recovery.

Re-Building

This theme emerged across all narratives no matter where the participants considered themselves to be in terms of recovery and returning to 'normal' life. Interestingly, despite participants recognising the support they had received from family, friends

and services, they all considered the process of re-building as something they ultimately had to take on themselves. This was captured by William:

> **William:** '*It's kind of a physically and emotionally draining to where you would just be happy to never to go through it ever again (hmm hmm) emm, and from that point onwards emm having people to understand what actually went wrong, how it could potentially go wrong and how to avoid it going again is, is very relieving (hmm hmm) I think (hmm hmm) emm and I think if you, I think you have to make of it what most you can (hmm hmm) you know you've got to kind of, if they're giving you an opportunity to try and fix it then it's up to you how much you want to go and try and do that (hmm hmm)*'.

<div align="right">Transcript 4, Page 13, Line 459</div>

The E.I. service seemed to provide participants with a construction of their experiences that made it easier to understand what had caused their experiences, and how they would be able to avoid them from occurring again. This gave participants the opportunity to use this knowledge and re-build from what they had learned about themselves and their experiences.

There were varied descriptions of how re-building happened, and what each person had learned about themselves. The majority of the participants felt that they had become a different person, often describing themselves as stronger, more resilient and learning about the supports that they had. Amy captured this well:

> **Amy:** '*You see I know this is gonnae sound mad bit am kind of a glad in a way I did become ill (right) because it's changed me (huh huh). It's no made me a better person but I feel as if it's kind of a opened my mind more (right) to see with, this is gonnae sound mad to you!*'

Researcher: '*No, I think it's really fascinating, that's really interesting to hear.*'

Amy: '*It's opened my mind more and it's made realise more and realise what I've got and (right) do you know what I mean? (yep hmm hmm) And all the bonds that I've got with my family, E.I. Service (huh huh) and everybody. It makes you realise who's there for you and who's no (huh huh).*'

Transcript 6, Page 17, Line 610

Re-building seemed to take on different meanings for the participants. For some, the re-building of social relationships and interpersonal contacts were the most important tasks, and for others re-building meant taking on an active, independent role in keeping well and looking after themselves. Amy talked about how she felt about trying to become more independent, and less reliant on her parents:

Amy: '*Well before I was really reliant on my parents, (right) very reliant (huh huh) financially, emotionally and recently I've been trying to like cut the ties (hmm hmm) and that's so hard cause I miss them (absolutely) do you know what I mean (hmm hmm) I don't think they understand (hmm hmm).*'

Researcher: '*In what way?*'

Amy: '*I don't think, I don't know if they will understand that I'm just trying to be who I am (hmm hmm).*'

Researcher: '*So It's quite difficult to do that?*'

Amy: '*hmm hmm. I'm trying to be who I am and no be the needy daughter, do you know what I mean?*'

Transcript 6, Page 15, Line 535

The process of re-building identity was apparent throughout some participants' narratives and seemed to reflect the acceptance of change in identity following the experiences which led them into contact with E.I. services.

Discussion

The starting point for this study was to explore the experiences of people with a recent FEP in the context of an E.I. service. The initial focus was on how people talked about the impact of this on their sense of identity, and how identity was expressed in relation to recovery following a FEP. The understanding of recovery was taken in the context of a service-user defined model, where the emphasis was not about the consideration of clinical outcomes but rather a subjective journey through experiences and interactions with services. Participants' stories developed from interactions with family, friends and services and were often told through complex and fragmented narratives. The analysis of the narratives revealed themes which related to the experiences of FEP, becoming involved with an E.I. service and re-building following FEP. Following initial descriptions about the experiences which led participants into contact with services, participants reflected on the journey of recovery which involved development of awareness and acceptance, experiences of shame, involvement of family and friends, experiences of loss and the process of re-building. The background of this journey was provided by the involvement of the E.I. service, which gave the participants a context in which to create an understanding of their experiences. The process of telling their stories seemed to help many participants make sense of their experiences. All participants organised their narrative with a clear beginning, middle and end which often featured characters who had influenced the person's journey. These characters usually featured throughout the stories, being mentioned in relation to many of the emerging themes. For example, parents were typically described throughout the narratives, being involved in several themes whereas psychiatrists or nurses tended to feature later on in participants' stories.

The process of explaining experiences meant that many of the themes were closely linked and overlapped with one another, and there were several which emerged as continuums. Feelings of shame and loss were apparent throughout the experiences of FEP, the processes of acceptance and the tasks associated with re-building. Much of the participants' narratives were embedded in social interactions, often providing the context for the feelings of shame. In particular, the construction of identity in the context of social relationships and the meanings assigned to the experiences of FEP appear to reflect perceived negative changes in identity. The theme of shame overlapped closely with the family and friends theme. Participants who felt most ashamed following their experiences tended not to involve people in their experiences, in particular their friends. Recovery for them seemed to be linked with wanting to 'get back to normal' and pretending nothing was wrong. From the narratives there was a strong sense that shame was associated with the stigma of diagnosis, and also about what others might think about them following their experiences. This reflected Birchwood et al.'s (2006) findings that following FEP a substantial proportion of individuals also experienced social anxiety. Social Rank Theory (e.g., Gilbert, 2000) can be used to explain the associated feelings of shame and stigma following psychosis. According to the theory, acceptance into social groups is linked to the ability to be attractive to others, and be chosen and/or included. Those who are deemed unattractive risk being avoided or excluded by the social group. The experiences of psychosis and stigma highlight this risk of being avoided or excluded, prompting many to feel anxious in social interactions as they try not to be deemed as 'unattractive' by the social group.

Shame also seemed to overlap with awareness and acceptance themes. From their work with patients with FEP, Miller and Mason (2005) suggested that the challenging processes of acceptance and adaptation to the diagnosis of psychosis brought painful feelings of shame and guilt. This seemed to be the case for those participants who struggled with the acceptance of an alternative explanation for their experiences (i.e., diagnosis of FEP). For many, the experiences of FEP, together with the stigma associated with a diagnosis, resulted in participants describing feelings of fear, hopelessness and shame. Miller and Mason (2005) posited that these feelings were related to internalised societal ideals and values, which were often compromised following an individual's experiences of FEP. This seemed apparent for many participants in the current study, where shame was associated both with the actual experiences of FEP and the meanings attached to receiving a diagnosis.

At the other end of the continuum, there were some participants who valued the involvement of family and friends. They emphasised the importance of having others play a part in their recovery, usually by providing support and also by being watchful for signs of potential relapse. These findings reflect similar themes identified in previous studies on social interactions in FEP (MacDonald et al., 2005; Mackrell & Lavender, 2004). MacDonald et al. (2005) found that participants valued being with people who were understanding and receiving support from family and/or other young people who had also experienced psychosis. The participants described feeling and being perceived as different, yet through building new relationships in the recovery they were able to adapt.

The narratives of the participants demonstrated how difficult the process of awareness and acceptance was. This study found that participants generally found the diagnosis of FEP a helpful explanation eventually, providing them with a context in which to understand their difficulties and enabling them to re-build following these. However, the process of acceptance seemed challenging for both individuals and service providers, where the two perspectives were often difficult to integrate. Much of the struggle participants described seemed related to explanation that their experiences were part of FEP, and it was observed throughout the narratives that the language participants used to talk about their experiences changed as they became involved with services. Initially there was little mention of medically influenced language (such as describing experiences as symptoms); but this changed as the narratives unfolded. It appeared that this incongruence in understanding came about through much of the language used by services, which did not match with the participants' vocabulary.

Loss and re-building were often described as two ends of the same spectrum. Participants talked about their feelings of loss in two contexts: loss of identity and loss of opportunity. For many, rebuilding had to occur in response to these losses and was a key part of the recovery journey. It was apparent from the stories participants told about their recovery that the process of rebuilding involved establishing a new sense of identity, taking on an active role in recovery and re-establishing their lives in relation to the path they had been on before the FEP.

Clinical Implications

The identified themes have implications for clinical practice, especially in relation to the involvement of E.I. services. Through telling their stories, participants were able to communicate their experiences of psychosis, enabling them to make sense of their experiences and understand them in the context of FEP. By understanding the stories behind the experiences, services can also begin to make sense of them, thus creating a shared understanding. For example, understanding the emergence of paranoia in the context of a person's difficulties with work colleagues might provide a mutually agreeable understanding that both individual and service provider can share. Through their narratives, participants in this study demonstrated the differences in language used as their journey progressed. Initial descriptions of experiences involved few clinical terms or explanations. In order to facilitate a shared understanding, it would be important for service providers to be sensitive to the language used to provide an explanation for service-users' experiences, and to try to align themselves with the language used by service-users.

The struggle with acceptance, as reported by many participants, seemed to reflect the difference in explanations of the person's experiences. Developing a shared explanation about FEP would seem an important task for services. The use of formulation, as favoured by Clinical Psychologists, would lend itself to enabling an understanding generated from the individual's unique experiences and might aid acceptance. It might also be useful to keep in mind therapeutic approaches for this experience. For example, interventions based on Acceptance and Commitment

Therapy (Hayes, 1999) might be useful for those individuals who are describing their struggle with acceptance.

For participants in this study, their experiences were embedded within social interactions. Social relationships and interactions with family, friends and services were a thread which ran through the narratives, linking many of the emergent themes. This indicates the importance of services seeing the service-user in the context of their social network, part of the wider system operating around them. Participants described the involvement of family and friends in their journeys in mostly positive ways (although some chose not to involve others in their journey). It would make sense for services to consider those people in the individuals' wider social network when planning care and interventions for them.

Limitations

The findings of this study are based on the experiences of nine participants, and the researchers' own interpretations of the data. It is acknowledged that this provides only one perspective from any number of possible interpretations, given the amount of rich and varied data obtained. The findings do not represent an exhaustive or absolute representation but rather seek to present the data in the context of the research questions. Rather than establishing categories saturated by the data, '*theoretical sufficiency*' suggests that there should be categories suggested by the data. The data from the nine transcripts in this study were used to develop the categories, which were then elaborated, further developed and challenged into the

emergent themes, therefore resulting in theoretical sufficiency being achieved. It is acknowledged that the sample could be seen as self-selecting, perhaps only reflecting the experiences of those who were willing to be involved in the interview. However, in order to maximise transparency excerpts from the narratives were provided to explain and justify the interpretation. This also allows for the reader to construct their own interpretations. In order to ensure validity the process of analysis and the development of themes was overseen by an experienced qualitative researcher, and followed established techniques. Validity could have been strengthened by through methods such as triangulation and respondent validation. Although Grounded Theory methodology was employed in the analysis of data it is acknowledged that other approaches could have been used (for example, Narrative Analysis or Interpretive Phenomenological Analysis).

Conclusions

This study represents the first qualitative exploration of service-users' experiences of FEP in the context of an E.I. service. The emergent themes demonstrated a journey through FEP which began with a build-up of experiences, leading to awareness and acceptance of a diagnosis. Family and friends were a common theme overlapping the experiences of shame and loss, with the process of re-building finally occurring. Through their narratives participants told the story of their recovery in the context of the E.I. service, documenting the beginning, middle and end of their journey through FEP. Being aware of this trajectory enables services to align themselves with the individual, providing support as appropriate wherever they might be in their journey. This study provides an initial understanding of the predominant experiences of

recovery for service-users within an E.I. setting, from which further qualitative studies could be developed. It would be interesting to develop an understanding of people's experiences of recovery following FEP in other service settings. Given that the evidence in support of E.I. services is still being developed it would be useful to gather data on the experiences of those not involved with E.I. services so as to provide a comparison.

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CHAPTER 3

ADVANCED CLINICAL PRACTICE I – REFLECTIVE CRITICAL ACCOUNT

What can Psychology contribute to services for an accommodated young person with atypical autism and challenging behaviour?

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin.Psy.)

Abstract

This reflective account describes the difficulties I faced when working with a young boy with atypical autism and challenging behaviour. During my placement with a CAMHS team I was asked to become involved with a young boy, who was accommodated, and had never received any input from psychology services. Although the staff team coped well with his difficulties, he was presenting with increasingly challenging and self-injurious behaviours which caused understandable stress amongst staff. Using several models of reflection to guide my learning, I have been able to make sense of my experiences, actions and reactions. Within this account I describe reflections on specific incidents using Gibbs' model of reflection (1988). For longer-term reflections over the course of my involvement with the case, my learning has been guided by Rolfe's framework for reflexive practice (2001). My actions and reflections during this case were also influenced by professional practice guidelines on working with young people with Autism Spectrum Disorder (ASD) and guidelines on supporting people with challenging behaviour. From my initial anxieties about working with such a complex case, to the understanding of my reactions to specific situations during my involvement with the young person, this reflective account brings together what I have learned both professionally and personally during my clinical practice.

CHAPTER 4

ADVANCED CLINICAL PRACTICE II – REFLECTIVE CRITICAL ACCOUNT

Team Work: How do Clinical Psychologists find a place in multi-disciplinary teams?

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Abstract

This reflective account describes my experiences working in a Community Mental Health Team (CMHT) during my final placement. I reflect on a range of experiences which made me think about my role within the team, and what contribution I could make as a Clinical Psychologist. I also reflected on the wider service and professional issues facing Clinical Psychologists, particularly in light of recent Governmental policy documents and ways of working. I describe how my understanding of these policies and strategies has changed over time, where my learning has been shaped not only by reading but by actually working within the systems and procedures. My reflections in this account are guided by two models. Firstly, Schon's distinction between reflection-in-action and reflection-on-action, which I use to enhance my learning about specific experiences. For my reflections over the longer term, I use Rolfe's Framework for Reflexive Practice (2001) to make sense of my feelings, actions and reactions about more general experiences of working within the CMHT. My reflections over time have also been guided by professional standards and guidelines. This account outlines my learning about the skills needed to be competent not only working individually as a Clinical Psychologist but also as a member of the team. On reflection I have found that I have needed to be flexible, adaptive and open minded about the role of Clinical Psychologists in teams, and also to have the confidence in my own skills to highlight the differences between psychology and other disciplines.

APPENDIX 1.1

Appendix 1.1 – Author Guidelines for Submission to Journal of Qualitative Research In Psychology

Full details at: http://www.tandf.co.uk/journals/authors/uqrpauth.asp
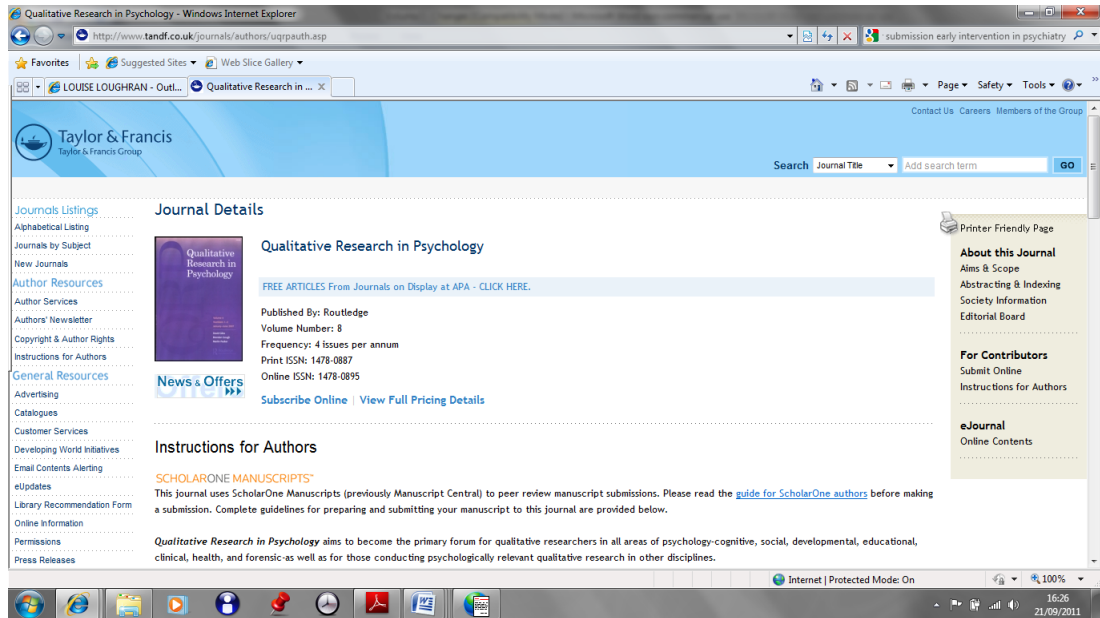
Qualitative Studies Appraisal Tool (Boyd & Gumley, 2005)

Title of paper reviewed: …………………………………………………………….

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1. How was the study *sensitive to context* in the following?

Relevant literature and empirical data:

- How were the understandings created by previous investigations, using similar methods and topics considered? (Yardley 2000, p.219)
- How did the work link to the work of others, including quantitative/empirical research?

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Initial Sampling:

- How was the original sample selected at the 'point of departure'? (Charmaz, 2003, p.85)
- **GT AGREED TENET:** Did sampling follow that, "initial decisions are not based on preconceived theoretical framework" (Glaser & Strauss, 1967, p.45)
- **GT AGREED TENET:** How were sampling and interview questions flexible and adapted to emergent theory as it evolved i.e. theoretical sampling? (Dey, 1999, p.5)

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Sensitivity to Sociocultural setting:

- How was the study sensitive to the language, social interaction and culture of participants? (Yardley, 2000, p 220)

- How was the social context of the interaction between researcher and participant considered (e.g. gender, status as mental health professional) and how was this incorporated into the study design? (Yardley, 2000, p 220)

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Participants' perspectives:

- To ensure sensitivity to different perspectives how were procedures for eliciting and incorporating the opinions of the population being studied or other relevant groups considered?

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Ethical issues:

- How did the researcher address ethical issues raised by the study e.g. informed consent or confidentiality or how they have handled the effects of the study on participants during and after the study? (CASP, 2002)

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2. How was _commitment_ and _rigour_ demonstrated?

Commitment through an in depth engagement with the topic:

- A clear immersion in the relevant literature.

- Competency and skill in method shown (Yardley, 2000, p221).

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Constant Comparative Analysis:

- **GT AGREED TENET:** How did the researcher constantly compare similarities and differences between instances, cases and concepts, to ensure that the full diversity of the data is explored? (Hayes, 1997, p.261)

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Negative case analysis:

- How was a case or instance used to challenge an emergent theme? (Hayes 1997, p270)

- Were cases presented which did not fit an emerging conceptual system?

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Coding:

- **GT DEBATE:** How did the research progress from open coding, i.e. "coding the data in every way possible…for as many categories that might fit", toward selective coding i.e. delimiting coding to the only variables that relate closely to the "core" variable of the emergent theory (Glaser, 1978, p.56)?

- **OR** using a preconceived coding paradigm e.g. axial coding as described by Strauss & Corbin (1990, p.96)?

- Were examples of theoretical codes provided?

- **GT AGREED TENET:** How were memos used in the allocation of codes (Dey, 1999, p.11)?

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Data collection and depth/breadth of analysis:

- **GT AGREED TENET:** Did analysis start with the data? (Charmaz, 2003, p.87).

- How were efforts made to collect data from a variety of sources i.e. triangulation (Barbour, 2001, p.1117)?

- How was multiple coding used i.e. cross checking of coding strategies and interpretation of data by independent researchers (Barbour 2001, p.1116)?

- How was variation built into the theory e.g. not based on a single example (Corbin & Strauss, 1990 p.10)?

- **GT AGREED TENET:** How did the synthesis provide "readily apparent connections between data and lower and higher level abstractions of categories and properties" (Glaser & Strauss, 1967, p.37)?

- **GT DEBATE:** Were interviews transcribed? (Charmaz, 2003, p.87 para 3).

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Theoretical saturation:

- **GT AGREED TENET:** How was theoretical saturation i.e. the non-emergence of new properties categories or relationships demonstrated? (Dey, 1999, p.8) Consider a proclamation vs. proof.

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Validation:

- **GT DEBATE:** How were views of participants validated or emergent themes/theory feedback to participants, i.e. respondent validation?

- OR How was the unsuitability of this technique explained?

- How was analysis/themes/theory opened to the scrutiny of others?

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3. How _transparent_ and _coherent_ was the research?

Clarity and power of description/argument:
- How clear was the narrative of the research?

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Transparent methods and data presentation:
- Detailing aspects of data collection process.

- Rules for coding data e.g. by presenting excerpts of textual data.

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Reflexivity:
- **Transparent through open reflection on how experiences or motivations or constraints of researcher may have influenced process, in both interactions with participants and with data at a theoretical coding level.**

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Coherence by showing a fit between theory and method adopted:
- A justification of choice for grounded theory including an understanding of its philosophical basis. In particular did they present a position on the debate of 'actively finding what is there' (i.e. social constructivist), vs. the 'emergence or discovery' (positivistic) of theory?

- How did the study demonstrate a grounding in the philosophy of the method and a discussion on the selection of method?

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4. Was the _impact_ and _importance_ of the research shown?

Theoretical (enriching and understanding):

- **GT DEBATE:** Was a 'grounded description' or a 'grounded theory' produced? (Charmaz, 2003, p.101).
- Likelihood of stimulating further studies or explaining a phenomenon.
- A novel insight on a phenomenon under study and *not* a replication of previous findings.
- Directions for future research.

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Sociocultural:

- Highlight the impact of wider socio-cultural processes on a phenomenon e.g. analyses of socio-political function of individualistic health promotion rhetoric can help to explain why the ideal that it is possible to maintain health through personal endeavour remains popular despite evidence that individual behaviour has much less impact on health than other factors such as socio-economic status.

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Practical (for community, policy makers; health workers):

- Meeting objectives of analysis
- Importance for intended community.
- New practical applications from research.

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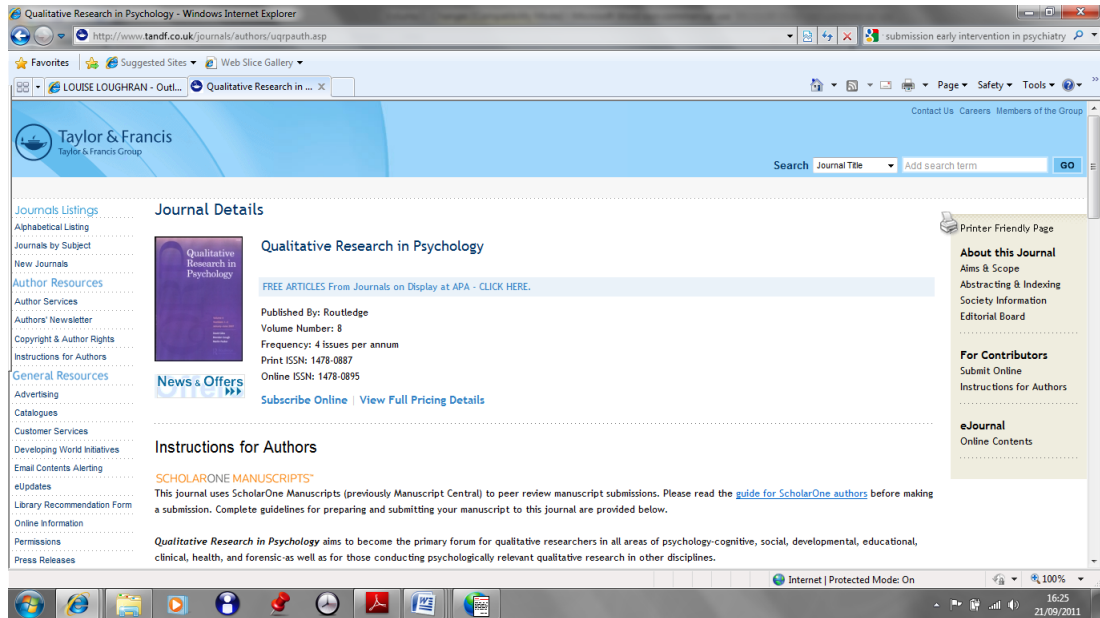……

Please note below if the papers reviewed was of particularly high quality in any of the areas above or in other additional areas.

Appendix 2.1 – Author Guidelines for Submission to Journal of Qualitative Research In Psychology

Full details at: http://www.tandf.co.uk/journals/authors/uqrpauth.asp

EVIDENCE OF ETHICAL APPROVAL

WoSRES
West of Scotland Research Ethics Service

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Mrs Louise Loughran
Trainee Clinical Psychologist
Section of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

Date	22 Sep. 11
Your Ref	
Our Ref	
Direct line	0141 211 2123
Fax	0141 211 1847
E-mail	Liz.Jamieson@ggc.scot.nhs.uk

Dear Mrs Loughran

Study Title:	**A Qualitative Exploration of Recovery following First Episode Psychosis**
REC reference number:	**10/S0701/67**

Thank you for your recent letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date	
Protocol	1-July 2010		
GP/Consultant Information Sheets	1	06 October 2010	
Response to Request for Further Information		18 November 2010	
Investigator CV		12 October 2010	
CV for Professor Andrew Gumley		02 September 2009	
Participant Information Sheet	Version 2	18 November 2010	
REC application		11 October 2010	
Participant Consent Form	Version 2	18 November 2010	
Interview Schedules/Topic Guides	1-July 2010		
CV for Suzy Clark		10 May 2010	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website. You are invited to give your view of the service that you have

received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S0701/67	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Liz Jamieson

Committee Co-ordinator

On behalf of EoinMacGillivray, Vice Chair

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: Dr Erica Packard, NHS Greater Glasgow and Clyde

West of Scotland REC 3

Attendance at Sub-Committee of the REC meeting on 03 December 2010

Committee Members:

Name	Profession	Present	Notes	
Mrs Bernadette Campbell	Primary Care Support Nurse	Yes		
Mr EoinMacGillivray	Lay Member – Vice Chair	Yes		
Dr Stephen Noble	Consultant Anaesthetist	Yes		

Also in attendance:

Name	Position (or reason for attending)	
Mrs Liz Jamieson	Committee Co-ordinator	

APPENDIX 2.3

EVIDENCEOF MANAGEMENT APPROVAL

NHS

Greater Glasgow and Clyde

Coordinator/Administrator: Dr Erica Packard/Ms Elaine O'Donnell
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

14 December 2010

Dr Suzy Clark
Consultant Clinical Psychologist
Esteem Glasgow North
21-23 Hydepark Business Centre
60 Mollinsburn Street
Glasgow G21 4SF

NHS GG&C Board Approval

Dear Dr Clark,

Study Title:	A Qualitative Exploration of Recovery following First Episode Psychosis
Principal Investigator:	Dr Suzy Clark
GG&C HB site	Esteem Glasgow North
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN10CP389
REC reference:	10/S0701/67
Protocol no:	Dated July 2010
(including version and date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

    1.   **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

        a. During the life span of the study GGHB requires the following information relating to this site

            i. Notification of any potential serious breaches.

           ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

    2.   **For all studies** the following information is required during their lifespan.

        a. Recruitment Numbers on a quarterly basis

Delivering better health

APPENDIX 2.4

PARTICIPANT INFORMATION SHEET

A Qualitative Investigation of Recovery Following a First Episode of Psychosis

My name is Louise Loughran and I am a Trainee Clinical Psychologist, working under the supervision of Prof. Andrew Gumley. We would like to invite you to take part in a research study which is being carried out as part of my Doctorate in Clinical Psychology. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the research about?
The research is being carried out by Louise Loughran from the Department of Psychological Medicine at the University of Glasgow. This study is designed to develop an understanding of recovery in people who have experienced a first episode of psychosis and have been involved with an Early Intervention Service. This kind of research can help mental health services to understand the needs of people who have experienced mental health problems, and to develop appropriate services that aim to help people recover.

Who is being asked to take part?
We are asking people who have experienced a first episode of psychosis and who have been involved with an Early Intervention Service to take part in this research study. The Esteem Glasgow Team is an Early Intervention Service.

Why have I been asked to take part?
You have been referred to us by a member of Esteem Glasgow Team who responsible for your care (e.g. Consultant Psychiatrist, Clinical Psychologist or Nurse).

What are you asking me to consent to?
Consenting to participate in this study means that you will meet with a researcher at the Esteem Glasgow offices to complete an interview describing your experiences. Depending on how long this interview takes you might meet with the researcher on up to 3 occasions.

What will I be asked to do if I agree to take part?
You would have the opportunity to meet with the researcher to ask questions about the study and discuss taking part before you agreed to be involved. If you decide to participate, we would arrange to meet with you at Esteem Glasgow Offices to talk about your experiences of recovery and your involvement with the Esteem team. You would be asked to tell us a little about how you came into contact with Esteem in the first instance, and a little about the problems you were experiencing at the time. We would also ask you about how the service responded to you and what your main sources of support have been, as well as what you feel you have learned from your experience of being involved with Esteem. This meeting will last approximately 1 hour and the interview will be recorded.

Will my information be confidential?
All the information you provide will be treated confidentially. All recordings, transcriptions and other data will be stored in a password protected computer. The interview will be fully-anonymised when it is transcribed. This means that it will not include your name, the names of people, schools or jobs you may mention or any other information which could identify you. Once the interview is transcribed, the recorded audio copy will be destroyed. The

transcribed and anonymised interview and questionnaires will then be analysed by the research team. I will ask for your consent to use quotations from our conversation in reports about the research, these will also be anonymous. The information obtained during this research will remain confidential and stored within a locked filing cabinet. The data are held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. If you share information that makes the research team concerned for your safety or the safety of other people, we may be required to tell others involved in your care (e.g. your key-worker or psychiatrist). We will always notify you beforehand if we are going to do this, and explain why.

What happens to the consent form?
To ensure anonymity and confidentiality, the consent form will be kept separately from the transcribed interview in a locked filing cabinet within the Section of Psychological Medicine.

What are the benefits of taking part?
In general, research improves our knowledge of what people's difficulties are and what can do to help overcome these and improve people's lives, so your participation will help increase our knowledge of areas and potentially improve treatment for others in the future.

What happens if I decide not to take part?
Nothing. Taking part is entirely up to you. If you do not wish to take part it will not affect any treatment that you currently receive. Also, if you do decide to take part, you are able to change your mind and withdraw from the study at any time without it affecting your care either now or in the future.

Can I change my mind?
Yes. You can change your mind at any time and do not need to give a reason. Your NHS care will not be affected in any way.

What will happen to the results of the study?
The results will be published in a medical journal and through other routes to ensure that the general public are also aware of the findings. You will not be identified in any report/publication arising from this study.

Who has reviewed the study?
The study has been reviewed by the University of Glasgow to ensure that it meets standards of scientific conduct. It has also been reviewed by the West of Scotland Research Ethics Committee (3) to ensure that it meets standards of ethical conduct.

What if I have a complaint about any aspect of the study?
If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms is also available to you.

Contact for Further Information

If you have any questions you would like to ask, please do not hesitate to get in contact.

Chief Investigator	**Academic Supervisor**
Louise Loughran	Prof Andrew Gumley
Trainee Clinical Psychologist	Professor in Clinical Psychology
Psychological Medicine	Psychological Medicine

University of Glasgow
Gartnavel Royal Hospital
Glasgow
G12 0XH
Email : l.loughran.1@research.gla.ac.uk
Telephone Number: 0141 211 0607

University of Glasgow
Gartnavel Royal Hospital
Glasgow
G12 0XH
Telephone Number: 0141 211 0607

PARTICIPANT CONSENT FORM

Title of Study: A Qualitative Exploration of Recovery Following a First Episode of Psychosis

Contact Address: <u>Department of Psychological Medicine</u>
<u>Academic Centre</u>
<u>Gartnavel Royal Hospital</u>
<u>1055 Great Western Road</u>
<u>Glasgow</u>
<u>G12 0XH</u>

Please Initial Box

1. I confirm that I have read and understood the information sheet about the study (dated 18/11/10, version 2).   ☐

2. I confirm that I have had an opportunity to consider the information, ask questions about the study, and have had these answered satisfactorily.   ☐

3. I understand that my participation in the study is voluntary and that I am free to withdraw from the study at any time, without giving any reason, and without my medical care or legal rights being affected.   ☐

4. I understand that it may be difficult or upsetting to talk about my experiences, and that I will have access to professional support if this is required.   ☐

5. I understand that sections of my medical notes may be looked at by the research team where it is relevant to my taking part in the research. I give my permission for the research team to have access to my records.   ☐

6. I understand that one of the interviews used in this research study will be recorded on an audio recording device as described in the Participant Information Sheet dated 06/10/10, version 1.   ☐

7. I give consent for the research team to use quotations from the transcribed interview in reports about the research.   ☐

8. I agree to participate in the above study.   ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____
_____
Name of Person taking consent   Date   Signature

APPENDIX 2.6

INTERVIEW SCHEDULE

Aims:

To develop an understanding of how recovery after a first episode of psychosis unfolds in the context of an Early Intervention Service.

Structure of Interview:

Part 1: [TIMEFRAME: Consider first few months]

In this interview I would like to gain an understanding of your experiences of recovering from psychosis.

Can you tell me a little about how you came in contact with ESTEEM in the first instance and a little about some of the problems you were experiencing at the time?

> Probe: Specific experiences such as first contact with the service, how this came about, the person's initial expectations and reactions. Who was around at the time? Sources of support?
>
> Examples of kinds of problems and experiences that lead to first contact.

How did the service respond to you at the time?

> Probe: Who were your main contacts within the service? How did they respond to you? What was helpful about how they responded at that stage? What was unhelpful? How did you react? How did you feel?

_____

Part 2: [TIMEFRAME: Consider changes over time]

How have your feelings changed over time?

> Probe: Using participants own language explore how their feelings and experiences have changed over time. Explore recovery in terms of changes in feelings about self and others, feelings about the future.

Who have being your main sources of support during this time?

> Probe: Range of supports as described by participant including family and friends. Explore how support from service has changed over time. Support participant in reflecting how this has impacted on their own recovery?

Part 3:[TIMEFRAME: Here and now]

This question really focuses the participant on the here and now enabling them to move away from reflecting on their past experiences.

What do you feel that you have learned from the experiences that we've been talking about today?

Secondary questions:

Is there anything that the service could learn?

Is there anything other service users could learn?

Is there anything family and friends could learn?

MAJOR RESEARCH PROJECT PROPOSAL

A Qualitative Exploration of Recovery Following First Episode Psychosis

Abstract

Specialist Early Intervention (E.I.) services are becoming increasingly accepted as the most effective way of working with people experiencing first episode psychosis. Although there have been a wealth of studies looking at the clinical outcomes of E.I. services, there remains relatively little research on the subjective experiences of people following a first episode of psychosis. Outcome studies have typically employed quantitative methods, collecting data on standardised measures of symptoms, assessments of overall functioning and quality of life. The results from clinical outcome studies remain inconclusive, (although it has been demonstrated thatE.I. services reduce hospital admissions, improve negative symptoms and reduce relapse rates). More recently there has been a steady increase in the number of qualitative studies which specifically explore the subjective experiences of people with first episode psychosis and their wider social networks, but there remains a very limited number of studies which have been specifically conducted into E.I. services. Recovery in the context of an E.I. service is an area which has not yet been thoroughly researched, therefore the overall aim of this study is to explore the individual's experiences of recovery following a first episode of psychosis, in the context of a specialist Early Intervention Service. It is proposed that a grounded theory study would provide the openness and flexibility needed to explore in-depth the individual experiences of people involved with an E.I. service.

<u>Introduction</u>

Early Intervention

In the last two decades the provision of Early Intervention (E.I.) services for people with first episode psychosis has become increasingly accepted as the most effective way of working with first episode psychosis (McCrone et al., 2010, Gafoor et al., 2010). In general, specialist E.I. services operate from a model of early detection and phase-specific treatment, which differentiates them from standard mental health care. The early detection element focuses on identifying those people in need of treatment for a first episode of psychosis and reducing the length of time psychosis remains untreated (known as the Duration of Untreated Psychosis or DUP). It has been established that longer DUP is associated with increased severity of symptoms, poorer responses to treatment and increased relapses in future (McGorry et al., 1996, Larsen et al., 2001, McGlashan et al., 1999). In their meta-analysis Marshall et al., (2005) concluded that a prolonged DUP had a negative effect on a person's recovery. It has also been suggested that the longer psychosis is untreated, the more the damage can be done to an individual's relationships, social networks and educational/career achievements, especially given the typically young age at which first episode psychosis usually emerges. Phase-specific treatments can be defined as treatments (psychological, social or physical) provided by E.I. teams for people in the early stages of psychosis (Miller & Mason, 1999)Phase specific treatments can be targeted at those people at risk of psychosis (prodromal), and those who have recently experienced their first episode of psychosis (Marshall et al., 2005).

Early Intervention services for first episode psychosis are now beginning to be established throughout Europe, America and Australasia. Killackey and Yung(2007) site a number of studies which have demonstrated that E.I. services offer improved

clinical outcomes, reduced hospital admissions and cost effectiveness of treatment, compared to that of standard care in community mental health teams. Preliminary evidence from two randomised controlled trials conducted to evaluate the effectiveness of outcomes of E.I. services suggests beneficial outcomes compared to standard care. In 2005, the OPUS trial (Petersen et al., 2005) assessed the outcomes of patients from integrated treatment for first episode psychosis compared to standard treatment. The trial included 547 people with first episode psychosis, 275 of whom were randomly assigned to integrated treatment and 272 to standard care. Those people involved with integrated care were provided with 2 years of intense, assertive outreach care provided by a multi-disciplinary team with a focus on social skills training, psycho-education and family therapy. The control group was provided with care from local mental health service centres following routine treatment plans, with much higher caseload. The results of the trial at 1-year follow up showed there was a significant beneficial effect from the integrated treatment, with this group having better symptomatic and social functioning compared to standard treatment.

A second randomised controlled trial was conducted to evaluate the effectiveness of the Lambeth Early Onset (LEO) team, which is a specialist community based E.I. team working with first episode psychosis (Craig et al., 2004). The LEO team use an assertive outreach model and evidence-based bio-psycho-social interventions. The trial assessed rates of relapse and hospital re-admissions of those receiving specialist care compared to standard treatment provided by community mental health teams. In total, 144 people presenting with first episode psychosis were randomly assigned to either the LEO team or standard care. Findings from the study demonstrated that those patients receiving specialist intervention were less likely to relapse, had fewer

hospital readmissions and were less likely to drop out of the study than the control group.

Other studies have considered the impact of E.I. services on family burden (Jeppesen et al., 2005), suicidal behaviour, mortality (Bertelsen et al., 2007) and psychotic symptomatology (Melle et al., 2008).The outcomes from these studies suggest beneficial effects of E.I. services for people with first episode psychosis, compared to standard treatment. A recent review of randomised controlled trials involving early intervention for people at risk of psychosis or a first episode of psychosis, found that as yet there was insufficient data to draw firm conclusions from but that more trials were expected in the future. Marshall et al., (2005) reviewed seven studies with a total of 941 participants involved in early intervention services for people experiencing first episode of psychosis. The review included all randomised controlled trials designed to either prevent transition to psychosis in an at-risk group or improve outcomes for people with first episode psychosis. The studies included in the review measured outcomes such as transition to psychosis, outcomes from phase-specific interventions such as CBT or anti-psychotic medication, hospital re-admission rates and changes in symptoms. The results of the review suggest that of the seven trials included some reported positive outcomes with regards to prevention of transition to psychosis or improved clinical outcomes, but many reported outcomes that were either not significant at follow up or failed to be maintained in the longer term. The review concludes that there are insufficient trials to draw any definite conclusions from, but that interest in E.I. is rapidly growing and further studies need to be conducted to address unanswered questions about the efficacy of E.I. services.

Although there have been a wealth of studies looking at the clinical outcomes of E.I. services, there remains relatively little research on the subjective experiences of people following a first episode of psychosis. Outcome studies have typically employed quantitative methods, collecting data on standardised measures of symptoms, assessments of overall functioning and quality of life. These methods are entirely appropriate when assessing the effects of E.I. teams or treatments, but by their nature fail to include an individual's subjective experiences in the context of E.I. services. As discussed, the results from clinical outcome studies remain inconclusive, (although it has been demonstrated thatE.I. services reduce hospital admissions, improve negative symptoms and reduce relapse rates) but there is also a lack of understanding about a person's experience of recovery for first episode psychosis in the context of E.I. services. Given this gap in knowledge, the past few years has seen a steady increase in the number of qualitative studies which specifically explore the subjective experiences of people with first episode psychosis and their wider social networks. In the first review of its kind, Boydell et al., (2010) describe the qualitative studies undertaken in early and first episode psychosis. They reviewed 31 published papers and organised the findings around 4 generic social processes: achieving identity, acquiring perspectives, doing activity and experiencing relationships. The authors conclude that the findings from qualitative studies enhance our understanding of the experiences of individuals affected by first episode psychosis, in the context of the meanings and interpretations they give to particular issues. Those studies organised under the 'achieving identity' heading were concerned with the subjective experiences of psychosis (including the pre-psychotic phase). They sought to explore the person's own experience of the behaviour changes, social withdrawal and more 'problematic' symptoms such as hearing

voices. Some studies also explored these changes from the family's or carer's perspective. The 'acquiring perspectives' heading included studies which explored the person's views on E.I. services, both from a service-user's perspective and family members' or carers' stance. Studies which focused on help seeking attempts, family coping strategies, obtaining or maintaining employment and social participation were organised under the 'doing activity' category. Some studies considered the pathways to care people with first episode psychosis took, including the decision making processes when seeking help and the factors which influenced treatment delay. Other studies under this heading described the experiences people had when trying to maintain employment or return to work following their first episode. The final heading of 'experiencing relationships' included papers which explored the importance of peers, social isolation and maintaining social relationships in the context of first episode psychosis.

This review demonstrates that information from these experiences can be used to design and develop early detection and early intervention for those in the initial stages of first episode psychosis. The nature of qualitative inquiry allows for researchers to explore in-depth the individual experiences of people, their interpretations of these experiences and the meanings they construct. This rich information contributes greatly to our understanding of the complex processes involved in first episode psychosis and how best mental health services can meet the needs of these individuals. The review demonstrated that a very limited number of studies have been conducted into E.I. services (seven in total), and the authors conclude that in terms of E.I. services, further exploration is needed into the social and cultural aspects of service engagement.

With this review in mind, the individual experience of recovery following a first episode of psychosis lends itself to qualitative rather than quantitative exploration. Recovery in the context of an E.I. service is an area which has not yet been thoroughly researched, most of the outcomes studies have focused on quantitative outcomes such as hospital re-admissions, reduction in symptoms and other clinically-related data. The qualitative studies conducted so far have focused on how people experience first episode services, exploring what was useful to the young person and what they found important in terms of intervention. Recovery from first episode psychosis in the context of E.I. services is an area which has been overlooked in qualitative investigations.

In qualitative research, grounded theory is a specific research methodology for the purpose of 'building' theory from data, rather than applying a theory to data (Glaser & Strauss, 1967). Grounded theory has emerged as a popular qualitative research methodology due in part to the focus it places on the systematic yet flexible guidelines for collecting and analysing data to contrast theories 'grounded' in the data themselves (Charmaz, 2006). Unlike other qualitative methodologies, grounded theory research methods use explicit guidelines where data collection and analysis are conducted together. This involves constant comparison of data gathered and coded, in order to develop the theoretical categories that are emerging. This comparison shapes future data collection in subsequent interviews. A grounded theory approach to peoples' experiences of recovery following first episode psychosis will be used in this study. It is proposed that a qualitative methodology would be most suitable when exploring these experiences, given the nature of individuals' subjective accounts. A grounded theory study would provide the

openness and flexibility needed to explore in-depth the individual experiences of people involved with an E.I. service, the influence of a person's culture and setting on the construction of their experiences and how they communicate these experiences with others. Grounded theory allows for the generation of theory from the data, which is important when exploring areas where little investigation has been undertaken previously.

Based in Boydell et al's identification of the four generic social processes, this study seeks to explore these processes in terms of recovery and sense of self, within the context of an E.I. service. Therefore a realistic starting point is an exploration of how people who have experienced a first episode of psychosis talk about the impact of this on their sense of identity.

<u>Aims & Objectives</u>

- Aim

The overall aim of this study is to explore the individual's experiences of recovery following a first episode of psychosis, in the context of a specialist Early Intervention Service.

- Research Questions

  o How is an individual's identity expressed in relation to changes in the person's social and interpersonal context, following first episode psychosis?

o How is an individual's identity expressed in relation to recovery in an E.I. service context?

o Are there any commonalities or divergences in how people express their experiences of recovery?

Plan of Investigation

Participants

The study will recruit people who have experienced a first episode of psychosis and have been patients attending an Early Intervention Service in Glasgow. They will be aged between 16 and 35, which is the current age range covered by the E.I. service. Participants will be patients who have been attending the service and are within 6 months of their discharge or transfer of care. Participants will be in the process of having their care transferredback to GPs or other secondary mental health services. Participants will be both male and female, and it is expected that participants will come from a varied demographic background.

Due to the qualitative nature of this investigation it is difficult to predict the number of participants needed in advance, but it is suggested that a sample of between 8 and 20 participants is desirable for good quality qualitative research (Turpin et al., 1997).Grounded Theory methodology employs *theoretical saturation* to guide sampling. This occurs when 'gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories', (Charmaz, 2006).Theoretical saturation is an area of some disagreement amongst qualitative researchers. Some argue that researchers 'proclaim' saturation rather than proving

they have achieved it (Morse, 1995 in Charmaz, 2006 p. 114). The ambiguous meaning of 'saturation' creates a problem in knowing when enough data have been collected, and this in turn relies on the researcher's assumptions that enough data have been collected, presenting a risk that some data be overlooked. Charmaz suggested that the concept of theoretical saturation be used more as a guideline than a 'machine', which allows researchers to be 'open about what is happening in the field' (p. 115) in order to collect rich and relevant data.

Inclusion/Exclusion

The study will include people who are within 6 months of their discharge or transfer of care from the E.I. service. The exclusion criteria will be for those people who have a learning disability, or where English is not their first language. Other exclusion criteria will be where individuals have experienced more than one episode of psychosis.

Recruitment Procedures

In preparation for the process of transfer of care, all patients involved with the service attend a multi-disciplinary review at around 18-24 months. At this review patients will be given an information sheet by one of the team members, along with a consent form if they wish to take part in the study. Patients will also be given the opportunity to meet with the researcher to ask any questions they might have before agreeing to participate. After this meeting, interviews will be conducted in the subsequent few weeks.

Measures

Data will be collected by in-depth semi-structured retrospective interviews with each participant. The questions asked in these interviews will be open-ended and flexible to act more as a guide for the interview, and to encourage participants to talk openly about their experiences. This open sampling method will ensure that the individuals are free to challenge and where necessary, correct any assumptions held by the researcher about the meanings and experiences being investigated. The initial interview agenda will consist of a small number of open-ended questions, which is likely to lead to participants elaborating on their answers (see Appendix 1 for Interview Schedule). In line with grounded theory, it is likely that questions will develop after each interview as new themes and topic emerge and these will be incorporated into subsequent interviews.

Design & Research Procedures

Grounded theory methodology has been chosen as the most appropriate methodology for this study on the basis that the researcher is interested in *how* something happens, rather than *what* happens (Charmaz, 2006).In addition, grounded theory emphasises the importance of developing new, context-specific theories from the data, rather than deriving from existing theoretical formulations. It is proposed that the constructivist approach to grounded theory will be used when collecting and analysing data. This stance acknowledges that both researchers and participants interpret meanings and actions, and that this impacts on how the theory is developed. Constructivism involves the researcher taking a reflexive approach to the process of data collection and analysis, and considering *how* the theories emerge, recognising that their own assumptions, values and interpretations will affect the research.

Each participant will be interviewed at least once, but may be interviewed several times in order to obtain as much data as possible, bearing in mind that interviews will only be as long as is comfortable for the individual. It is suggested that several interviews may be required in order to build a relationship and rapport with the participants. Establishing good rapport is important to allow participants to feel able to talk freely and openly about their experiences. Information about socio-demographic details will be collected from the participant during the initial part of the interview, e.g. date of birth, gender, etc. The second part of the interview will focus on the experiences of the individual and their recovery in the context of their involvement with the E.I. service.

Settings and Equipment

Interviews will be conducted within the clinical base of the E.I. service. Digital recording equipment will be needed to record the participants' interviews. A computer will be required for transcribing the interviews.

Data Analysis

In grounded theory methodology, data collection and data analysis inform each other, whereby emerging themes from data analysis will shape further data collection. Data analysis therefore, cannot be separated from the data collection. All interviews will be transcribed, coded and categorised to identify core topics and themes. Initial coding will take place to establish 'segments' of data which can then be used in more focused coding to identify and develop the most salient categories. Coding the data is a crucial link between data collection and the development of a theory to explain the data. The process of coding in grounded theory involves creating codes which firstly define what is seen in the data, and then secondly begin

to construct meanings of this. Coding will continue until the point of theoretical saturation i.e. where no new categories or themes emerge from the data.

Throughout the data analysis process, grounded theory emphasises the importance of memo writing by the researcher. Through writing memos and informal notes about the process, the researcher can reflect on the codes created, inform areas of further data collection and develop ideas about the data. Memo writing constitutes a crucial method in grounded theory as it prompts the researcher to data and codes early in the research process.

Health & Safety Issues

- Researcher/Participant Safety Issues

Participants will be interviewed in clinic settings, where existing health and safety guidelines will be followed, and established risk procedures (such as panic alarms in rooms etc) will be used appropriately. Home visits will not be conducted. Every attempt will be made to identify and minimise risk before participants are seen for interview (e.g. all participants have been involved with E.I. service for some time and are known well by clinical case managers).

Ethical Issues

Interviewing participants about their experiences may be upsetting for some, and may cause distress. Recalling and reflecting on experiences of first episode psychosis may bring back upsetting or traumatic memories for some participants, and the researcher acknowledges the impact exploring these experiences might have on individuals. Participant comfort will be monitored throughout the interviews, and the participants will be made aware they can end the interview at any time. The

researcher also acknowledges the impact the timings of the interviews might have on participants, as they begin the transfer of care from the E.I. service to other services. It is important to recognise the impact this change might have on some participants, as they are being asked to reflect on their journey of recovery. All ethical issues will be addressed through appropriate ethical committees.

Timetable

The required Research Costings and Health & Safety Forms will be submitted in July 2010. Application for Ethical Approval, R&D Approval and organisation of site/materials for data collection is expected to take place from August 2010 onwards. Providing ethical approval is granted, data collection is expected to be undertaken from early September 2010 until approximately December 2010.

Practical Applications

It is hoped that this study will provide a greater understanding of individuals' experiences of recovery in the context of an E. I. service. This information may be used to consider which elements of the E.I. service patients valued, found most helpful or would need improvement. It is hoped that information gained from the participants can be used to build on the current E.I. provision and inform service development in future.

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Excerpt from Transcript

Transcript 5 – 'Simon'

So, what we'll do is we'll think about your kind of first contact with *E.I. Service* so I wonder if you could tell me how you came to be in contact with *E.I. Service* how you met them and (*eh*) what was going on for you at that time.

I went to the doctor I was hearing voices in the hoose (*mhmm*) that was my neighbours (*mhmm*) and they were wantin to kill me (*right)* and it was nae good (*mhmm*) em ……{3 secs} I had went to my mum and told her, I told my wife first (sniff) and she kept telling me I canny hear anything but it wiz like I could hear them it was like they were up the stairs (*yep)* I always thought voices in your head were different (sniff) but it wiz as though they were actually there (*mhmm*) em ……{2 secs} then I tolt ma mum …… {3 secs} she took me to the doctor but I only went to the doctor so that the doctor could tell them there was nuttin rang wi me (*right*) em …… {3 secs} then they sent me to *CMHT 1* (*right*) and *CMHT 1* contacted *E.I. Service* and then a had a meeting wae the two of them (*uhu*) and they decided that I should go wi *E.I. Service* rather than *CMHT 1*, (*right*) *CMHT 1*'s more medication based (*mhmm*) (sniff) eh … … {1 sec} that's how I got (*right)* *E.I. Service* (laughs) (*okay*)

So how long had that been going on for that you had been hearing the voices?

A couple of months (*a couple of months, right*).

And what was that like for you?

Very very scary (*mmmm, mhmm*). Its one night I sat behind my door wi a hammer and a baseball bat greeting (*mhmm*) just waiting on whoever it wiz coming through (*mhmm*) waiting on *[indecipherable 1 sec].*

Really terrifying by the sounds of it?

Mhmm (*uhu*) I kept thinking my wife's sitting here if somebody comes through that door I'm gonny kill them (*right, uhu*).

So a real expectation that there was somebody there?

Mhmm (*mhmm, okay*).

And that had been going on for a few months?

Aye (*right*)

And then to your GP or to your mum first?

Well to my wife then my mum (*right right*) eh …… {1 sec} and she took me to the doctor (*right uhu*).

What did you think about going to the doctor? Can you remember?

I wanted the doctor to tell tell them there was nuttin wrong wi me (*right*) I didnae feel no well or anythin (*mhmm*) I felt fine (sniff) then eh but it wasn't in the house (*right*) if I was anywhere else I was dead dead paranoid (*right*) of …… {2 secs} everybody (*right*) if anybody was walking by me I was pure staring at them (*mhmm*) like as though the whole country was oot to get me (*right, uhu*) eh …… {1 sec} it sounds stupid noo (*no not at all not at all it's*) it's eh ……{2 secs} she took me to the doctor it was a wee trainee doctor I hadnae seen her before (*right*) havnae seen her since either (*right*) then she referred me to *CMHT 1* (*mhmm*) eh she told me not to go back to the house (*right*) so I didnae.

And what did you think about that?

………{4 secs} In a way a was glad (*mhmm*) cause I wanted ma wife oot the hoose (*right*) ……… {5 secs} just because I thought well if am no there a canny look after her (*right*) then if somebody does go in then ……{2 secs} she's on her own (*mhmm*) it wouldnae be good (*mhmm mhmm*) but.

Gosh, so a really scary (mmm) **experience really scary time uhu. So you went from the GP straight to *CMHT 1*?**

Eh … … {3 secs} was it the next day? (*right*) I think it was the next day (*uhu*) (sniffs) I went to *CMHT 1* eh …… {1 sec} and then I had to go and see them a coupla times (*right*) em …… {1 sec} they never gave me any medication or (*uhu*) or anything like that (*uhu*) I just went back to my mums (*right okay*) and I stayed there, I ended up staying there for a year (*uhu right okay with your mum*) mhmm (*mhmm mhmm*).

So you saw *CMHT 1* a couple of times and then int .. were introduced to *E.I. Service* sort of through them?

Through *CMHT 1* do you mean (**ye**) they had a meeting *CMHT 1*, *E.I. Service* (**mhmm)** and masel (**mhmm**) …… {3 secs} then they were just asking me questions aboot whit's been happening (**mhmm**) how ye feeling (**mhmm**) aw this (**mhmm**) eh … … … {2 secs} then they decided between their sells a had nuttin tae dae wi it man (**right uhu**) a wiz oot the room (sniff) (**mhmm**) they decided that I should go with *E.I. Service* rather than *CMHT 1* (**uhu okay**).

And when you were out the room while they were making that decision do you remember what that was like? Do you remember how you were feeling?

Em … … {1 sec} a thought it was a lot of nonsense (**mhmm**) coz I was kinda hinking I'm no no well (**mhmm**) a remember ma aunty had eh schizophrenia when she, when she got no well you could tell she was no well (**ihi**) but I didnae feel any different (**mhmm**) (sniff).