An exploration of the meaning of 'hearing voices' and dreams for people with learning disabilities

By

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Declaration

This work has not been submitted to any other institution or for any other qualification.

Summary abstract

The literature concerning outcomes of interventions for mental health difficulties in people with learning disabilities was reviewed. This was discussed in terms of the quality and quantity of available evidence and with reference to the state of research in the field. Conclusions concerning the effectiveness of interventions were drawn. Gaps highlighting the need for research were identified and ideas for future research topics and methodologies explored.

A qualitative study was then conducted to explore the personal meanings of ‘voices’ and dreams for eight adults with learning disabilities based on semi-structured interviews. Transcripts of these were analysed using Interpretative Phenomenological Analysis (IPA) and super-ordinate and sub-ordinate themes were drawn from the data. These were discussed in terms of their implications for research and clinical practise. Conclusions were drawn concerning similarities and differences to previous research findings and the clinical implications of these explored. Future research was suggested to promote evidence based practise.

Based on a research diary, a critical appraisal outlined the process of conducting the research and highlighted issues learnt. The implications for how these experiences will inform future practise were discussed.

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Word count

Research literature review

Article	7663
References	1608
Total	9271

Research report

Article	11550
References	660
Total	12210

Critical appraisal

Article	4020
References	274
Total	4294

Appendices	9297

Total (excluding appendices)	25775
Total (including appendices)	35072

List of Contents

A review of the current psychological literature concerning interventions with adults with intellectual disabilities and mental health difficulties

Abstract

Background: This paper reviews the evidence for the effectiveness of psychological and psychosocial interventions for adults with a dual diagnosis of intellectual disabilities and mental health difficulties.

Method: The evidence was systematically reviewed in terms of specified criteria for group and single case experimental designs. These included: experimental phases (baseline, intervention, follow-up), adequate and appropriate measures, sample size sufficient for detecting difference, use of statistical analysis, randomised control group allocation, participant selection, homogeneity of participants and clinical issue, and clear details of interventions used. Studies were grouped into cognitive, multi-modal and psychotherapeutic approaches.

Results: Limitations of the different types of evidence and methodologies are considered in relation to 'power' issues and robustness of the conclusions stated.

Conclusions: Conclusions are drawn concerning the state of this research field. Ways forward are suggested for the emergent field and the implications of this presented in terms of clinical and research issues.

The field of mental health difficulties in people with intellectual disabilities (ID) is a relatively new one. Clinicians have seemed reluctant to acknowledge dual diagnosis; some suggesting that people with intellectual disabilities did not have sufficient emotional or cognitive capacity to suffer such difficulties. Fletcher (1988) noted, “The mildly retarded have been characterized as worry-free and thus mentally healthy. The severely retarded have been considered to express no feelings and therefore do not experience emotional stress” (p255)

Difficulties that occurred were attributed to the original organic condition leading to the ID (Nezu and Nezu, 1994). More recently such wide spread dismissal has reversed (Deb, Thomas & Bright, 2001; Sturmey, 1998; Moss, 1995, Khan, Osinwo & Pary, 2002; Tyrer and Dunstan, 1997; Lowry, 1998; Caine & Hatton, 1998) and clinicians in the field seek appropriate interventions to ameliorate the symptoms and associated distress of people who experience these and those around them.

Prevalence figures for psychiatric illness in people with ID vary widely between 10-80% (Caine & Hatton, 1998) depending on the assessment methods and criteria used. Where non-clinical populations have been studied, prevalence rates vary between 25-40% (Lund 1985, Reiss 1990). Recent figures based on a community sample indicate a prevalence of 16% (Deb et al, 2001) for ‘functional psychiatric illness’ which is similar to the general population, but that rates of schizophrenia and phobic disorder were higher than in the general population.(0.4% and 1.1% respectively).

No research on the course of mental illness in people with ID has been identified. This makes it problematic to interpret, for instance if research effects stem from the intervention or natural course of difficulties. Control group members are assumed to be highly similar to those in the treatment group in terms of diagnosis, IQ, age, sex ratio. Given the epidemiological data it would be arduous to find such a homogenous group in

ID services. In addition, the use of a control group assumes that they will not change if untreated. The lack of research concerning the course of mental health in people with ID means that we have to make such assumptions on the basis of research on the non-disabled population and /or clinical experience or anecdotes.

Issues that complicate diagnosis of mental illness for someone with ID will be briefly outlined here. (See Russell, 1997; Weisblatt, 1994; DC-LD, 2001; Caine and Hatton, 1998 for further details). Mainstream diagnostic systems such as ICD-10 (WHO, 1992) or DSM-IV (APA, 1994) rely largely on verbal reports. Communication difficulties in people with ID may prevent them accurately expressing their experiences or mental state (Caine and Hatton, 1998). Acquiescence and compliance, common in people with ID, necessitate changes in interview style; including open-ended questions (DC-LD, 2001). Carer reports are a common and important source of information, but not biased-free. Diagnostic overshadowing may occur (Caine and Hatton 1998). In addition, the validity of clinical diagnosis has been questioned as unreliable and bias (Caine and Hatton, 1998), particularly where inexperienced clinicians conduct initial assessments (Moss, 1995).

Past assumptions were that people with ID would not benefit from psychotherapeutic approaches since they did not have the cognitive or emotional ‘apparatus’ necessary for the complex and abstract tasks of therapy (Nezu and Nezu, 1994). Such assumptions continue to be re-evaluated in the light of an ethos that stresses equality of provision for all sectors of society. A reasonable body of evidence exists concerning the efficacy of psychotherapies in the ‘mainstream’ population (see Roth and Fonagy, 1996). The next section questions whether it is possible to utilise existing ‘mainstream’ approaches or how these might need adapting in a reliable and valid way.

People with ID have a wide range of abilities in different spheres of life including cognitive, emotional, social and cannot be considered as a coherent ‘whole’.

However, commonalities such as poor problem solving strategies, poor emotional recognition or labelling, limited verbal communication and concrete understanding might impede their use of 'standard' psychotherapies and complicate the measurement of outcomes or indices of distress.

Some authors have developed screening criteria to judge if an intervention might be useful for an individual. For instance, Black, Cullen and Novaco (1997) propose basic skills needed by people with intellectual disabilities for CBT, including communication, emotional identification, cognitive aptitude, and social interaction skills.

Lindsay, Neilson and Lawrenson (1997a) advocate a change in emphasis from the 'deficit' of the individual to a need to develop interventions in line with individual needs. Few clinicians would argue with the need for this for good and ethical practise and research should therefore develop accordingly. However, it presents challenges for large scale efficacy trials where uniformity of practise is needed. Clinicians increasingly offer a range of interventions for people with ID, adapted from 'mainstream' techniques. This review aims to establish whether empirical evidence supports this practise.

Search criteria

The literature search covered the years 1990 to 2004. Given the paucity of research in the field, this review concentrates on evidence for the efficacy or effectiveness of psychological and psychosocial interventions for mental health difficulties in adults with IDs. This dearth precludes focus on using one type of therapy for one type of problem. Research is quoted where considered relevant and where psychological processes would contribute to changes in a person's mental health. This may impede definitive conclusions, but it seems essential to review the current limited evidence-base, since what exists may have greater influence over practise in the field than might normally be the case.

Behavioural interventions were not included due to their wide coverage in previous literature, which mainly predates 1990 (see Whitaker, 1993, 2000). The term ‘Mental health difficulties’ includes a range of problems such as depression, anxiety, psychosis, obsessive-compulsive disorder (OCD) but excludes Alzheimer’s disease and other organic disorders. Forensic (including anger) issues were excluded in view of two special issues of journals with recent reviews in 2002. Mental health diagnostic methods for people with intellectual disabilities and prevalence figures have been covered widely (Reed 1997; Sturmey 1998; Deb et al 2001; Ross and Oliver 2002; Clarke and Gomez 1999; DC-LD, 2001) and are therefore mentioned only briefly.

Search terms used included: Intellectual disability, learning disability, mental retardation, developmental disability and mental handicap. ‘Intellectual disability’ is synonymous with mental retardation or learning disability, based on the DSM-IV (APA, 1994) definitions of a person with an intellectual quotient (IQ) below 70 and significant impairments of adaptive behaviour functioning whose difficulties began before 18 years old.

Criteria for review

Studies were critiqued in terms of efficacy and effectiveness. Salkovskis (1995) describes an hourglass model of research evolution beginning with effectiveness evaluation through practise-based exploratory case studies then SCEDs (single case experimental design), or small-scale comparative studies drawn from the normal clinical pool. They have strong external validity but lack internal validity through methodological weaknesses.

At the 'pinch of the hourglass', small numbers of funded efficacy research trials emerge using homogenous samples with strict inclusion criteria for participants to allow replicability, reliable and valid measures, manualised treatments, statistical techniques, and randomly allocated control groups. Such randomised controlled trials (RCTs) promote strong internal validity but have questionable external validity since they struggle to reflect clinical reality. RCT results then become tested within clinical environments as the hourglass widens once more.

This review failed to find efficacy trials and thus focussed on effectiveness studies using SCEDs and group designs. SCEDs should ideally employ: baseline, follow-up, pre-and post- (preferably multiple) measures including global measures of change as well as daily ratings; all being sensitive measures of change. Ratings may be difficult for people with learning disabilities to complete without help, thus compromising validity; also true for respondent measures. Traditional designs would include baseline (A), intervention (B) and return to baseline (ABA) reversal designs. However these are unlikely to be ethical or possible, where interventions seek internal psychological change. AB follow-up is therefore more appropriate. Statistical tests can compare phases of the intervention to evaluate change where autocorrelations are not significant for serial dependency. Where measures are robust, a reliable change index (RCI) (Jacobsen and Truax, 1991) can be computed which can be compared across studies for a meta-analysis to consider cumulative evidence.

In addition to the criteria for SCEDs above, group designs need sufficient sample sizes to detect differences, with random allocation to control or treatment group. Comparison of treatment groups would need a larger sample (60-70 per group) than treatment-control (or waiting list) comparisons (20-30 per group) (Kraemer, 1981) because the difference between groups tends to be smaller (half a standard deviation compared to one; Kazdin and Bass, 1989). Power equations computing statistical significance, effect size and sample size deduce whether a design is adequate in being able to detect differences.

Cognitive approaches

Papers looking at cognitive approaches with people with intellectual disabilities cover a range of mental health issues. Cognitive and Dialectical behaviour therapies (CBT and DBT) have been included in this group. The studies will be briefly outlined, then critiqued later as a group. (See figure 1. for table of all studies reviewed)

Dagnan and Chadwick (1997) distinguish between deficit models, teaching self-instructional techniques; and cognitive psychotherapy, addressing distorted cognitions. They view much of the research in ID as within the deficit school, and call for more study of cognitive psychotherapy.

Single case experimental designs

Lindsay, Howells and Pitcaithly (1993) describe two SCED studies where cognitive psychotherapy was used in a modified form for depression with two adults with mild ID. They use a baseline and four month follow-up, using pre and post depression and anxiety scales and analogue scale daily diaries to record symptoms. All measures showed improvements at end of intervention and follow-up, suggesting clinically meaningful change although statistical significance is not given.

Lindsay et al (1997a) present two SCED study of anxiety management, with 18-month follow-up and multiple measures where daily thoughts and ratings were self-recorded. Ratings of anxiety, ‘bad thoughts’ and Beck depression and anxiety scores all moved from the clinical to non-clinical range following intervention; maintained at follow-up. The adapted techniques were considered effective but the schema and presentation were judged as dissimilar warranting further research specific to ID.

Names/ date	Sample (N)	Baseline	Daily ratings	Pre/post-measures	Follow-up	Multiple measures	Statistical analysis	Reliable change index	Random allocation to control/intervention group(s)	ID only	DSM-IV diagnosis	Therapy
Cognitive												
Lindsay, Howells & Pitcaithly 1993)	2	Yes	Yes	Yes	4 month	Yes	No	No	n/a	Mild	Depression	Cognitive
Lindsay et al (1997a)	2	Yes	Yes	Yes	18 month	Yes	No	No	n/a	Mild	Anxiety	Cognitive
Lindsay (1999)	5	Yes	Yes	Yes	2-6 month	Yes	No	No	n/a	Yes	Depression	Cognitive
Dagnan & Chadwick (1997)	1	Yes	Carer's	No	No	Two	No	No	n/a	Mild	Depression	CBT
Bradshaw (1991)	1	No	Yes	No	3 month	No	No	No	n/a	'Down's syndrome'	Nightmares	Cognitive manipulation
Leggett, Hurn & Goodman (1997)	1	Yes	Yes	Yes	No	Yes	No	No	n/a	Mild	'Voices'	Cognitive
Wilson (2001)	1	Yes	Yes	No	Yes	Two	No	No	n/a	Mild	Borderline Personality Disorder	DBT
Nezu, Nezu & Arean (1991)	28	No	No	Yes	3 month	Yes	Yes	No	Yes with 2 intervention groups plus waiting list control (N=10)	Yes	No	Social problem-solving

Names/ date	Sample (N)	Baseline	Daily ratings	Pre/post measures	Follow-up	Multiple measures	Statistical analysis	Reliable change index	Random allocation to control/ intervntn group(s)	ID only	DSM-IV diagnosis	Therapy
Multi-modal												
Holden & Leff (2000)	28	12 month	No	Yes	No	Two	Yes	No	No control	68% mild	'Severe' but various	Multiple
Bird, Sperry & Carreiro (1998)	10	Yes from prior setting	Yes by carers	Yes	No	Yes	No	No	No control	No – Borderline / mild	Various	Multiple
Van Minnen, Hooghuin & Broekman	50	Yes	No – but at 7, 14, 21 and 28 weeks	Yes	No	Yes	Yes	No	Yes	No – borderline/ mild	Various	Multiple
Tyrer, Hassiotis, Ukoumunne, Piachard & Harvey (1999)	104	No	No	No	No	No	Yes	No	Yes between comparative treatment groups	No - borderline	Psychosis	Intensive/ standard case management
Davidsen et al (1995)	267 (199 with ID)	Retrospective	No	No	9 month	Yes	No	No	No control	As part of larger group, including children.	19% of ID had diagnosis	Crisis intervention programme

Names/ date	Sample (N)	Baseline	Daily ratings	Pre/post-measures	Follow-up	Multiple measures	Statistical analysis	Reliable change index	Random allocation to control/ interventn group(s)	ID only	DSM-IV diagnosis	Therapy
Psychotherapeutic												
Leifer & Smith (1990)	1	Yes	No	Yes - during 13 month intervention at 3 month intervals	No	Yes	No	No	n/a	Yes	Depression /parenting	Multiple including psychotherapy
Newman & Beail (2002)	1		No, sessions 1, 4 and 8.	Yes		Qualitative and quantitative	No	No	n/a	Yes	No	Psychotherapy
Beail & Warden (1996)	10	Intake only	No	Yes	3 month	Yes	No	No	n/a	Yes	Various	Psychodynamic psychotherapy
Beail (1998)	25 (20 finished therapy)	1 month	Frequency data	No	6 month	No	No	No	n/a	Yes	6 retrospectively	Psychoanalytic therapy
Stoddart, Burke & Temple (2002)	21	No	No	Yes	Yes	Yes	Yes	No	No control group	No – 7 in borderline range.	Yes, for 9 of 21	Bereavement

Lindsay (1999) describes five SCED studies where simplified cognitive therapy for depression was used for people with IDs. Average, scores on pre and post measures (Beck or Zung depression) fell from 50 to 25%, maintained at two to six month follow-up. Statistics were not used due to low numbers involved. Cumulatively these SCED studies support the hypothesis that the interventions were effective.

Dagnan and Chadwick (1997) present a SCED study where CBT was used with a woman with mild IDs. Carer ratings of 'behavioural and emotional signs of depression" during baseline assessment and intervention phases indicated that depression lessened and days when no symptoms were seen increased.

Bradshaw (1991) presents a 'successful' case study of cognitive manipulation of a 'stereotypic nightmare' in a man with Down's syndrome. No baseline was recorded as high distress levels necessitated immediate intervention. Nightmare frequency fell from 'virtually every night' pre-intervention to 'zero' at three months post intervention. No systematic data was presented.

Leggett, Hurn and Goodman (1997) report an SCED of cognitive group work for a woman with mild ID in secure provision, experiencing 'auditory hallucinations'. Baseline, pre and post measures are reported with daily records of frequency, duration, content and level of distress, but no follow-up data. The multiple pre and post measures of coping responses, depression and anxiety used do not have norms for people with learning disabilities so should be treated with caution. A semi-structured assessment interview examined coping strategies, antecedents, behaviours and consequences, subjective distress, content, frequency and duration of voices. Frequency of voices did not decrease post-intervention but the intensity, associated distress and use of coping strategies did. Anecdotal reports indicated that the coping responses were still utilised

15 months post-intervention. Research should establish whether these results from a secure setting generalise.

Wilson (2001) describes the use of dialectical behaviour therapy (DBT) for people with ID and proposes a model of treatment. He presents a SCED study with baseline and follow-up data. Treatment included medication, a behaviour programme, learning of coping strategies, weekly psychotherapy (which was later discontinued) and staff training. Outcome was measured as the number of 'acting out' episodes (clearly defined) before and after staff training and the four-stage treatment plan. Mean frequency of major and minor episodes per day was measured for baseline, then months one, two, six and ten. Decreases in overall episodes occurred from .34 per day at baseline to .13 per day ten months post treatment. PRN medication also reduced and this was taken as a measure of change. Wilson (2001) asserts the 'essential elements' of the treatment, without presenting data to support this. However, the results seem promising and need further research.

Group designs

Nezu, Nezu and Arean (1991) used a counterbalanced design with 28 dually diagnosed adults to evaluate the effects of social problem-solving training. Participants were randomly assigned to one of three conditions. The first group received five weeks of problem solving training followed by five weeks of social skills training. The second group had the reverse and the third group were in a waiting list control group. Results indicated significant decreases in aggressive responding, psychiatric symptoms, feelings of distress, and increases in adaptive functioning, assertive behaviour and problem solving skills in both treatment groups relative to the control group and this was maintained at three month follow up. No differences were found between the two treatment conditions but the sample size was insufficient to identify them.

Most of the evidence for the use of cognitive therapies with adults with intellectual disabilities has to-date come from single case experimental studies. Unfortunately designs frequently lack baseline or follow-up, use single measures or those lacking norms for ID and lack statistical analysis. Frustratingly this undermines promising results, and/or makes cross study comparisons inappropriate affecting the validity of claims for cumulative evidence. Although the ‘effectiveness’ evidence increasingly supports the assertion that cognitive approaches can be used successfully for people with intellectual disabilities across a range of mental health problems, more robust research is needed.

Multi-modal treatment programmes

These use interventions from different agencies as a package. Outcome data are typically presented as arising from a single intervention. The research is varied in scope, participant selection criteria and type of problem included; making comparisons difficult. However, review is need since the limited papers with quantitative data may be unduly influential in the absence of more widespread findings.

SCED series

Holden and Neff (2000) outline a pilot study of intensive outpatient treatment of 28 people with ID (sixty eight percent with mild ID) and various psychiatric disorders. The outpatient treatment; offered in community and clinic settings; involved individual, family and group psychotherapy, psychopharmacology, consultation, crisis intervention and substance abuse therapy. Length of stay and hospitalisation rate served as measures in a single group, no control, pre and post-test design with twelve-month baseline and treatment phase. Parametric statistics showed significant decreases in rate and length of hospitalisation after programme entry, which is suggested to lead to significant reductions in service costs. With no control, this is a series of SCEDs, comparing baseline to intervention phase data. However, the multiple interventions make any meaningful interpretation about change difficult, particularly with the lack of measures relevant to different interventions or psychological experiences.

Bird, Sperry and Carreiro (1998) used psychiatric rehabilitation principles and behaviour support strategies for ten patients with borderline and mild ID with various psychiatric diagnoses, who had ‘failed’ in their community placements. They aimed to improve a person’s skills and supports to enhance their community ‘performance’. Two major goals (with measurable indicators) were identified with the patient to assess intervention efficacy. The quality of life questionnaire (Shalock and Hoffman, 1989) was administered pre-intervention then at six and twelve months. Inter-observer ratings agreement ranged from 87 to 100%.

The small sample and percentage data weakens claims of ‘positive’ results in perceived quality of life, challenging behaviours, psychiatric hospitalisations and average days spent in the community. Additionally, no data is given to support assertions about interventions of ‘proven’ effectiveness with people of ‘similar psychiatric, cognitive and behavioural challenges’ or comparisons about staffing costs between services. However, this study uses multiple measures and unusually, includes the person’s own ratings of goals and quality of life. Greater sample size and use of a control group could increase reliability of the results and enable statistical analysis through increased power; particularly necessary if different components were to be compared.

Control group designs

Van Minnen, Hooghuin and Broekman (1997) presented a randomised trial comparing hospital and outreach services for ID patients (mild and borderline range) with different psychiatric disorders. With 25 participants randomly assigned to each group, it includes quantitative data on multiple measures. Intervention lasted 28 weeks. Follow-up data is not yet available. Independent psychologists rated measures of ‘psychopathology’: Dutch versions of the Reiss screen for maladaptive behaviour (Van Minnen, Savelsberg & Hooghuin, 1995) and Psychopathology inventory for mentally retarded adults, (PIMRA) (Van Minnen, Savelsberg & Hooghuin, 1994); aggression (Scale for aggressive behaviour for people with mental retardation, SAB) (Kraijer & Kema, 1981), subjective improvement (Global rating scale for improvement, GSI – not referenced), social competence (SCS) (Kraijer & Kema, 1981) and perceived burden on carers (Nijmegen child-rearing situation questionnaire, NCSQ) repeatedly during baseline and treatment phases. Except the last measure, these are specific to ID and presumably have appropriate population norms. However diagnostic measures such as the REISS and PIMRA are not designed as measures of change.

Results showed no significant differences between the hospital and outreach groups at baseline on psychiatric symptoms, aggression, social competence or family burden. Through treatment and at ‘end-point’, no significant differences were found in psychiatric symptoms or family burden between the two groups. Estimated treatment costs showed 40% less for outreach treatment for equivalent results. No follow-up data or measures of patient satisfaction or quality of life were used. Van Minnen et al (1997) go beyond what can be derived from the data in stating “this renders the outreach treatment not only curative but also preventative in nature”.

Tyrer, Hassiotis, Ukoumunne, Piachard and Harvey (1999) compare intensive with standard case management for 104 people with borderline intellectual disabilities (IQ between 70 and 80) and psychosis. Two levels of the same treatment are randomly assigned and used comparatively as controls. Issues involved may be relevant to people with mild ID.

Assessment of psychosis is not discussed. ‘Borderline’ IQ was assessed using the NART (National adult reading test – Nelson, 1982). The authors acknowledge the difficulties in assessing intelligence in people where psychotic symptoms lower scores. In addition, the use of the NART as a measure of intelligence may not be so useful at its lower ranges. It would also not be sufficient to meet DSM-IV (APA, 1994) diagnostic criteria for ID, which include adaptive behaviour functioning and age of onset.

The sample (104), large for this area of the literature, is inadequate for detecting meaningful change (Kraemer, 1981). Statistically, those with borderline intelligence on standard care spent twice as long in hospital and had almost thrice as frequent admissions as those on intensive care management over two years. This contrasted to the findings, which found no significant differences between standard and intensive case management for 708 patients (total IQ range). They concluded that intensive case management should concentrate on the ‘borderline’ group. No measures of symptom change or patient views were taken. Details of the exact interventions are absent, limiting replicability of the study with ID participants.

Davidson et al (1995) assessed outcomes of a crisis intervention program for 267 adults and children with developmental disabilities and behavioural or psychiatric crises. Strictly this seems to be a series of SCEDs as there is no control group, but is included in the group section due to the large number of participants. Full data was available for a subset of 199 with IQs below 70. Of these, 19% (50) had a recorded DSM-III psychiatric diagnosis, with 18% of the overall sample receiving psychiatric services. It is difficult to ascertain what proportion of the sample is relevant to this review and so whether the intervention is helpful for adults with ID and mental health needs.

Measures included retrospective data records of the cohort, a nine-month follow-up interview and retrospective referrer satisfaction survey. After closure of the original referral, 68.8% of individuals were not re-referred after four years. The lack of control group means that we don't know what would have happened without the interventions, for instance in the 'normal' course of mental health difficulties.

Overall multi-modal packages show some evidence of positive effects. However, methodological flaws weaken their credibility. Sample sizes were often inadequate to detect differences. Assertions made about best practise were not always backed up by empirical evidence. More complex models of treatment need to consider how to evaluate what works with what. Many use a limited view of patient well-being lacking measures of clinically important aspects of distress and quality of life. Measures need to be chosen that are sensitive to clinically meaningful issues rather than just time spent in hospital or service costs. They need norms for people with ID and to be sensitive to change. Qualitative measures would be useful in conjunction with the quantitative measures.

Descriptions of therapeutic components for replication in future research are needed, particularly given issues with interpreting results concerning multiple interventions and possible confounding variables. Multiple measures help evaluate intervention packages. Phased interventions might help assess possible synergetic effects of intervention components. Considerably larger samples and robust measures would be needed to isolate different components statistically.

A traditional research paradigm seeking a single efficacious 'active ingredient' is at odds with a multi-modal approach, which needs to be supported by empirical evidence if the academic or health care system is to take it seriously. These multi-modal research studies are practise based; showing promising findings, but need more reliable and valid designs for innovative practice to be based on stronger evidence.

Psychotherapeutic interventions

There are few studies with empirical data, which assess the effectiveness of psychotherapeutic approaches with adults with ID. In view of this, a broad definition of psychotherapeutic has been used, including non-directive or counselling as well as psychodynamic or psychoanalytic in this review. Case studies with no data are not reviewed.

SCEDs

Leifer and Smith (1990) studied an intervention with a depressed mother with ID and her infant. It employs a longitudinal, multi-method design to assess the infant's development, mother-infant interactions and components of the 'family's ecology'. Interventions included individual psychotherapy, vocational/reading training and parent training at three monthly intervals throughout baseline and intervention. It is not clear whether the data supports the conclusions that the interventions resulted in increased maternal and infant competence and more adaptive patterns of mother-infant social transaction. The SCED makes it difficult to know what would have happened without the intervention and the ongoing development of the child is not a stable variable through the time period. In particular their assertion that the child's secure attachment, as assessed by the 'strange situation' (Ainsworth and Wittig 1969) was attributable to the intervention, is uncertain since the attachment was not assessed prior to twelve months when the intervention began at seven months.

Further research could evaluate their claims for effectiveness of the approach. A 'no action' control group or use of a long baseline as control might be unethical due to issues in not intervening at such a critical period in parent-child development. The use of comparative approaches may be helpful but would need a group design.

Newman and Beail (2002) used the ‘Assimilation of problematic experiences scale’ (APES) (Stiles et al, 1990) as a psychotherapy process method in a man with ID to produce quantitative and qualitative outcome data. It examines change in the client’s understanding of a problem through eight stages over the course of a therapeutic session and/or a number of sessions. Transcripts from weekly psychodynamic therapy weeks one, four and eight were taken and rated by two teams using the APES. Inter-rater reliability was high. Symptom Checklist-90 (SCL-90) (Derogatis 1975) scores from weeks one and eight assessed overall ‘psychiatric caseness’, falling to just below the cut-off point for males by week eight. This change correlated with APES data as shown by positive movement through assimilation model stages. The SCL-90 has published norms for adults with ID and mental health problems (Kellett et al, 1999)

This study used qualitative procedures with clearly defined criteria and methodology to produce quantitative data; helpful for future research. The authors state that the data demonstrated face validity, remaining clinically plausible. Generalisability of therapeutic changes from the therapeutic setting was not the focus of this study but could be considered for future research.

This paper demonstrates how ‘mainstream’ psychotherapy methodology can be used in the ID field and the importance of published ID norms for adapted scales used (Kellett et al, 1999). The APES methodology needs a multiple raters and this reduces its general utility. Nevertheless, such developments broaden the research tools available across a range of therapeutic approaches; the challenge being for clinicians to use available tools available consistently to develop the evidence base.

SCED series

Beail and Warden (1996) outline preliminary outcome data for a psychodynamic psychotherapy service for ten adults with ID in normal clinical practise. Referral reasons included aggressive, bizarre/psychotic or inappropriate sexual behaviour. Measures were the Symptom Checklist-90 revised (SCL-90R) (Derogatis, 1983) and Rosenberg self-esteem inventory (1965); administered at intake, eight session intervals and three month follow-up. Norms were not available at the time for people with ID but this is discussed. Symptom and general severity index (GSI) scores fell and self-esteem rose significantly at outcome and follow-up. Longer follow-up would have been helpful.

Beail (1998) presents a preliminary outcome study of twenty five men with ID using psychoanalytic psychotherapy for behavioural problems. Twenty men finished therapy. The study is included in this review since challenging behaviours can mask underlying issues; six men were later found to have mental health difficulties. All twenty had attended schools for moderate or severe ID, although this may not correlate with formal ID assessment. Treatment was not problem focussed which differs from the diagnostic emphasis in other research. No evidence was given for the assertion that a Kleinian interpretative approach was successful.

‘Problem’ behaviour frequencies over the previous month served as an ‘intake’ measure for the twenty men who finished therapy. Offending behaviours were less frequent; the index offence was taken as the ‘intake’ and any incidents in the last three months of treatment for the ‘outcome’ measure. Six month follow-up data was obtained.

Eleven of twelve participants showed reduction to zero behaviour problems at end of treatment and six month follow-up. The other showed a reduction from daily to weekly frequency. Of the offending group no incidents were reported by six-month follow-up. Given the lower initial frequency of offending behaviours a longer follow-up period could establish more evidence of long-term effectiveness. Ethical issues about withholding input precluded use of a control group. Those who did not complete therapy were used as a comparative group and their original behaviours continued.

This study gives promising evidence that this approach can be helpful for men with ID. Since no other interventions were offered, it is credible that treatment effects stem from therapy. This research could be repeated with women and longer follow-up periods employed.

Stoddart, Burke and Temple (2002) published outcome data for a bereavement group for 21 adults with intellectual disabilities, which is included in this review since bereavement reactions can adversely affect a person's mental health. Seven were borderline IQ range. Nine had a dual diagnosis and this group were considered separately on a post hoc basis. Outcomes measures of depression, anxiety, knowledge of death and bereavement were used pre and post intervention but it is unclear whether these have ID norms. There was a significant decrease in depressive score but no change in anxiety or knowledge of death and bereavement, based on non-parametric statistics. Post hoc analysis indicated that people with a dual diagnosis had a significant decrease in depression but not anxiety. Single diagnosis showed no significant changes. Further research could explore this effect, which suggests that those with a dual diagnosis suffer higher levels of distress following bereavement than others. This would fit with stress vulnerability models of mental health, although it is not clear whether the dual diagnosis predated the bereavement.

Given the lack of control group it is not possible to see whether changes that occurred would have happened anyway during 'normal' bereavement processes (Worden 1993). In addition, the measures do not appear to reflect assessment of changes of bereavement processes, which one would presume is an aim of such a group. Future research could employ methodology, which attempts to explore this.

Prout and Nowak-Drabik (2003) used an 'expert consensus rating method' to review 92 studies (published and unpublished dissertations) from 1968 to 1998 evaluating various psychotherapies (37% unspecified) for any issue with people with ID of any age. They concluded that interventions yielded a "moderate amount of change and are moderately effective or beneficial" (Prout and Nowak-Drabik, 2003). No information is given about whether participants had mental health difficulties and which papers were from peer-reviewed journals.

The psychotherapeutic studies reviewed support their use with adults with dual diagnosis but as for cognitive and multi-modal approaches, methodological flaws weaken such evidence.

Discussion

This paper has reviewed the evidence for psychological and psychosocial interventions for people with intellectual disabilities and mental health problems and seeks to evaluate the state of the evidence against empirical and clinical standards.

The evidence for cognitive approaches is mainly single case experimental studies and limitations of this methodology will be discussed below. However, cumulatively these studies support the hypothesis that it is an effective approach for a range of mental health difficulties. This is further supported by the one randomised control trial (Nezu et al 1991), which has an inadequate sample, but positive results whose credence is strengthened by the overall design.

The multi-modal interventions have larger sample sizes and there are two randomised control trials with positive therapeutic effects (Van Minnen et al 1997; Tyrer et al 1999). The range of interventions employed is wider in these papers, making it more difficult to group them for comparison. There are methodological limitations (see below) but overall they set out positive gains and the cumulative sample sizes are larger than for the cognitive studies, some utilising statistical analysis.

The psychotherapeutic literature is sparser, the bulk being single case experimental designs. Two studies have reasonable sample sizes. (Beail, 1998; Stoddart et al, 2002) and again overall the results are positive. Beail (2003) suggests that a lack of interest generally in outcome research in psychoanalytic practitioners may explain the lack of outcome data. He disputes that outcome data is incompatible with psychoanalytic therapy and discusses methodological ways forward.

This review has found evidence of effective interventions and support for their clinical use, mainly from studies carried out in clinical practise not as part of funded research trials. Efficacy trials were absent. The evidence must be taken in the context of methodological shortcomings, which will be outlined collectively in the next section in order to focus ideas for the future. In addition, we should remain aware that ambiguous or negative results are less likely to be published than positive ones.

The Samples

Psychiatric diagnostic criteria were often unclear, which may reflect difficulties with this issue in the field (see above). Imperfect diagnostic techniques, variations of presentation across people's lives and life experiences must inevitably confound research design. DC-LD (2001) presents 'consensus diagnostic criteria' which may help cross-study comparisons. It claims good 'face validity' from pilot studies but validity and reliability data is yet to be published.

Where information about inclusion criteria is lacking or unclear, it is difficult to differentiate evidence about what works for which mental health issues. A separate body of research is trying to develop diagnostic measures such as the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Moss et al 1993), which will help future research but may be less useful as sensitive measures of change for outcome studies.

Information about assessment of ID or acknowledgement that this would be compromised by concurrent mental health difficulties was frequently unclear or absent.

Homogeneity of participants seems unlikely, for instance borderline ID is often included which is not in the learning disability range (DSM-IV, APA, 1994). Use of standard criteria would simplify the task of interpreting and comparing outcome studies.

Measures

Participants in the papers reviewed, tend to have mild/borderline ID, with fewer from the more severe range. Findings may not therefore generalise to the latter group. People with 'borderline' might share with people with 'mild' learning disabilities; limited problem solving strategies, a more concrete thinking style and some difficulties in adaptive functioning. These groups may have more in common than a 'mild' sample would for people with 'severe' ID. For instance, people with more severe ID may continue to need prompts to use strategies. Lindsay (1999) discusses the use of standardised measures where there are no norms for people with intellectual disabilities, and in particular adaptations that facilitate a high degree of reliability. This review indicates that adapted methodologies have been successful but further research is needed regarding how ability levels or individual needs interact with the utility of interventions. Standardised, valid and reliable diagnostic tools and measures of change will help replicability and enable cross-study comparisons. See Reed (1997) for more details.

Researchers tended to ask carers their view of changes, although one quality of life measure was used with person with ID. The carer's viewpoint may not be valid for the individual with ID. However, whilst efforts should be made to ask them, some people with ID would not be able to complete ratings scales or diaries so third party support would be needed. Mental health issues may exacerbate these difficulties. Observational techniques could be helpful but are difficult in community settings.

Consumer satisfaction measures were not frequently used. Such data tends to be positive and may not be an objective measure of change; particularly for an acquiescent group; but is an important clinical indicator. Studies don't address the issue of who judges validity and it could be a useful focus for future work, e.g. aim of interventions for different people in the system. This is particularly pertinent for a dependent group living within support networks.

The research lacked information concerning informed consent, which would be vital for future ethical research. It may be difficult for people with IDs, for instance in understanding intervention and control group allocation. Mental health experiences may further hinder this, making it difficult to conduct research, particularly with a more severe ID group. See Beail (2004) for further discussion.

Methodology

Based on the criteria identified earlier, methodological flaws were identified including lack of statistical analysis, small sample size, non comparative treatment or control groups, poor measures for diagnosis or change or those not normed for the ID population. No efficacy trials were identified. Many studies used short (or no) baselines or follow-up measures. This reduces power and increase the likelihood of type I and II errors, particularly where the predicted effect size is low, measures not sensitive or for small samples. These flaws make it difficult to establish whether the intervention is responsible for any changes shown, rather than for instance life events or other support systems, particularly for SCEDs. Larger samples have more power so one can be more confident in interpreting effects. It is not clear to what extent non-ID research generally acknowledges these possible confounding issues

Details of interventions used allow the replicability of research through using the same intervention or comparisons where they differ. For an SCED, adaptations for individual needs should be reported with the basic techniques employed. It is important that sufficient baseline, intervention and follow-up data is collected and reported, which should be feasible as part of ongoing good clinical practise. Multiple interventions make it is difficult to establish which factor is therapeutic if a change occurs or if combinations work synergistically.

Several papers mentioned the difficulties in establishing a control group due to ethical and clinical pressures. This would be particularly pertinent where people are distressed or risk of harm to self or others is an issue. In addition, informed consent might be more difficult to obtain. However, lack of a control group makes it more difficult to evaluate interventions reliably. Alternatives compared different interventions; requiring larger samples since predicted effects would usually be less. Waiting times can be used as a baseline period and pseudo control measure before an intervention is introduced. However, it is difficult to predict how willing to participate people might be

Single case designs and SCEDs dominate the literature. They are strong in external validity yet lack the statistical power or large-scale reliability of the RCT. A sample of one has no statistical 'power' and can lack credibility, particularly where design flaws are evident. Few theory-practise links were identified. It would be difficult to develop or support a theory based on a single case. Many papers do not employ statistical comparisons, even where this could be possible.

Multiple measures increase the reliability of changes recorded. There are few measures with published norms for people with intellectual disabilities, thus results should be treated with caution whilst acknowledging their utility as measures of change for the individual rather than in comparison with the population. It remains important to consider alternative hypotheses for findings.

SCED's help to evaluate individualised or adapted interventions with the advantage of clinical validity as participants come from the normal clinical pool. Since clinicians do not readily have the research option of strict inclusion criteria, SCEDs increase the likelihood of research being conducted. Where a series of case studies builds up, it gives credence to results and hypotheses, forming the basis for larger future studies. Meta-analyses would be difficult given the meagre literature, particularly for SCED's since they vary in methodology, measures, population or diagnoses included, design, generally lack statistical analysis and omit Reliable Change Indices (RCIs) (Jacobsen & Truax, 1991). Prout and Nawik-Drabik (2003) employed an alternative comparative method but measures were subjective and scope extremely diverse.

RCTs employ strict inclusion criteria such as use of treatment manuals, selected participants, same length of treatment, type of issue, level of ID and large sample. These give empirical and reliable evidence with strong internal validity, yet their external validity suffers in not reflecting clinical reality; thus results may not generalise to clinical situations. Generalisability is important for meaningful clinical utility and quality of life, is seldom addressed and yet particularly pertinent in community settings and for a client group who tend to be 'concrete' in cognitive style and may perhaps struggle to generalise. Whitaker (2000) found insufficient evidence to state whether interventions for challenging behaviours, found to be efficacious in institutional settings would work in community settings with less frequent behaviours.

Only one qualitative study was identified; Macdonald, Sinason and Hollins' (2003) explored the experiences of and satisfaction with group analytic therapy of people with ID. Qualitative research would compliment quantitative, for instance through establishing user views and perceptions of their dual diagnosis experiences. The literature will be the richer for covering a range of approaches and aiming these clearly at the specific research question in mind.

More research is needed, employing more rigorous methodology. Roth and Fonagy (1996) propose clear research methodologies for both evidence-based practise and practise based evidence. However, very real difficulties arise from the limited population of people with ID and mental health difficulties, which includes a wide range of abilities and difficulties. Only 2.2% of the population have ID; 16% with a psychiatric difficulty of some sort. It is often outside the scope of a typical clinical service to find sufficient participants to test out one intervention method on one 'problem' for a large group. This would necessitate multi-site (or country) collaboration, itself creating issues of homogeneity of sample and therapeutic application.

Implications

The types of psychological approaches reviewed have been varied. They include increasing the persons (and their systems) practical or internal coping mechanisms, or supports and decreasing environmental stressors. The research cannot yet support specific theoretical approaches given this range of interventions. The evidence is not sufficient to be convincing and no comparisons between cognitive, multi-modal or psychodynamic approaches were identified. The evidence is developing to support the use of psychotherapeutic approaches for people with ID and that adaptations to meet individual needs appear helpful.

This review indicates that ID research is very early in its evolution, mainly producing SCEDs and small clinically-based effectiveness studies with many methodological flaws. The 'hourglass pinch of Salkovskis's model (1995) is some way away. Clinicians need to be aware that approaches remain unproven. They have a responsibility to develop their practise in line with research but also to build the evidence base, particularly in the field of ID where it is developing but remains meagre

Conclusions

There is some evidence that psychological approaches can be helpful for people with dual diagnosis. This developing field has yet to address specific ‘mental health problems’ in people with ID or the experiences of those receiving services.

The lack of research about psychological interventions for people with ID who suffer psychosis or ‘hear voices’ is noticeable, despite higher prevalence rates. It is vital that we evaluate the use of ‘mainstream’ therapies for these issues and explore commonalities and differences in presentation and experiences for those people with ID. An investigative starting point could be to focus on one area of symptoms experienced such as ‘voices’ in a group that can verbally report these. Qualitative methodologies would be a useful way forward in terms of validity and richness of data in such an emergent and complex field of inquiry. They provide information, which is fascinating in its own right but can also contribute to quantitative research, generating hypotheses to be tested further. The latter is more likely to be accepted by academia and government and therefore to influence the future. In this way theories based on experiences of people with ID can be developed where appropriate, redressing the balance for such a disenfranchised client group in increasing validity of ideas used to support them.

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Exploring the personal meanings of ‘voices’ and dreams for people with learning disabilities

Abstract

This paper describes how qualitative approach was used to explore the personal meaning of 'voices' and dreams for eight people with learning disabilities using semi-structured interviews. Interpretative phenomenological analysis (IPA) was used to draw themes from the data, which are illustrated by quotations from the transcripts. The theoretical and clinical implications are discussed and conclusions drawn. Limitations are outlined and suggestions made for further research.

Exploring the personal meanings of 'voices' and dreams for people with learning disabilities

Mental health difficulties in people with learning disabilities

Prevalence figures for mental illness in people with learning disabilities vary between 10-80% (Caine and Hatton, 1998) depending on the assessment method and criteria used. Based on a non-clinical community sample, Deb, Thomas and Bright (2001) found a prevalence of 16% for 'functional psychiatric illness' and 0.4% for schizophrenia. The little research, which concerns this group tends to be epidemiological or examines the validity or reliability of assessment tools (see Caine and Hatton, 1998; Russell, 1997). (See Royal College of psychiatrists, OP 48, 2001; for discussion of diagnostic issues for people with learning disabilities).

There is developing evidence for the efficacy of psychotherapies with people with learning disabilities (Prout and Nowak-Drabik, 2003; Beail, 2003, Lindsay, 1999) but little specifically for those who hear voices. One case study found support for the use of a cognitive behavioural group approach for a woman with mild learning disabilities who heard voices (Leggett, 1997). Other studies for multi-modal approaches tend not to specify diagnostic labels (Holden and Neff, 2000; Van Minnen, Hoogduin and Broekman 1997; Tyrer, Hassiotis, Ukoumunne, Piachard and Harvey 1999). Given the lack of learning disabilities research, it is relevant to briefly outline mainstream literature.

'Mainstream' hearing voices literature

Cognitive therapy for non-learning disabled people who hear voices is an emerging field for which there is some evidence of efficacy. (See Kingdon and Turkington 1991a; Chadwick and Birchwood, 1994) Leudar and Thomas (2000) promote the use of 'focussing' and 'dialogical' approaches and state that "the outcome of our study suggests that, contrary to perceived wisdom, attending to the content and meaning of hallucinatory voices may be beneficial" (Leudar and Thomas, 2000, p147).

Knudson and Coyle (2002) used an Interpretative Phenomenological Approach (IPA) to analyse interviews of two people about their experiences of hearing voices. They considered the most notable aspects were "the relationship that they forged between the meanings they attributed to their voices and the strategies they used to manage or cope with this experience" (Knudson and Coyle, 2002). This is congruent with Romme and Escher's (1993) survey of 173 people who heard voices. They concluded that people's explanatory models developed through organizing experiences of voices and were important in learning to cope with them.

There are many theories why non-learning disabled people might hear voices (see Leudar and Thomas, 2000; Romme and Escher, 1993; Bentall, 1990). Briefly there appear to be two schools of thought. One states that schizophrenia ('voices' being a symptom of this) is a pathological disorder arising from abnormal mental processes of mental disease. Jaspers (1963) viewed schizophrenia as a biological disorder affecting all experiences and changing personality profoundly. He asserted that schizophrenia and verbal hallucinations had no meaning since they were not part of a 'connected whole'. Talking about the content or meaning of 'voices' has been seen as colluding and harmful; the implication being that psychological approaches cannot help and might be damaging.

The second school of thought would be that schizophrenia and experiences associated with it are disturbances of normal psychological functioning (Leudar and Thomas, 2000). Research thus seeks to find out how changes in normal mental processes lead to the experience of hearing voices. See Bentall (1990) for a review of this field.

Behrendt (1998) commented that “perception is thought to reflect external reality” which “corresponds to our experience” but that it “leaves dream imagery and hallucinations to be a mystery”. He suggested that internally generated perceptions are ‘constrained’ during wakefulness by the effects of external sensory stimuli. During sleep, less incoming sensation reduces and therefore internal perceptions are ‘underconstrained’ leading to dreams. He theorised that in schizophrenia, internal representations are somehow ‘underconstrained’ so that the brain reads them as ‘real’. As for other ‘mainstream research’ this theory may be relevant and would need empirical investigation since it is based on reviews of previous literature.

Dreams and people with learning disabilities

Research concerning dreams in people with learning disabilities is relevant given the potential link to ‘voices’. Kroese, Cushway and Hubbard (1998) investigated how a non-clinical group of fifty four people with learning disabilities conceptualise dreams. They found that 40% were incorrect about the non-physical, private nature of dreams and that less than a third were confident that individuals can’t share the same dreams. “In addition, a large proportion of the sample did not consider it possible to dream about fictional entities” (Kroese et al, 1998). They suggest that people with learning disabilities may have different experiences or conceptions of dreams and more negative emotions in relation to dreams “because the difference between real and dream life is unclear to them”. Behrendt’s theory links dreams and voices, which may be experienced differently too. Research to explore this uncharted area has implications for therapeutic interventions and techniques.

Aims of the current study

The lack of evidence for causes of, or therapies for, voices in people with learning disabilities, leaves little to base theories or practise upon. This research aims to explore peoples' experiences as a starting point for building relevant theories and interventions for the learning disabled population. Asking people about their dreams and 'voices' aims to explore links suggested by Behrendt (1998), for instance in the way they view real from non-real experiences. The term 'voices' is used rather than ascribe to a particular model of pathology.

Qualitative approaches can explore little known areas; "their central purpose is to contribute to a process of revisions and enrichment of understanding, rather than to verify earlier conclusions or theories" (Elliott, Fischer & Rennie, 1999, p216). The 'analytic unit' in qualitative research is the person's understanding of an issue (Flowers, Hart and Marriott 1999). It does not claim to be an accurate representative sample or generalise for a wider population but has a broad goal of transferability of findings to other similar populations (Flowers et al, 1999).

Interpretative phenomenological analysis (IPA) (Smith, 1996) aims to explore "subjective perceptual processes involved when an individual tries to make sense of his or her health condition"(Smith, Jarman & Osbourn, 1999); identifying themes arising from the data that reflect shared understandings of given phenomena. "It shares with the social cognition paradigm a belief in and concern with the chain of connection between verbal report, cognition and physical state" (Smith et al, 1999). Researchers inevitably adapt the IPA methodology as a personal process, and "the analysis itself is the interpretative work which the investigator does at each of the stages" (Smith et al, 1999). Researchers specify their conceptual framework and methodology for others to follow the empirical link between the subject matter and the emerging understandings.

Given the lack of research in the area, IPA was used since it allows flexibility in following interesting areas that emerge and is helpful where research aims to explore unknown areas. Its link between the physical, cognitive and verbal report is relevant and congruent with the researcher's epistemological position of acknowledging the difficulties of establishing an 'objective' view but that we can make inferences about people's experiences based on what they say. However, these are influenced by the context of the interview and one's interpretation of them. Kroese et al (1998) suggested that people in their study reported less confidence about saying things that might make them seem more 'bizarre ' and less 'normal'. Using the IPA approach to ask people about voices and dreams would fit with their conclusion that open-ended question elicited a range of response similar to the normal population.

Other qualitative approaches were considered. Discourse analysis (Potter & Weatherell, 1987, 1995) challenges the idea that verbal reports reflect underlying cognitions, intimating that what people say is dependent on the situation which they find themselves in. (Potter & Weatherell, 1987). This was incongruent with the proposed research, which seeks to explore how people think and feel about their world. The lack of clear theoretical premise to develop meant that "Grounded theory" (Charmaz, 1995) was not considered appropriate. This tends to assume a 'realist' objective view of the data is possible with less acknowledgement of the role of the researcher in the analytic process (Charmaz, 1995).

Method

Participants

Participants were eight adults whom their consultant psychiatrist considered to have mild learning disabilities and to 'hear voices'. Ages ranged from 18 to 50. There were 4 men and four women. Three lived in residential accommodation, three with their parents and two in their own flats.

Sample size

As discussed earlier the small percentage of people with learning disabilities in the population and the small number of those that have clinical contact for hearing voices limits the potential pool of participants. Given this and the sensitive nature of this research, recruitment was difficult. Eight was therefore considered an adequate and pragmatic sample. No changes were considered necessary following the pilot and the two people involved were included in the overall number of participants.

The interviewer

The interviewer (a white middle class female) conducted the interviews in the service for people with learning disabilities where she had worked for eight years as a clinical psychologist and had an interest in working with people who heard voices. She had not met any of the interviewees before. She hoped the research would enrich the literature both through asking people with learning disabilities who hear voices about their experiences, and by making links to emerging therapeutic approaches with this group. In particular she wondered how people's understandings of reality would influence these.

Ethical considerations

It is important to consider the issues of informed consent when conducting research with people with learning disabilities. This study included procedures for obtaining 'consent to be contacted' and clear information sheets, simplified as appropriate (see appendix iii.). These included details about confidentiality. Opportunities were provided for these to be discussed. In particular, it was made clear that they could say no at any point and withdraw from the study without justifying themselves.

Procedure

A psychiatrist or community nurse known to the person obtained 'Consent to be contacted' and gave the potential participant and their carer information sheets. A simplified version of this was given to the person with learning disabilities. Consent was then sought in an initial meeting with the participant and carer where any questions could be asked and the information sheets were discussed. The carer (paid or family) was used for a screening process where relevant items were drawn from the Mini-Psychiatric assessment schedule for adults with developmental disabilities (PAS-ADD) and the 'Vineland adaptive behaviour scale' to assess whether the person was currently hearing or had recently heard 'voices' and that their communication was adequate for the interviewing process. (See appendix iii. for copies of the screening tools). No attempt was made to present the findings of the analysis to participants. Due to extended leave three and a half years lapsed from the interviews to the completed analysis. What was credible at the time of interviews may have changed for various reasons and it was considered too long for participants' views of it to act as a credibility check.

The interview

A semi-structured interview schedule was used to provide a framework and structure to illicit participants' experiences and perspectives of the research issue using semi-structured interviews (Smith, 1995)(See appendix iii. for schedule). The interviewer's role was to establish rapport and trust, use additional prompts to clarify, follow up on or gain insight into issues arising from the participants' accounts. These were recorded on audiotape and transcribed verbatim. Copies of tapes were sent where requested to the participants.

Analysis

Interview transcripts were analysed using the interpretative phenomenological method (Smith, 1996) as follows:

Interviews were transcribed verbatim and codes used to ensure anonymity. An initial analysis involved repeated reading of transcripts. Important words or phrases were drawn from the transcripts and noted in the right margin then the spirit or essence of such words labelled as 'emergent themes' in the left margin. (See appendix iv. for excerpts). These were summarised for each transcript.

Themes of the first three transcripts were summarised in a grid (See appendix iv.). It was noted which transcript contained which themes. This provided an audit trail back to where extracts could be found to represent a particular theme in the transcripts. Any new themes were added to the grid and tested against previous transcripts. Themes were merged if similar or naturally subordinate to another. They were then grouped into recurrent themes; where arising from two or more transcripts. Transcripts were checked to ensure these captured the meanings for individuals. Themes evolved in subordinate and super-ordinate levels and were labelled carefully to convey their essential meanings. Such analysis necessitates becoming 'immersed' in the data, using 'interpretative engagement' (Smith 1996) to make insightful links yet retaining participants' essential meanings.

As a credibility measure (Elliott et al, 1999), one transcript was shared with the researcher's supervisor for the initial analysis and emergent themes stage. This sought to check that they would pick out similar words and themes from the transcript. However inevitably in the latter stages of analysis there would be differences due to the interpretative nature of this methodology and the contribution the researcher brings to the process. A research diary was kept throughout the study, recording practical issues as well as the researcher's dilemmas and influences in interpreting the data.

Results

Super-ordinate and subordinate themes emerged concerning the meaning of voices, dreams and other related phenomenon for the individual. Extracts from transcripts are quoted to illustrate the 'essence' of recurrent themes or are striking examples of these.

Figure 1. shows the super-ordinate and subordinate themes that emerged from the data. The super-ordinate theme "My Personal Other" (MPO) relates to the three subordinate themes; "Understanding 'MPO'", "Coping with 'MPO' and "Telling you about 'MPO'". The remaining super-ordinate theme; "Interactions with the world" stands alone but also influences and is influenced by the others.

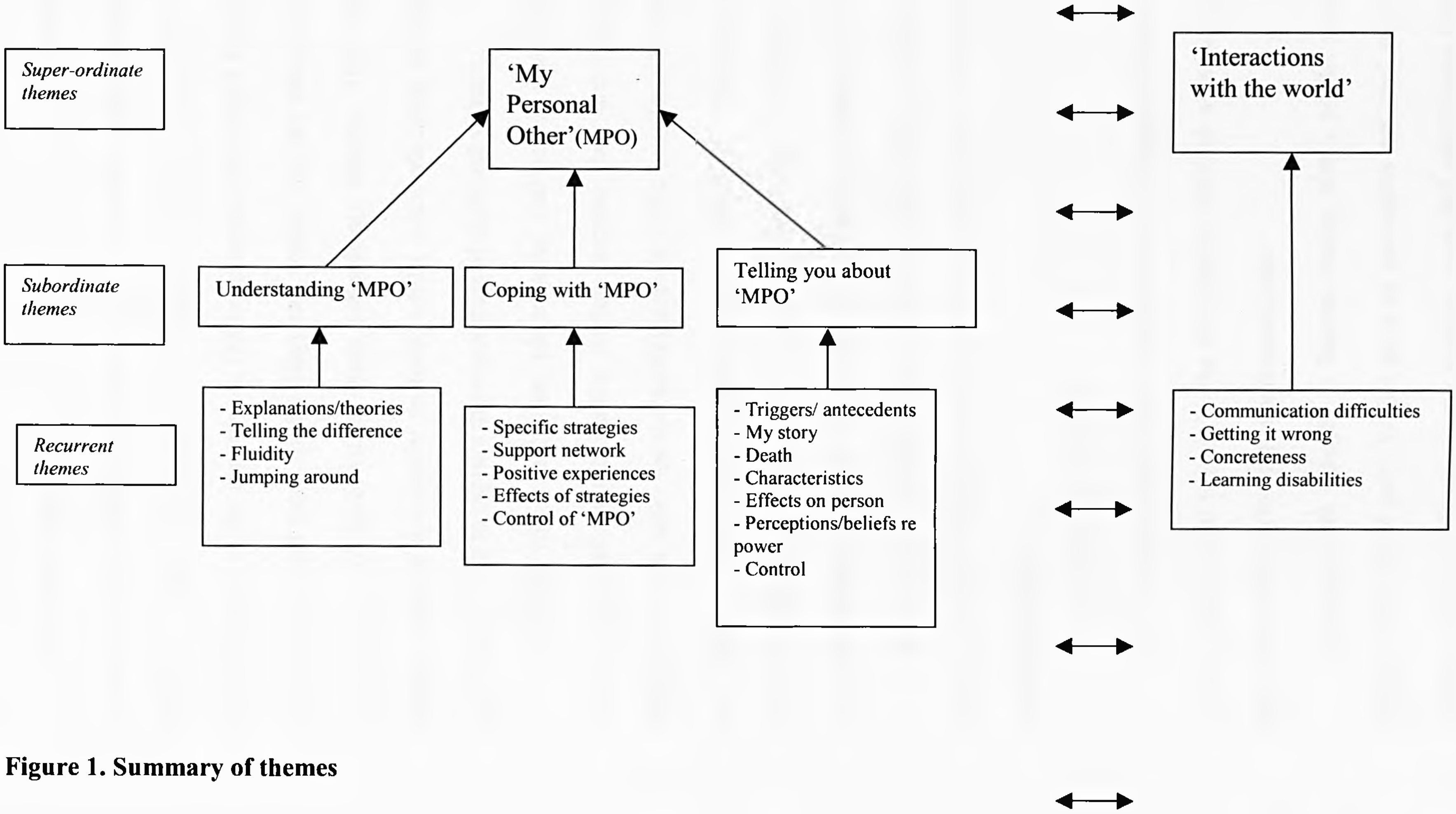

Figure 1. Summary of themes

The three subordinate themes contributing to the super-ordinate theme of "My Personal Other" (MPO) (see figure 1) are not discrete categories but grouped in what seemed the most meaningful way during the analysis to maintain the essence of what people brought to the interviews. Different researchers might have interpreted the data in other ways and some of the dilemmas around this are acknowledged. A number of recurrent themes link within these subordinate themes. The following attempts to present these in a coherent manner, whilst acknowledging the imperfections of any system that seeks to capture the experience of eight individuals.

Dreams, voices and other 'phenomena' that people described during interviews are not separated in the results section because they are closely inter-related and reflected in each other for the participants in many instances. It seemed important that the 'feel' of the data remained true in terms of meaning rather than clearly differentiating each phenomenon in separate sections. In addition, they are linked by the superordinate theme of 'MPO' and its subordinate themes as presented below.

There were a number of key differences identified by participants, which will be briefly outlined. Dreams were seen as universal in that it was thought 'normal' to experience them.

I "who else has dreams?

A "everyone, that's if they dream normal" (03-page 21, line 26)

Voices were seen as unique to the participants although some acknowledged that they had known others who had experienced them.

Dreams were thought to happen during sleep, whilst voices occurred whilst awake for the most part. Whilst most of the voices reported were distressing for the recipient, there were also some positive ones and some more neutral. This was also reflected in the variety of dreams although there were more ‘everyday’ dreams for instance about family, pets.

“My Personal Other”

This super-ordinate theme overcasts the others in that throughout the interviews participants talked about varying manifestations of an entity (or entities), which can be represented by ‘My Personal Other’ (MPO). Within the context of this interview, ‘MPO’ was what participants viewed as causing their experiences, being the source of the varying phenomena that people experiences such as voices, visions and dreams. This provided some sense of overall meaning to ‘psychotic’ and other experiences emanating from ‘MPO’, as if it were a schematic ‘filter’ on the world. For a potentially suggestible group of people, it is possible that this linking of experiences to form ‘MPO’ in part stemmed from the asking of questions about the phenomena (dreams and voices) together. However, the transcripts reveal multiple instances where this ‘MPO’ had been considered previously by the participants, demonstrated within the three subordinate themes described later. ‘MPO’ as a superordinate theme therefore seems a valid representation of the data.

Participants described relationships with an “MPO”.

A “think, I’ve got to think: I can that’s me mam, I can keep her”

I “you can keep your mum”

A “yeh, it’s me mam talking to me”

I “oh what now?”

A “yeh” (04-170 to 174)

> A "*like you could see his flesh and blood, when I put me hand through him and he's like a ghost he is and I put me hand in it and you could see his heart and that lot*
>
> *I "and what did he do when you did that"*
>
> *A "he slapped me"* (02-418 to 420).

This 'shadow' spoke, was seen in dreams and whilst awake, and could be felt physically. These entities were experienced as 'real' yet nevertheless, recognised as different to people.

> "*well they're a bit different now to how they was when, in, me dream about it"* (04-256)

The person who stated

> "*the voices speak like us*" (02-325)

makes an implicit assumption that the voices are different to 'us'. MPO appeared sentient, as in the following extract:

> *A "- social woman*
>
> *I – "uh?"*
>
> *A – " talking to me mam"*
>
> *I – "oh right sorry. What's she saying to you?"*
>
> *A – "who is it trying, what's seeing you, I said social worker" (04-200 to 204)"*

and in the way it reacted to actions of participants:

> "*well sometimes the voices are nice sometimes and sometimes if I don't listen they turn really horrible"* (02-485).

The extent to which 'MPO' was regarded as sentient varies between people and which experience they refer to. For some, 'MPO' was used to convey the experience of a medical illness and all its manifestations

A *"Well I got schizophrenia in't I"*

I "have you"

A "yeh"

I "right"

A "that's a part of it in't it, hearing voices and that"

I "it's part of the schizophrenia?"

A" yeh" (01-26 to 32)

and

A "well it's confusing for a start, I managed to get to a psychiatrist and they said you've got schizophrenia"

I "yeh"

A "schizophrenic"

I "yeh, what does that mean?"

A " hear voices, some people have hallucinations and things" (01-61 to 65)

For others all experiences relate to each other as part of the same 'MPO' such that descriptions of them 'flowed' between each other. For instance, one person hears voices, dreams about these voices and sees shadows, spirits and ghosts coming from walls that create the voices and are in the dreams. Another has a core experience of the 'shadow' in dreams, voices and sees and feels 'him' whilst awake. This 'fluidity' between experiences will be explored later in terms of people's theories and how they make sense of the phenomena.

Participants implicitly and explicitly knew that "MPO" was different from 'normal' experiences but was nevertheless very real. "MPO" forms the basis of a schematic pattern and meanings attached to this; a core theme that pervades participants' worlds and their way of being.

"Understanding "My Personal Other""

This subordinate theme demonstrates people's understanding of 'MPO' and their efforts involved in developing this. An element of 'testing out' occurred in the interviews suggesting that this development continued. This theme is not always clear or coherent but is vital in appreciating people's experiences. The recurrent themes within this illustrate different aspects of participants' discovery process.

Explanations for the purpose and origins of phenomena

This recurrent theme was striking in its universality. All participants sought to make sense of their experiences, finding meaning in these and developed theories and explanations, which were both implicit and explicit. These were more developed for voices than dreams, which seemed to be regarded as more 'ordinary' and in less need of explanation.

> *"My dad and mum used to. I know my dad did, my step dad did, used to dream a lot, about the war and different things*" (01- 379)

Theories about dreams were perhaps more implicit and participants were able to discuss their understandings if asked. Nightmares were frequently linked as part of the overall 'MPO' experience;

> *I "so what is it you dream about, what's the nightmare about?"*
>
> *A "about voices, hear voices*" (08-34 to 35)

More positive dreams appeared to be seen as separate:

> "*I ride a unicorn or something like that*" (02-113)
>
> *"that I met Eninem in real life" (02-121)*

One person described different 'phenomena' as coming from different physical locations:

A *"there's a graveyard, the cemetery... well I go sometimes there and I see pictures from there (06-92)....from the sky when you look up (06-123)";*

I "*where do the voices come from?"*

A *"from B"* (a city) (06-395).

Other concrete sources of phenomena included;

"from the tele." (07-318); (nightmares and voices*)*

*"comes from the back of my head" (*nightmares) (*08 -94)*

Theories about the origins and purpose of phenomena were implicit and explicit. They cluster into medical, psychological, spiritual/religious, extra-terrestrial and others. Medical theories included ideas of illness or injury;

"*I managed to get to a psychiatrist and they said you've got schizophrenia*" (01-61),

; "I had them when I was poorly" (07-354).

An implicit idea that something cerebral causes voices is illustrated by:

"X said why don't you go for a brain scan or something like that, cos I get a pain in me head when they're there" (05-262).

Psychological theories are highlighted by the following quotes;

"*well I think I can hear them talking....but you can't really. Just your mind innit"* (01-20);

"*always thought they were about pretend people*" (dreams) (07-124),

"think it's just inside me head" (07-310).

A range of spiritual or religious ideas were mentioned such as;

"from the graveyard.....skeletons..... Christ, Jesus Christ from the cross" (08-414 to 420)

Extra-terrestrial explanations included:

> "*thought they were, something from another planet*" (voices) (02-258),

This search for meaning and explanation was an ongoing process, perhaps more so where the onset of experiences was recent or constantly changing.

> "*cos it's not easy at the beginning, that you wouldn't understand, but as the months and the years go by, you are learning, now it's an illness*" (03-page 5, line 5 to 3)

Participants expressed uncertainty about their theories and strove to make sense within their framework of understanding.

> *A "I don't think you can hear them as such can you"*
>
> *I "you can what?"*
>
> *A "don't think you can hear them as such; think it's just your imagining"*
>
> *I "uhm, how do you know?"*
>
> *A "I don't know, I think it is" (01- 301 to 305)*

This man used external evidence for his views:

> *A "Well it's not, you know, magic people, it's imagination innit, might be able to hear people I don't know"*
>
> *I "right"*
>
> *A "it's in my case notes a lot anyway" (01-311 to 313)*

Struggles came where internal beliefs or models did not match what the person had been told by others. For instance where a person experienced phenomena as 'real' but took medication to make an 'illness' go away.

Some participants related experiences as linked through a single entity, rather than viewing them as arising from separate sources. This implicit and explicit assumption pervades their explanations and theories about their experiences. They did not see voices, dreams, visions etc as the same thing but as manifestations of the same thing. Their understanding and theories associated with this are central to the concept of 'MPO' as a super-ordinate theme. It was not always clear whether the implicit assumption whilst experiencing 'MPO' came first or the linking of different phenomena as of 'MPO' as they strove to make sense of their experiences. However, one might propose that the implicit assumption occurred followed by an interweaving of experiential evidence over time that implicitly confirmed the experience of "MPO".

Telling the difference

A recurrent theme of 'telling the difference' illustrates the efforts people made to make sense of their world on a day-to-day basis, showing they were not the passive recipients of 'experiences'. For instance in considering how 'voices' sound different;

I "how do you, well, if it's in you imagination, how is it different then from voices you hear when people, say I'm here, sitting talking"

A "*not so clear sometimes*" (01-316 to 317);

Or:

I "how are they different"

A "speak funny, speak phone, speak phone"

I "phoney?"

A "no, it's like different people, sometimes, different things all the time"

I "different things all the time"

A "yeh, uhm"

I "so what was the phoney/funny word? You know the one I couldn't understand?"

A "…………and dizzy……………and dizzy"

I "dizzy?"

A "yeh"

I "is that how you're feeling now?"

A *"yeh, hear voices now, hear voices now*",

I "right so you're dizzy when you hear the voices",

A "yeh, yeh" (08-320 to 332);

or that they can be heard at the same time as the person speaks

"*Sometimes when I'm talking I hear those voices*" (06-409).

The use of the term "those" in this quote suggests an understanding that "those" voices are different to people speaking. This differentiation also occurred for dreams;

"that weren't a dream that were real" (04-86)

One person described the process of 'telling the difference' for her:

"I hear them talking things and that, see, it's it's, you got to think, oh that's them, and that's the illness. You know you got to, uhm, sit there and think, you know, is it right or is it wrong?" (03-page 6, line 5 to 8);

I "how do you tell the difference then?"

"*because your thoughts tell you something, that you hear in the distance after" (03- page 6)*

"I know I used to feel very ill and that I could hear it so clearly" (voices) (03-page 6, lines 20-21)

Both implicit and explicit beliefs and assumptions emerged through participants' accounts. Unsurprisingly they differed and could be contradictory for and across individuals. Two participants believed their voices stemmed from illness and were not 'real' and yet their dreams could foretell the future and had experience of this happening. For instance:

"*dreams can come reality, dreams that shouldn't come reality"* (03-page 21, line 20)

Some participants made implicit assumptions that experiences can be invented and may not be real;

> *"they're not real....they're invisible"* (pretend people with voices) (07-401)

By trying to tell the difference these participants perhaps assume 'MPO' is not real or that it is different in some way. The person who says:

> *"well they're real voices they are"* (04-246)

implies an assumption that there is an external reality and one which can be created. It is important to consider the influence of other people on participants' views. People with learning disabilities tend to be compliant and used to having their views corrected. It is therefore possible that through compliance or suggestibility some of their statements echo what they think the researcher would want to hear or what they have been told in the past.

Fluidity

A strong recurrent theme that emerged was 'fluidity' or 'loose boundaries' between phenomena,which 'flowed' or merged into each other. For example, one person (02) dreamt of the 'shadow', which was the origin of her voices. She saw the shadow whilst awake, had felt him and could describe what his internal organs felt like. She also dreamt of voices. These were experienced as different parts or manifestations of the same entity. In this way, 'MPO' held a coherent identity, which would lead to 'fluidity'.

> *"the only, the last thing I dreamt was the pictures that I see" (06-71)*

Fluidity is also apparent where one person dreamt about the voices she heard;

> *"I dream about these voices...........only they're the same voices"* (04-258)

Others might have interpreted 'fluidity' as evidence of psychosis since it could be indicative of 'pathological' changes in thought processes and associations. However, this analysis sought the meaning for the participants of their experiences and the linking of phenomena within this seems important in influencing their search for meaning over time.

Jumping around

'Jumping around' captures the disconnectedness that occurred during interviews. Stories jumped from one thing to something apparently not connected. This illustrates the interviewee's confusion in making sense of and describing their experiences in a way that the interviewer understood and vice versa. Such confusion may stem from 'psychotic thought dissociation' combined with the impaired problem solving of learning disabilities.

> *A "I see, I look at the flat that it's all there set out for me and ready, then if I go over the road they're going to take my stuff, cos these people that in the flat if I go out the flat they take me keys and me flat, oh where me keys oh aye it's in your pocket have a look, go and fetch em back, I mean they're telling me lies, cos that's future, or have I done it before and I can't just, I find it so hard to know if I've done it before or not*
>
> *I "so it's hard to know sometimes whether you're thinking about things you've done before or whether it's things that are going to happen"*
>
> *A "true I am, cos the way the people sound like it sounds like it's all past and I know it all and they've been on these machines all round me head trying to forget it"*
>
> *(03-pages 22 to 23)*

The strong emotions emerging during the telling of the stories may have increased the disconnectedness as well as the communication difficulties. The two recurrent themes of 'fluidity' and ''jumping around' were both striking during the interviews but initially appeared incongruous and confusing to interpret. Although it is not necessary for all themes to be congruent, it was part of this researcher's interpretation to attempt to reconcile themes in the context of others and then consider the implications of this. "Fluidity" illustrates how experiences of the phenomena flow into each other; "Jumping around" is the way the story is told and may be accounted for in part by the impact of 'fluidity' on the listener. If the participant experiences the world in a way that is not immediately obvious to the listener then the listener may experience this as disconnected because it is not in their realm of 'normality'. This would be important clinically or in future research.

The themes contributing to 'Understanding MPO' are the context for the super-ordinate theme of 'MPO'. The other two subordinate themes link closely as people told how they coped with 'MPO' and described it.

Coping with 'My Personal Other'

Participants in this study related both positive and negative experiences of 'MPO'. However, a need for coping strategies assumed a negative experience and formed an important part of people's stories. Recurrent themes included: specific strategies, supports networks (including supportive voices), positive experiences, and effects of specific strategies.

Specific strategies (including effects of treatment and the system)

Various strategies were used to cope with distressing voices and bad dreams. These tended to relate to the individual's understanding of 'MPO'; for instance a person who felt their experiences stemmed from ghostly or satanic influences might use holy water. Most participants used a range of coping strategies including:

Ignoring the voices;

> *"they tell me to have a lager and that but I say no I can't cos I'm on tablets" (05-170);*

medication;

> *"but that ECT took some of it away I think*" (01-250)
>
> "*see if it's not for the tablets I'll just fall ill again*" (03-page 28 – line23);

distraction;

> "*used to try and read or listen to music*" (01-457);

relaxation;

> "*well what you've got to do is slow down, relax, listen to some music, try and slow your mind down*" (03-page 7, line19);

drinking;

> "*I drink holy water*" (06-226);

Uncertainties were expressed about coping strategies:

> "*don't think it does you harm though does it, not after convulsive treatment…don't think it does anyway. The psychiatrists gives it you don't they*" (01-159 to161);
>
> "*I don't think it's the tablets that get rid of it, it's coping with it to be honest*" (03, page 3, line11)

Support network

These were clearly important in people's lives and ranged from family, friends, pets, professionals, work colleagues and the voices and/or dreams.

> "*my granddad told me to tell it to go away and leave me alone…my grandma said the same thing and me auntie goes, me auntie goes, if you hear them voices you can talk to me*" (02-386);

Pets;

> "*they're to do with the family I've got....got four lovely cats I have*" (04 - 58 to 60);

Friends;

> "*One of the chefs said 'you alright mate' and I said 'I'm alright'*" (05-542);
>
> "*Good doctors, kept me out of here for a few years anyway*" (01-541);

Mutual support through sharing of experiences could be helpful and appeared to imbue self-worth;

> "*think perhaps I've helped him, he says oh thank you X you've helped me*" (03-page 10, line 21)

Where the voice or dream was described as helpful or supportive it became a coping method in itself rather than something to be coped with.

> "*voices are helping me I think...by what they say*". [04-276 to 280];
>
> "*hear my dad say I'm a bit confused, so he's trying to put me on the right track, but then he don't come to me sometimes*"(05-78).
>
> "*If I'm bored or fed up and I talk to him at the grave" (05-90)*

It seemed that where participants lacked care from others the voices provided this or represented the continuation of a relationship severed by death.

Positive experiences

Participants described 'everyday' aspects of life and its importance to them. These provide positive quality of life and serve to protect against negative experiences or fears;

> "*when I was working I loved the job, it was something to do, keep me occupied*" (05- 540)

> *" used to have some lovely pictures, at that time I were picture mad, every time I went out I used to buy a picture" (04-220);*

There was a sense of fragility in the life style they had achieved;

> "*I want to live my life with all the hope in the world*" (03 – page25, line17),

fearing what could happen if they said or did the wrong thing and what could be taken away from them;

> "*cos if I explain that people are going to get the wrong end, not the right end*" (03- page22, line 20)

Despite such fears, some participants remained positive about the future

> *"I've got lots to look forward to with my flat and that, I'm proud of it"* (03-page 25, line 6)

Time itself was helpful, giving some people resources to feel resigned or neutral about their experiences:

> *"just years of voices" (01-119)*
>
> *"got used to it now" (01-248)*
>
> *"yeh know it's not a nice thing you understand but I just feel as if I've got a lot going for me" (03-page 11, line 13)*

For these participants, current lack of affect was evident in their accounts and contrasted with emotions conveyed when talking of the past.

Effects of treatment or other strategies

Not all attempts to cope were viewed as successful.

> *"one lot of that convulsive treatment... yeh I signed for it, signed too soon I tell you; leaves you a bit funny for a few days…….bad headaches for years after that" (01-127 to 147)*

I "you know the ECT, did it do anything about the voices? Did it change them in any way?"

A "No!" (01-156 to157)

One person related how his attempts to talk to staff did not change the voices

I "who do you talk to about them?"

A "staff"

I "what's that like, talking to them?"

A "alright"

I "does talking to staff change the voices?"

A "no, stay and talk, stay and talk, still hear them"

I "you still hear them"

A "yeh, I hear them now"

(08-387 to 394)

The major theme of 'Coping with 'MPO'' shows how people found ways to cope both with the phenomena described and the effects of these in everyday life. Ways in which learning disabilities and 'psychosis' might interact with coping are explored later.

Telling you about 'My Personal Other'

This subordinate theme represents participants' stories, both in their details and in the importance and processes of the telling. They relayed a rich history, making concerted efforts to share this despite some misunderstandings in the interviews.

I "did you tell Dr X this week?"

A "no, feel ....? sometimes"

I "you do what?"

A "hem, myself, hem, cut yourself"

I “hem – that’s the word I don’t understand”

A “it’s like cutting yourself off”

I “hang?”

A “no, sorry, I get confused with words”

I “it’s OK, sorry, but you mean to cut yourself off?”

A “yeh” (05 -553 to 562)

“Telling you about MPO” includes a number of recurrent themes arising from the data such as triggers, my story, death, characteristics effects on person, perceptions/beliefs re power and control. In some ways it is the most difficult of the subordinate themes to condense in a meaningful way since people’s descriptions varied greatly and the details mattered to them. The following attempts to present the essence of these.

Triggers/antecedents

All participants had come to some understanding about things that preceded their voices or distressing dreams. The level to which they had processed this and recognised them as triggers varied.

I “who else has dreams?”

A “uhm usually my little sister does”

I "right"

A "about when she watched a horror film cos she don’t like horror films, sometimes she wakes up: sometimes I wake up when I have a horrible dream, horrible one”

I “yeh, do you know what sets dreams off?”

A “yeh, when you’ve had a bad day or summat” (02-146)

Or:

I "you said you get wound up sometimes"

A "yeh"

I "uhm, do the voices happen before that or after?

A "ooh, after!" (04-291 to 294)

The people who seemed more aware appeared to be those who coped better; thus understanding related to coping and the way experiences were described.

My story

Participants seemed to regard the interviews as an important opportunity to talk about and record their experiences, as well as answer questions:

(Participant gestures to the paper)

"What do you want me to write down?"

"bout the voices.....and spirits....and spirits, spirits,....and ghosts and skeletons" (08)

The experiences and understanding of phenomena changed over time, for instance:

A "when it happened, voices came and pictures came and very were scaring me"

I "yeh"

A "couldn't work, couldn't thinking, couldn't write too"

I "couldn't write"

A "my hands are shaking"

I "not a good time for you. What did the voices say?"

A "go away, get out of the way, and something like a snake, pictures were coming, a big snake"

I "uh-huh, what did you think of that?"

A " it was scary and I couldn't do anything"

I " right, so the pictures then were scary as well"

A "yes!"

I "so they're different to how they are now" (06-307 to 318)

Telling the story lead to strong affect for some. One man appeared calm whilst talking about his current experiences and did not use emotional labels yet whilst relaying his previous experiences appeared agitated and used clearly emotive language. This linked to 'Coping with MPO' since time appeared to lessen affect or distanced it.

A "yes they make me sleep. When I wake up this thing frighten me, then. Now it's not any more, it's gone away" (06-289).

Repetition occurred throughout the interviews. At times it was a result of misunderstandings concerning questions or answers and at others seemed to be a way to emphasise their story.

I "what we were going to talk about was dreams as well as voices"

A "yeh yeh yeh, and nightmares and dreams, nightmares

I "yeh"

A "nightmares"

I "what kind of nightmares?"

A " shouting in sleep, shouting in sleep, shouting in sleep"

(08-16 to 21)

Death/bereavement

Death featured in several accounts. The researcher struggled to decide whether this constituted a recurrent theme since it seems pervasive through other themes. For instance participants' theories and understanding about their experiences are conveyed as important in their stories, for instance where devils or spirits are origins of voices or dreams, then these are significant in that person's account.

> *I "the spirits are in the wall but do you know where they come from before that?"*
>
> *A "from the graveyard"*
>
> *I "the graveyard"*
>
> *A "the skeletons"*
>
> *I "whose ghosts are they?"*
>
> *A "uh?"*
>
> *I "are they of a person or?"*
>
> *A "yeh, Christ, Jesus Christ, Jesus, Jesus, Jesus, from the cross" (08-413 to 420)*

Characteristics of phenomena

It was striking to hear the details of the phenomena that people experienced and the richness in their accounts. These ranged from particular details such as colour, clothes, tone of voice, smells, emotions to opinions of the phenomena about events and people the participants knew, as the 'sentience' of 'MPO' emerges from the data. A few characteristics are as follows:

> *I "so what else happened in the dream?"*
>
> *A "went shopping, popped in the paper shop and got four tins of cat food and then the bag were beginning to get heavy so I come home then and went home*
>
> *I "uhm"*
>
> *A "and then I said to Blackie, momma's come back now, with all the bags, two bags, I put em away and I said to Blackie, I'll go and have me tea now, a tin of*

tomatoes, egg and bacon and that and tomatoes. About me dreams and dreams all muddled up at the moment" (04-68)

A "Yes can you hear them? You can hear them moving; you can hear them moving about"

I "moving about?"

A "in me head"

I "in your head"

A "yeh, like a drum's beating in your head" (08-404 to 408)

Although the interviewer asked about voices and dreams, participants also described a surprising diversity of different phenomena such as flashbacks, cartoons, spirits, shadows, pictures, devils, ghosts and angels.

Effects on person

Unsurprisingly, people were affected in different ways by their experiences. Direct effects included feelings evoked or poor sleep:

A "yeh I can, well, uhm, last night I had a dream about, last night"

I "yeh"

A "and night came and like, I seen this shadow, seen the shadow"

I "yeh"

A "he's black and he's got red eyes and he's telling me to do horrible things to my family"

I "right. In your dreams?"

A "yeh Like I've got to kill my mum and step dad and all that but I just ignore it I do"

I "right, what's that feel like then, to have a dream like that?"

A "feels really horrible and I couldn't get any sleep I couldn't" (02-12 to 20)

Indirect effects included jobs lost or children being removed from the persons care:

A " not very happy, it depressed me becos I wanted to keep me kids"

I "right. What were the voices about then?"

A "take baby away, that's one thing, or has she done anything wrong yet, you know" (03-page 8, lines 19 to 23),

presumably as mental health difficulties affected daily functioning.

Own perceptions/beliefs re power of phenomena

Some fears arose from a sense of the power of voices and dreams such as foretelling the future:

"sometimes dreams can come true...I said I wish me granddad were dead...and he died the following day and I felt guilty" (05-368 to 372)

This included a sense of blaming the voices for their own actions:

"and I tell her. done terrible thing, bad things and she said 'it's your own fault' and I thought the voices were wrong again" 05-466)

Control by 'MPO'

'Control' creates a need for "coping with 'MPO'' where a person felt controlled by phenomena;

"they won't let me concentrate ...... it makes me move" (06-151 to153)

"it's something like I've got no will, well I ain't got a will, it's like a robot that controls" (05-494)

Where control appeared malevolent, conflict or violence was experienced as feelings of paranoia or persecution.

"Trying to kill you" (08-426),

"it's like someone's got a tape recorder in your bedroom, coming to spy on me, felt trapped and I thought, how they spy on you" (05)

Voices' or entities could be positive or negative at different times and sometimes in reaction to the behaviour of the recipient, got louder and nastier if they didn't listen.

"it's like a whisper you know, do this, do that, then I try to say, say something, no I can't do that……then it gets stronger, starts, it shouts " (05-214 to 216) '

For some, this feeling of malevolent control may reflect previous negative experiences rather than be a result of phenomena.

"well I only heard voices when I was 14, then when my brother and my stepbrother locked me in the room I saw the shadow"(02-390)

Feeling controlled by phenomena is significant for participants, particularly where their attempts to cope have not been successful. They described behaviours in response to this that the 'world' may view as unhelpful but which make sense when viewed as reactions to 'MPO'.

A "sometimes I might do something stupid like that"

I "like what?"

A "that when I got, one time I went to my brother and I got a piece of glass and I cut me arm up" (02-158 to 160)

A "you know get a knife and slash it up, then nobody would have the settee. That's how I felt"

I "and where did the voice come in?"

A "the voice came in and told me to get a knife and slash it up" (05-116 to 118)

As mentioned earlier, the essence of this subordinate theme of "telling you about MPO" is complex. Perhaps more than the other subordinate themes, it encompasses the roles of storyteller, listener and the processes between them. The efforts and struggles within this were important to come to an understanding. The next section concerns the super-ordinate theme "Interactions with world" and will consider further some of the influences upon the three subordinate themes to 'MPO'.

Interactions with the world

This second super-ordinate theme represents the participants' struggles to interact with the world everyday. The recurrent themes contributing to this represent aspects of what complicates the interactions, including communication difficulties, getting it wrong, concreteness and learning disabilities. These are frequently part of having a learning disability but also psychosis and these will interact with each other.

Communication difficulties

These arose during interviews for a number of reasons, which are likely to be reflected in everyday life. This included two-way misunderstandings between the interviewee and interviewer

"I get confused with words" (05-560)

'Voices' or 'pictures' could interfere with the conversation during the interviews:

"yeh there (gestures), I hear voices now" (08-96)

"he's coming back.... Trying to kill me" (08-424 to 426)

There were instances where people contradicted themselves during the interviews and it was not always clear whether this was due to their having contradictory understandings, communication difficulties or whether acquiescence occurred. For instance:

I "so what else happened when you heard the voice about Kylie Minogue?"

A- yes they keep saying it

I -they keep saying it"

A "yes"

I "they say the same thing?"

A "The same thing but different things

I "Can you tell me something they said?"

A "Sometimes they said I'm fat" (07-167 to 176)

Where participants did not give very detailed accounts, this appeared consistent with their general presentation. For example:

I "can you tell me, what is a dream?"

A "uh, about a dog"

I "about a dog"

A "his name's X"

I "X"

A "yeh"

I "what does X do"

A "plays with me with balls"

I "how do you feel when you dream about X?"

A "well it's alright, he likes playing and something to eat"

Simplicity can be as meaningful as more complex accounts if that is how the person communicates about and experiences life.

Getting it wrong

Participants talked about times when they were unsure about things they had done or said:

A "yeh and uh, I got confused and I thought I'll go outside"

I "right"

A "I felt trapped, thought has I done the right thing or the wrong thing in that way" (05-126 to 128)

Their experiences could leave them confused; their history of getting 'things wrong' reducing self-confidence in their own perceptions or actions;

" you know it hurts me to hear it inside, that person inside say do something about it, I can't do anything about it and you get more confused" (05-344).

Concreteness

Accounts implied assumptions, which were inherently concrete such as 'if I believe them then it must be true' or 'if I experience them then it must be real'.

I "Is this in a dream?"

A "no this is real, this is future"

I "right"

A "but it's not happened yet"

I "right, so how do you know about it?"

A "cos, something there that tells me that I know it's going to go off"

(03-page 16)

I "how do you tell, what's real and what isn't real?"

A "the devil, well I believe in the devil and God and that, but"

I "uhm"

A "what did you say again?"

I "how can you tell what's real and what isn't?"

A "what's real and; well all of it's real!" (02-333 to 338)

Concrete thought and interpretation of the world was pervasive in some accounts. For instance concrete origins of phenomena

I " do you know where they come from?"

A "like sometimes when I go somewhere, you know like Safeway, you know that, Safeway?"

I "the shop?"

A "no, the supermarket and there's a graveyard, the cemetery"

I "oh, in X, yeh"

A "there, well I go sometimes there and I see pictures from there, sometimes near the church" (06-87 to 92)

This concreteness influences the way people interact with the world, giving them a very literal interpretation of what they experience.

Learning disabilities

This is a recurrent theme due to its pervasive presence in the interviews rather than being explicit in the data. Participants did not mention learning disabilities but did talk about poor memory, confusion, and finding it hard to understand questions and events in their lives.

I "can you tell me about a dream that you've had?"

A "don't know quite what it said"

I "you heard? What was that?"

A "no I forgot, sometimes I remember sometimes I forget, it's ever so difficult" (03-page 1 line 21 to page 2 line1)

People with learning disabilities often have difficulties in understanding and/ or expressing language:

> *A " I get confused when people ask me questions"*
>
> *I "right"*
>
> *A "I don't know how to answer sometimes" (05-302 to 304);*

or impaired daily living skills

> *A "Sometimes I'm scared at work cos I have to clean the knives and that"*
>
> *I "at work?"*
>
> *A "yeh I do the washing up for the chefs"*
>
> *I "right"*
>
> *A "and they've got a load of knives sharp knives. I cut myself now and again"*
>
> *I "on purpose or?"*
>
> *A "no"*
>
> *I "no"*
>
> *A "uhm I feel real scared you know. I'm scared I'm going to pick them up and use, and how to hold them and that, whether I'm doing the right thing or the wrong thing" (05-42 to 52).*

Dependency is often a feature of their lives:

> *"well I used to wake up and I can hear my mum's voice telling me to get up – have some breakfast, then you have bath so I got up and got some clothes on" (07-274).*

The data implicitly suggests that learning disabilities are meaningful for participants in the context of their interactions with others and the world.

Discussion

This study aimed to explore the experiences of people with learning disabilities concerning their dreams and ‘voices’. The themes arising from the data show a fascinating insight into these (and other) experiences and the meanings they ascribe to these.

The analysis indicates the super-ordinate theme “My Personal Other” (MPO) representing the source of phenomena they experience, pervading their lives and interactions with people and things. ‘MPO’ held different forms but for seven of the eight participants it was described as if it were sentient. The transcripts revealed implicit and explicit assumptions about a concrete reality of ‘MPO’ and their relationship with this entity in its different manifestations.

Their understanding of ‘MPO’ influences the way they cope but in turn their experiences of coping with ‘MPO’ affect how they understand ‘MPO’. This indicates a dynamic process of discovery that continued during the interviews. For participants, telling their story was important both in being listened to and as a chance to tell the details of their personal experiences. In a world that often disapproves of talking about voices and has little time to listen generally, this seemed a precious opportunity.

‘Interactions with the world” for people with learning disabilities, are made more problematic by experiences of ‘MPO’ which others might frame as psychosis. In turn, people’s experiences of ‘MPO’ are affected by their customary difficulties in interacting with the world. It appears that a synergetic process emerges where people’s learning disabilities and concreteness affect the way they understand their ‘psychotic’ experiences. If they assume that experiences are concretely real then where phenomena link in content or theme then somehow they ‘must’ emanate from the same presence or

MPO. Even where this 'MPO' is framed as an illness it retains a concrete identity with which a personal relationship exists.

Participant's overriding issues concerned 'MPO' and the three subordinate themes attached to this. The 'interactions with the world' appeared more secondary to them and more implicit in the data. This may be because they had been invited to talk about voices and dreams rather than their learning disabilities. It may also be because 'MPO' provides an explanatory framework and gives coherence to self in the midst of 'psychosis'. Perhaps their learning disability has always been part of them but their 'personal other' is new (er) and in need of explanation.

Strength of findings

For this qualitative research, the concepts of reliability, validity and statistical power weigh differently from those in quantitative studies. Qualitative research does not attempt to prove reliability or statistical power but seeks data that is valid based on rich testimonial evidence from a small number of participants. Validity of the data is strong for the individuals yet reliability is unproven. The aim of transferability can only be ascertained through further studies and perhaps through clinical experience.

A credibility check (Elliott et al, 1999) was to use a supervisor in the initial stages of analysis to confirm that emergent themes were recognisable from a transcript. As mentioned in the introduction "testimonial validity" was not sought (Elliott et al, 1999) and ideally this would have been used. A clear audit trail from transcripts to later stages of analysis and conclusions arising from these also provide a way of replicating to some extent whilst acknowledging different 'creative interpretations' inherent in IPA.

For a county population of one million, Deb et al's (2001) non-clinical community sample suggests 100 people with both learning disabilities and a diagnosis of schizophrenia. This potential 'pool' is relatively small, since not all would have contact with services at any one time and it proved difficult to recruit participants. Small-scale studies such as this one are a pragmatic as well as meaningful way of conducting research within demographic limitations.

Whilst there are limits to the conclusions that can be drawn from this data without further research, it provides a clear process of analysis and interpretation to elucidate a field where little previous research exists. The theoretical and clinical implications of the results are discussed as follows.

Links to previous research

This research was not designed to test existing theories but adds to the body of evidence from other research both of people with and without learning disabilities who hear voices and have dreams or other phenomena

'MPO' represents an overarching explanatory framework, which illustrates how people are poised within their own world of meaning yet moved by and moving external influences. Although this may not concur with the views of others, it is meaningful to them and embodies their history and efforts to develop understandings and ways to cope with distressing experiences.

This is interesting in connection with Jasper's (1963) assertion that for something to be meaningful it has to be part of a "connected whole". The results of this study suggest that voices and other phenomena form part of a whole represented by 'MPO' and their understanding of 'MPO'. It is not clear how congruent this 'whole' would be if it were possible to compare it to their pre-morbid selves or in connection with co-existing schemas. Further research could explore this. However, the disintegration of self, described by Jasper (1963) is not consistent with 'MPO'. The coherence of self may therefore change with the onset of 'voices', encompassing new elements, which prove elusive without careful efforts to comprehend the person's understanding. This appears to be more consistent with the idea that 'voices' arise from changes or disturbances in 'normal' mental processes as discussed in the introduction.

The work of Romme and Escher (1993) and Knudson and Coyle (2002) point to the importance of people building an explanatory framework in developing coping strategies for their voices. This research would support that view. However, it would suggest that the experiences of coping also feed back into the framework of understanding and the relationship with 'MPO'. For some, the act of seeking help at the beginning of their experiences shaped their understanding and vocabulary surrounding 'MPO'. For instance taking on board a medical label for their experiences shaped their coping strategies of using medication.

Participants struggled where life was dissonant to their 'MPO'. Cognitive dissonance theory (Festinger, 1957) would suggest that they would filter out information inconsistent with their views. The individuals who had experienced 'MPO' for longer appeared more accepting of its different manifestations (voices, dreams, visions etc.) They had developed more complex theories and attempted to reconcile ongoing experiences with these. Their coping strategies had been tested over time and they retained the more successful, identifying when strategies could prevent deterioration.. Their affect as they told their stories was generally less distressed than two people who didn't have helpful strategies. This could reflect particular crises that they were experiencing at the time, which made it hard to use strategies or an ongoing difficulty. Further research could investigate how longevity of 'voices' influences affect and whether this correlates with success of coping strategies.

Knudson and Coyle's (2002) IPA study of two non-learning disabled people who hear voices bears striking similarities in themes arising from this study, including the search for meanings, particularly when they first experienced voices; the struggle to match experience to understanding and that understanding affected coping. However, notable differences include the lack of "interactions with the world" theme and also their more complex data. Current participants were less likely to discuss issues at length perhaps due to communication and cognitive difficulties, concrete thinking and less experience of being listened to. However recognising that shared themes can be expressed more simply helps build a knowledge base.

Simplicity should not rule out a group of people from a research methodology any more than it should restrict their access to clinical approaches. Further research requires time and energy in listening to people with learning disabilities, adapting to meet their needs and innovative ways to record information from communications sources other than purely verbal if we are to include people with more severe learning disabilities. It will help us build knowledge that is pertinent and develop practise that is effective.

Kroese et al (1998) found that many of their participants could not distinguish between dreams and real-life. The current findings would support an extension of this to include voices and other phenomena where people struggle to distinguish real from non-real events. Concrete perceptions of phenomena seem relevant here as people described sentient entities with whom they had a relationship.

Implications of these findings question conventional views of what is real or not. Some participants in this research worked hard to tell what was real or not but would construe parts of their experience as 'real but different' when 'observers' might assume them to be unreal. What seemed important to them was that they were believed and taken seriously in their experiences, whilst knowing (often from experience) that others did not share their views and would discourage these.

In considering Behrendt's (1998) assertions that dreams and voices are both the result of 'underconstrained' perceptions, this research was not designed to test them. However, it suggests that for the individual, dreams and voices can be linked in meaning and explanatory framework. Asking people about both voices and dreams was valuable in eliciting links that would not otherwise have been clear. Interviewer expectations shape questions used in semi-structured interviewing, although these allow tangential exploration by the participant. People with learning disabilities may be less likely to do this because they tend to be more compliant and less sure of themselves. This should be part of ethical and design development for this type of research.

Whilst people's learning disabilities have a widely varied genesis, it is perhaps not surprising that many would broadly experience difficult "interactions with world". Themes similar to those of "interactions with world" were discussed by Kroese et al (1998), in particular that of concrete thinking. It is interesting that they comment on aspects of living with a learning disability, whilst Knudson and Coyle (2002) highlight themes shared with 'MPO'. The current findings suggest that these two aspects of meaning for people with learning disabilities who hear voices interact with each other.

In addition, this study aimed to explore people's experiences of dreams and hearing voices, yet ended with additional 'phenomena' to consider. The complexities of people's relationships with their 'phenomena' and their perceptions of relationships between these may add to the body of knowledge about mental health experiences of people with learning disabilities. Ways to elucidate these and set them in the context of our therapeutic approaches to alleviating distress needs more investigation.

Clinical implications of findings

Distress about hearing voices or experiencing other phenomena would commonly be a reason for referral. The implications of these findings are therefore important to consider how better to help them. Some participants in this study interpret the world in a concrete way; their perceptions are assumed real and the possibility of invention not considered. This is consistent with many participants in Kroese et al's research (1998) a non-clinical sample of people with learning disabilities. Flashbacks, nightmares, 'voices', visions might then be experienced as distressingly real and some mainstream therapeutic techniques particularly worrying. Research could examine whether this differs from non-learning disabled people.

Participants also mentioned abstract concepts such as reality, pretend, subconscious, spirits. Interestingly some used a concrete interpretation of such words. The analysis suggests there may be a continuum from implicit acceptance that experiences are real to acknowledgement that they can be invented. Assessment of this could have implications for therapeutic approaches used and distress levels.

Professional support systems commonly offer particular explanations (e.g. medical, psychological), which seek to structure the person's internal model of the world. They assume a reality based on these explanations and therefore seek to 'correct' the person's 'erroneous' personal theories. A focus group or other qualitative method could explore whether a group of professionals have a view of 'MPO' or factors associated with that aspect of the clients' experience.

Communication issues were perhaps the most striking difficulty encountered both in understanding people's speech, what they meant and following the thread of the conversation. Using IPA with this group needs time and care to ensure they can be heard effectively. The relative simplicity of accounts was discussed earlier and framed as a feature of people with learning disabilities. This does not negate the significance of findings, which appertain to individual experience and the subsequent implications for research and clinical practise.

The concept of 'MPO' appeared to change how people related their experience as if everything is connected. Listeners might experience confusion and disconnectedness because a lack of mutual explanatory framework clouds their understanding of the person's story. This may help to understand why the outside world struggles with people who hear voices (and they with it). It may affect how effective particular approaches are and how acceptable to the person. This is important in a population whose impairments lead to experiences of failure and compliance due to dependency. Future research could help establish how far 'consumer' perceptions and choice influence the success of strategies.

This small study doesn't necessarily generalise but illustrates that participants strive to understand experiences and this links to attempts to cope. Where they struggled to find coherence, coping strategies seemed unhelpful. If professionals can work with people to understand 'MPO' this may help establish better individual coping. Supporting them to develop their 'MPO' where they are struggling also seems likely to be fruitful. This is consistent with findings from Romme and Escher (1993) and the 'Hearing voices' movement (Coleman & Smith, 1997).

The accounts of participants in this research implicitly and explicitly remind us of their vulnerability in terms of compliance, suggestibility and acquiescence. This should continue to be noted for ethical research and clinical practise in gaining an understanding of how best to enable informed consent, for instance people might want medication or therapy to reduce distress rather than their voices. Services can begin to consider these issues if they acknowledge that the person may have a different but valid view of 'MPO'.

Methodological issues

IPA facilitated exploration of this under-researched area in a non-threatening, ethical way, appropriate for people with both mental health and learning disabilities labels. Rich data concerning personal meanings were systematically analysed revealing a matrix of themes as interpreted by the interviewer. These themes represent valuable insights in people's worlds, which would have been difficult to gain through quantitative approaches. Despite this, the dominance of quantitative research may limit the influence of these findings, since quantitative evidence is still valued more highly in many arenas. This prompts a debate about the benefits of different approaches, acknowledging their attributes and developing a broad spectrum of knowledge.

The impossibility of getting away from ones stance in such analyses illustrates this. IPA acknowledges the interpretative role of the researcher yet it is difficult not to become embroiled in internal chaos in teasing out self and participants' meanings; for instance, implicit assumptions about accepted reality. In clinical situations one maintains a balance between what the person perceives and difficulties this exacerbates; thus how far to work with their view or counter this.

This highlights both professional and service level quandaries about how best to help people and whose viewpoints are the most influential in determining this. IPA has allowed these issues to surface and yet seems unlikely to provide the 'solid' evidence that organisations like NICE seek in order to change services. As mentioned earlier the epidemiology and ethical issues of research into learning disabilities and 'hearing voices' means that the potential pool of participants is very small in any given area. This would make quantitative research difficult, necessitating a long collection period or multi-site collaboration to establish evidence.

These findings could promote further research as suggested through the discussion, to build up further qualitative knowledge for instance about transferability of findings, or to investigate quantitative concepts of reliability where feasible.

Conclusions

The findings were broadly consistent with previous research findings that developing an understanding of experiences aids development of coping strategies; yet unique aspects of 'dual-diagnosis' were found. A concept of 'It' was identified as people's overarching explanatory framework for their experiences of voices, dreams and other phenomena which are often viewed as emanating from the same entity. 'It' influences and is influenced by coping strategies, develops and may become more explicit over time. Participants' 'Interactions with the world' are made problematic or more complicated by issues associated with their learning disabilities and 'It'.

These findings imply a need to establish greater knowledge of people's experiences and meanings attached to these to promote clinical formulations and interventions that engage and motivate. Ethical considerations are vital for this group who are vulnerable to compliance and unused to having their views held as valuable. Particularly where they hear 'voices', they are faced with a double labelling process and all the disempowerment this involves. Research was suggested to address the current shortage with the ultimate aim of promoting appropriate and effective evidence-based interventions.

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Critical Appraisal

This aims to relate the practical, professional, theoretical and personal lessons learnt from this study, which were recorded in a research diary. These influence each other, providing a broad picture of the research process and how this can be facilitated and improved.

Progress and time scale of research

It took five years from the first ideas to finishing the research (including a year's maternity leave). This was interspersed with completing the other academic course requirements. The research proposal developed in late 1999 and was accepted early in 2000. The research and ethics forms then went to the local committees and after some amendment, ethics approval was given in October 2000.

As discussed below, it took 18 months to recruit participants. Interviews were transcribed as they occurred. In summer 2001, an ethics amendment request was submitted so that community nurses could seek consent to be contacted and later that year, another request that interviews could take place away from the hospital, which evoked bad memories for some. Interviews were finally completed by early 2002 and transcriptions by summer. A draft research literature review and the early stages of analysis were done in autumn 2002. The analysis and research report was completed after maternity leave in summer 2004.

Pivotal meetings

The processes that aided and hindered the research will be discussed below. However, it is worth noting the importance of meetings with important stakeholders in facilitating progress. Agreement of the lead consultant psychiatrist was judged to give credibility for the ethics committee. Nurse managers agreed that community nurses could help recruitment and Trust research officers gave much support and advice. Ongoing supervision meetings supported and shaped ideas for research areas, methodologies and feedback for written material. Peer group meetings promoted motivation and reassurance in a supportive milieu. Many meetings took place along the way, some more helpful than others. However, they were integral to the research process in informing others about the research, asking for information, help or approval, and in shaping progress. Ultimately the pivotal meetings were the interviews with participants; the first and last being most memorable in terms of markers of progress.

The origins of the project

This research was triggered by reading the paper by Kroese, Cushway and Hubbard (1998) concerning experiences and perceptions of dreams by people with learning disabilities. It seemed consistent with clinical observations about how people with learning disabilities can be very literal/concrete in their interpretations of the world. I have a particular interest in working with people with learning disabilities and who hear voices or have a label of mental illness. I began to wonder about the implications of Kroese et al's (1998) paper for psychotherapeutic techniques such as working with flashbacks, dreams and voices. This is particularly relevant for a population who experience higher figures for sexual abuse and mental health problems (Emerson, Hatton, Bromley & Caine, 1998) than the general population. It prompted a myriad of ideas about interpretations of experiences and the area of reality versus non-reality was intriguing. Berendt's (1998) paper linked people's experiences of dreams and voices but was not specific to people with learning disabilities and no relevant literature was found for this population. This identified gap in the literature begged investigation and given the dearth of research, qualitative approaches seemed appropriate. Of these, Interpretative phenomenological analysis (IPA) (Smith 1996) seemed fitting because it acknowledges a link between physical, cognitive and verbal report, allows for flexibility in probing interesting areas but does not set out to build theories per se as grounded theory does. This was a new research approach for the investigator and so importantly, my supervisor was familiar with it.

From the basic area of interest, the application of IPA was researched and the protocol developed, bearing in mind the possible needs of the participants. For instance people with learning disabilities would not find very complex or abstract questions helpful. IPA has not traditionally been used with this group perhaps due to doubts about their ability to provide 'rich' enough data. It was decided to approach people with mild learning disabilities to minimise communication difficulties in the first instance. An interview schedule was designed to explore people's experiences of dreams and voices in a non-leading way. This is part of the methodology of IPA but is particularly important for people with learning disabilities since they tend to be acquiescent and/or compliant.

The organisation and implementation of the project

Barriers to progress

These included difficulties in recruiting participants, gaining ethical approval and some practical issues.

One of the main barriers was the difficulty in recruiting participants, stemming from two areas; the epidemiological picture and practical issues of gaining 'consent to be contacted'. As discussed in the research report, based on a normal distribution with a mean of 100, 2.27 per cent of the population will fall into the range of learning disability with an IQ score under seventy (two standard deviations below a mean) and impairments in adaptive functioning. This increases slightly to 2.5 to 3.0 per cent when you include people with "specific pathologies" (Fryers, 1997). Deb, Thomas and Bright's (2001) figures, compute to one hundred people with learning disabilities and schizophrenia based on an approximate county population of one million. Of these, people with moderate or severe disabilities were screened out as part of the protocol. Of the remainder, only a small number will 'hear voices' at any one time, not all of these will be in contact with services and some of those who are will be in crisis and therefore not considered able to take part due to ethical concerns about distress.

Unsurprisingly recruitment was challenging. This is a major difficulty with research with people with learning disabilities, especially for those who also 'hear voices'. The demographics would make large quantitative studies (e.g. randomized control trials) difficult, necessitating long data collection periods or multi-site collaboration.

The second aspect affecting recruitment was gaining 'consent to be contacted'. Initially consultant psychiatrists were to do this as part of their regular consultations with people but these were infrequent and forgetting once meant a long wait until the next one. Asking their secretaries to put copies of my forms with their clinic lists was designed to 'jog' their memories, as was the occasional verbal reminder. However, as colleagues it was important to remember that their priorities were not the research however willing they were to help. In retrospect one of the most difficult barriers to this process was that one of the consultants died that summer and may have been ill for some time. Naturally this was difficult for the service and patients but for the psychiatric team in particular who needed to deal with their own distress and cover his work.

Following this, an ethics amendment allowed community nurses to gain 'consent to be contacted' and this was more successful. The option of seeking a reciprocal ethics agreement with another county was considered but would have taken a long time. It took eighteen months to see five participants and given the difficulties, eight was considered sufficient for this project, although a broader sample of participants might have been beneficial.

Ethics forms are lengthy and rightly consider many aspects of a proposed research study, which can take time to address. There were misunderstandings within the ethics committee about issues of consent for people with learning disabilities which needed clarifying; for instance the misapprehension that the person's carer should (and could) give consent. The law regarding capacity to consent (recently updated in the Capacity Bill 2004) means that a person with a learning disability can consent to taking part in research if they have capacity. However, if they don't have the capacity for that decision, another person (or people) cannot do it for them as they could 'in their best interests' for treatment.

Trust policy required that certain phrases concerning liability for negligence be included verbatim in the information leaflets and consent forms. These did not seem meaningful because participants with learning disabilities wouldn't understand them. In addition to the original wording, I reworded them to maximise chances that the participants would understand them.

A number of events affected the ability to focus on this research in terms of the balance between home and academic work. Two house moves and a year's leave during this research disrupted the pace and thought processes of the analysis. Chronic tiredness and multi-tasking that comes with a baby affected concentration. A close friend's death during the time of writing up was difficult, perhaps giving a sense of balance where the research is viewed in its place. Such life events inevitably affect motivation; developing clear study routines and protected time for these helps.

The time out also meant that going back to the participants to present the findings was not considered meaningful or ethical due the time since their interviews. Future research with people with learning disabilities may need to consider how they can feasibly present their analysis to them within a reasonable time frame.

Facilitators of progress

These included support systems, practicalities, and qualities of the interviewer.

Supervision facilitated progress in many ways through shaping of ideas, availability of feedback for draft reports, acting as a credibility check for the analysis, basic information about course requirements, relevant references and importantly as containment for the inevitable ‘ups and downs’ of research. The supervisor’s knowledge of the methodology and client group helped, both practically and in considering methodological issues in this area. The peer group at Sheffield also supported everyday struggles and provided opportunities for regular reviews of progress, which if missed, would neglect the chance to reassure oneself or change practise to move on. Discussing findings with colleagues helped with motivation because they were interested in them and their implications for clinical practise. This highlighted again how little is known in this area, enhancing its value and acted as a spur to write up and publish.

The ethics procedures help ensure that all documentation and protocols are organized before commencing the practical aspects of the research. Submission to both Sheffield and local research and then the local ethics committee covered different aspects of this. The trust research officers were approachable and extremely helpful in checking forms and e-mailing back any comments.

A few practical issues made a big difference. Using blocks of study time rather than single days allowed me to concentrate and retain the details to gain broad picture. During the analysis and write up phases this avoids having to get to know the data again each time.

As a post-qualification candidate, using annual or unpaid leave and extra day's child care to work at home for study was a good solution, but requires financial commitment. Maximising the use of available time was important; for instance, trying to time supervision and peer group meetings on the same day, since they involved a four hour round trip. Time management helps prioritise tasks and focus energy for the appropriate task. Patience in accepting that research has different paces at different times facilitates your job as researcher.

The use of computers has revolutionised the writing process and for this research, the transcription. However, two hard drives failed during this research and this experience has taught me the value of backing up data on discs and through e-mail.

Being a qualified clinician in the role of researcher has helped due to the sensitive nature of this study, calming other people's worries and establishing credibility for the recruitment process. In addition, I suspect that experience may help establish rapport where people are anxious, for instance during interviews; or in more easily understanding where communication is difficult.

Problem resolution and use of particular strategies

Barriers to progress are difficult if beyond your control. Utilising support systems and problem solving to devise helpful strategies is vital. Equally important is the ability to not worry too much about things you can't change.

Attempts at problem resolution

Issues concerning recruitment of participants have been discussed above. The problem solving surrounding these included a mixture of practical solutions such as changes to where I might see someone or who would recruit; to attempts to increase motivation of others to help e.g. reminders from their secretaries or making the process as easy as possible. Maintaining good will is important; clinical skills of empathy, rapport, clarity of information and purpose all help. Organisation of tasks and materials was a key task throughout the many aspects of the research journey. Sourcing of information was vital and knowing who to talk to about what, essential.

Adoption of particular strategies

Many of these have been mentioned earlier. However, the decision to transcribe tapes myself was a time consuming but effective strategy; enhancing personal absorption and knowledge of people's stories. In addition, others may have struggled to decipher people's words where unclear. Remembering the context within interviews helped this process, as did transcription as soon as possible after interviews.

Voice activated software was used initially for transcription but quickly abandoned since it is programmed to change people's grammar and doesn't recognise colloquialisms.

My supervisor acted as a credibility check for the early stages of analysis, which also improved my confidence in my analysis. Clear records of the analysis process aided discussion of this within supervision and for the thesis report.

Lessons from the research process informing future practice.

Some lessons learnt from this research study have been described above. Others are discussed below in terms of the methodology, analysis, ability to draw implications from this and the use of IPA for this particular project.

Methodological issues

The screening tools were developed from the communication domain of the Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cichetti, 1984) and the Mini- PAS-

ADD (Moss et al, 1993), which are both third person informant scales. This process was effective, for instance in checking that the participants had reported experiencing voices in the last few weeks and that their communication skills would enable them to participate. It also helped promote the carer's cooperation to enable the participant's involvement. However, the use of a third person (carer) seemed incongruent with the methodology's emphasis on the participant's view and the same information could have been elicited by meeting the participant. However meeting them and then deciding they would be unable to help might make them feel they had failed in some way. On balance, the informant strategy seems more appropriate but consideration could be given to developing other screening tools in future.

For most participants, the interview question asking what they did today provoked a puzzled reaction and the responses to it were factual and short. Although it was designed to 'tease' out how they knew what happened in 'real' life instead of during dreams or voices, it wasn't particularly helpful for this. Perhaps people with learning disabilities need specific questions about issues, which although non-leading and open, give some direction since they are less likely to expand extensively. An alternative might have been to think more carefully about probes/prompts to illicit more from that question. Whilst all interviewers direct their participants to some extent through the interview schedule towards an area of interest, the risks of leading the interview too much should be considered.

As discussed in the research report, the findings were not presented to participants because the time lag between interviews and analysis was considered too long to be meaningful or ethical for this population. This credibility check is not mentioned in Smith's 1996 IPA paper, nor in many published IPA research papers, but generally seems to have been accepted as good practice (Elliott et al, 1999). It would be interesting to find out how helpful participants with learning disabilities or the researchers find it in future studies involving this group. For instance, the layers of interpretation that the investigator develops are an important part of the analysis but may be more abstract than someone with a learning disability could easily understand. The challenge would be to present the findings simply without losing the meaning or it would struggle to act as a credibility check. I am not aware whether this has been explored for non-learning disabled participants.

Amongst the ethical issues that emerged during interviews was action to take when a participant relayed information related to risk to themselves or others and which need action if told in a clinical situation. This was not necessarily covered by the safety net system of having another clinician available to talk to should the participant want it. However, when it arose they said they had told their psychiatrist and that strategies were in place. My understanding of recent research protocols would be that you would disclose such information and this is now routinely included in ethics protocols.

The Interviews

Learning a new methodology provoked anxieties about the minutiae of interviewing techniques, for instance when to probe further or if it was acceptable to refocus the conversation. Difficulties in understanding what some participants said (and them understanding what I said) exacerbated these anxieties, for instance how requests to repeat statements would affect the process of the interview. A conversation analysis (Drew, 1995) could illuminate aspects of repetition in the future. However, participants were tolerant and persistent in their attempts to make themselves understood. It was not felt that these issues would be outside people's normal experiences, and were illustrated by 'interactions with the world' (see research report). In this way the processes inherent to the interview may illuminate people's experiences elsewhere and were used to inform the analysis.

When considering areas where more or better or different probe questions could have been used it is important to recognise that the transcripts didn't show the affect or processes in interviews that could influence interactions. For instance, where the theme of 'jumping about' was strongly represented, the interviewer might find it hard to follow the conversation and her response/questions would reflect this.

Whilst some people seemed distressed about their experiences they were not considered unduly distressed and thus the interviewer did not feel it necessary to terminate any interviews. Clinical judgment seemed important here and is an instance where clinicians conducting research may have fundamental skills that they bring to clinical research. Conversely, participants had varied histories associated with the 'helping' professions. It is not clear how this may have affected their responses during the research process, for instance the influence of perceived power relationships. It may have led them to acquiesce more readily to taking part in the research, particularly since those seeking 'consent to be contacted' were nurses or doctors and then the researcher asking for their consent to take part was a middle class psychologist.

The Analysis

The literature acknowledges that inevitably everyone uses IPA differently and it was not always clear how far to interpret people's words or how many levels of analysis are appropriate. Discussions in supervision helped elucidate the interpretation as central to the methodology but that this is repeatedly checked with the original words to ensure it remains 'true' to the meaning. However, the next paragraph will explore ways that the ability to remain 'true' is compromised by ones own stance both before and during the analysis.

An important part of qualitative methodology is to own one's own perspective. I found that my assumptions were challenged by the participants' views and acceptance of some experiences as ‘real but different’. Previous assumptions would have been that if they could recognise it as different from what others experience then they would recognise it wasn’t real. In this sense the premise that you can tell real from unreal should not be assumed. Perhaps what we call reality is as we experience it, although if this is not consistent with society’s views then it is likely to create difficulties.

The interview questions illustrate the investigator’s interests. Someone else might have chosen to explore another aspect of experience for the same group of people. The analysis and discussion of it will also have been influenced, for instance, by a desire to explore issues likely to be helpful clinically and to relate developing knowledge or theory with practise.

Psychiatric settings might view participants’ views as evidence of pathology and discussion of these without disagreement, as ‘collusion’. Thus different philosophical or professional perspectives will change the IPA. The stance of recognising and accepting that another person sees the world differently whilst not agreeing with it seems helpful. It stems from clinical experience and previous knowledge of the literature and appears compatible with IPA.

As a novice IPA researcher with a quantitative background of natural sciences, the underlying tenets of qualitative research were unfamiliar except for the increasing enthusiasm I heard from trainees on placement for it. I have therefore aimed to approach this study with an open mind to learn. It appears to have presented people’s views well and the findings are consistent with my experiences of working with people with learning disabilities who hear voices. However, my experience will have influenced my analysis to some extent and recognition of this is important. Further research in this area would help explore if its findings generalise to others.

The thematic diagram in the research report evolved in an attempt to present the findings as representing the core of participants' concerns and views. It was important not to lose this focus by arranging it, for instance, in the most personally resonant way. A clear audit trail from transcripts to analysis helps in linking the original words to the conclusions drawn and acts as a reassurance that the interpretation has not gone beyond reasonable bounds.

The Discussion

The research took a number of years from inception to writing up so ongoing literature searches were vital; for instance discussion issues needed recent research papers to connect with. The qualitative tactic of including new papers in the introduction or writing it based on information gained after data collection seemed helpful.

This research aimed to explore an unknown area and not to test out preexisting theories. As such the mainstream literature about hearing voices or reality was not covered extensively and this may have enriched the debate. However, as discussed in both the research literature review and the research report, theories based on research with the 'mainstream' population do not necessarily apply to the learning disabled group. This study used an open exploration in order to see what experiences are like for those with learning disabilities; and to begin to build knowledge of what is applicable for them.

Use of IPA methodology with people with learning disabilities

The participants in this research had mild learning disabilities and might be viewed as able compared to those generally seen within a specialist learning disability service. One of the key markers for qualitative approaches is that of 'richness' of material gleaned from interviews. Prior to interviews the understanding of how rich is 'rich enough' was a concern and might be predicted since this group will have less complex language and understanding. However, this is how people are and their themes can present in less complex ways but be valid. Concluding that responses are not rich ‘enough’ would misrepresent people with learning disabilities as not ‘enough’. It is important not to exclude them as has been done with therapeutic approaches in the past. There is a need to recognise difference and value its contribution to knowledge about the area. However, adaptations would be needed for future research in line with peoples needs.

In addition, research with people with mild learning disabilities should not be routinely assumed to be relevant or generalisable to those who have more severe disabilities and research methodologies may not be suitable for all. Imaginative ways of investigating and exploring the needs of varying groups presents a challenge for the future.

Conclusions

Overall then, there have been many valuable lessons learnt along the way and there are things that might be done differently in future. However, my knowledge of the theoretical area and of the IPA methodology has been greatly enhanced. I hope that it adds to the literature concerning people with learning disabilities and helps us understand better where to begin to support them, in changing where they are distressed or in their views where they are not.

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Appendices

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Proofs must be returned to the Production Editor within 3 days of receipt, ideally by fax. Only typographical errors can be corrected at this stage. Major alterations to the text cannot be accepted.

Assessment and Editing Procedure

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure

Offprints

Authors will be provided with electronic offprints of their paper. Paper offprints may be ordered at prices quoted on the order form, which accompanies proofs, *provided that* the form is returned with the proofs. The cost is more if the order form arrives too late for the main print run. Offprints are normally despatched within three weeks of publication of the issue in which the paper appears. Please contact the publishers if offprints do not arrive: however, please note that offprints are despatched by surface mail, so overseas orders may take up to six weeks to arrive. Electronic offprints are sent to the first author at his or her first email address on the title page of the paper, unless advised otherwise; therefore please ensure that the name, address and email of the receiving author are clearly indicated on the manuscript title page if he or she is not the first author of the paper.

Top ↑

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology
Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification
Clinical supervision training and NHS research training and consultancy

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Clinical Practice Director: Ms Joyce Scaife
Course Administrator: Carole Gillespie
Prof Nigel Beail

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12 August 2004

Bridget Cryer-Rolley

Dear Bridget

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Option A

Please remember to bind in this letter and copies of the relevant Instructions to Authors with your thesis.

Yours sincerely

Andrew Thompson
Chair, Research Sub-Committee

Appendix ii. Ethical approvals

- Copy of letters of approval from the ethics committee

Health for Leicestershire
LEICESTERSHIRE HEALT
Gwendolen Road, Leicester LE5 4Q
Tel: (0116) 273 1173 Fax: (0116) 258 857
DX 709470 Leicester 12

Mrs Viv Merry
Direct Dial 0116 2588565

29 September 2000

Ms Bridget Cryer
Clinical Psychologist
Learning Disability Service
Leicester Frith Hospital
Groby Road
Leicester LE3 9QF

Dear Ms Cryer

Exploring the personal meaning of 'voices' and dreams for people with learning disabilities – our ref. No. 5984

I have received your letter dated 17 September responding to the points raised by the Leicestershire Research Ethics Committee concerning the above study.

On behalf of the Leicestershire Research Ethics Committee, and by Chairman's action, final approval is given for you to undertake the above-mentioned study.

Your attention is drawn to the attached paper which reminds the researcher of information that needs to be observed when ethics committee approval is given.

Yours sincerely

Rev P Harbord
Chairman
Leicestershire Research Ethics Committee
(Signed under delegated authority)

(NB All communications relating to Leicestershire Ethics Committee must be sent to Leicestershire Health)

Leicestershire NHS
Health Authority

Melanie Sursham
Direct Dial 0116 2588610

Gwendolen Road
Leicester
LE5 4QF

Tel: 0116 2731173
Fax: 0116 2588577
DX 709470 Leicester 12

19 July 2001

Please quote ethics ref no 5984

Ms Bridget Cryer-Rolley
Clinical Psychologist
Learning Disability Service
Leicester Frith Hospital
Groby Road
Leicester
LE3 9QF

Dear Ms Cryer-Rolley

Exploring the personal meaning of 'voices' and dreams for people with learning disabilities – our ref no 5984

I have received, via Alison Cooper, your letter dated 11 July 2001 outlining amendments to the protocol for the above study.

On behalf of the Leicestershire Research Ethics Committee, and by Chairman's action, approval is given to the amendments proposed subject to identification of patients by Consultant but the initial approach being made by a community nurse.

Yours sincerely

P G Rabey pp
Chairman
Leicestershire Research Ethics Committee
(Signed under delegated authority)

(NB All Communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire Health Authority. If however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way)

Leicestershire NHS
Health Authority

Melanie Sursham
Direct Dial 0116 2588610

Gwendolen Road
Leicester
LE5 4QF

Tel: 0116 2731173
Fax: 0116 2588577
Mini Com: 0116 2588640
DX 709470 Leicester 12

19 February 2002

Please quote ethics ref no 5984

Mrs Bridget Cryer-Rolley
Clinical Psychologist
Leicestershire and Rutland Healthcare NHS Trust
George Hine House
Gipsy Lane
Leicester
LE5 OTD

Dear Mrs Cryer-Rolley

Exploring the personal meaning of 'voices' and dreams for people with learning disabilities – our ref no 5984

I have received your letter dated 29 January 2002 requesting a further amendment to the above study as additional people have requested that the interviews take place away from the hospital site.

On behalf of the Leicestershire Research Ethics Committee, and by Chairman's action, I have reviewed and approved this protocol amendment.

Yours sincerely

P G Rabey pp .
Chairman
Leicestershire Research Ethics Committee
(Signed under delegated authority)

(NB All Communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire Health Authority. If however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way)

Appendix iii. Measures

- Screening tools
- Information sheets and consent forms
- Interview schedule

Screening criteria for communication

Based on the communication domain of the expanded form of the Vineland (See appendix C, scoring criteria). As with the Vineland, it is to be scored concerning what the person does, not what they can do.

0 = does not do this
1 = occasionally does this
2 = habitually does this

0 1 2
(Tick as applicable)

1) Uses sentences of four or more words / speaks in full sentences(i.e. sentence and verb – I like my new coat; she went to the shop

2) states own name

3) Relates experiences in narrative form when asked (e.g. we had orange juice at break; I went to George's house) or spontaneously.

4) Relates experiences in detail when asked (the amount of detail in the individuals language, not the grammar or articulation is the important part.

5) Speaks intelligibly – must speak clearly enough to be understood with careful listening (not ok if only close friends, staff, or carers can understand)

6) Expresses ideas in more than one way, without assistance.
I.e. if not understood at first, the individual may clarify a previous statement with "I meant...." Followed by an explanation. They may clarify the statement spontaneously or in response to questions.

7) Follows instructions requiring an action and an object. E.g. get your book; find your glasses.

Bridget Cryer
Clinical psychologist

Screening criteria for voices

[to be verbally administered by the reseacher]

Based on the mini pas-add assessment schedule for the detection of mental health problems in adults with developmental disabilities

The person completing the checklist should have known the adult with learning disability for at least six months. The checklist refers to symptoms present in the last four weeks, although the symptom may have been present prior to that as well. If the symptom has been present during the previous four weeks but is not at the time of completing the checklist, it should still be rated as present. It is important that a person who is experiencing a recent acute and severe escalation of their psychotic symptoms is not included in the research. This is because they could be distressed and / or are unlikely to be in position to give informed consent to their participation.

Definitions

"Hallucinations are false perceptions. They can occur in any of the senses (such as sight, touch, hearing, smell or taste). Hallucinations are not beliefs about things existing – they are immediate perceptions, which are as real as if the perceived thing actually existed." (Mini pas-add glossary)

1) Hears voices that others do not hear:

Auditory hallucinations may be experienced as noises music or voices. People will sometimes say that they can hear a voice or voices talking to them or about them. Auditory hallucinations may be experienced either inside or from somewhere outside the person's head. It is important to establish that the voices are really hallucinations i.e. excluded such events as hearing the neighbours television or radio through the wall. Additionally ensure that the individual is not merely misinterpreting the action or gestures of other people and only thinks that they are talking about him/her, rather than actually hearing 'voices'.

There may one voice or multiple voices. They may be heard clearly and talk in single words, phrases or sentences or thy may mutter indistinctly. Voices may talk to the person directly or the person may hear the voices talking to each other.

2) See things that others do not see

Include any of the following; unformed images (e.g. flashes, shadows, coloured lights, abstract shapes); full images of people or faces, objects; or whole scenes.

3) Experiences touching or other bodily sensations

Individuals with this symptom may feel that someone or something is touching them when there is no evident explanation. One person reported that she could feel someone stroking her face and arm when there was nobody there. Other experiences include sensations of being pricked, strangled, or of things crawling under the skin.

4) Smells things which others cannot smell

Individuals with this symptom can substances, either offensive or pleasant, which other people do not smell. Be sure to check that the person is not merely misinterpreting a smell that really is present

Screening tool for voices – scoring table

	Not past four weeks	Mild	Moderate	Severe
Hears things that others do not hear	0	2	2	2
Sees things that others do not see	0	1	1	1
Experiences touching or other bodily sensations when there is not one or nothing around to do the touching	0	1	1	1
Smells things that others do not smell	0	1	1	1
Total				

The four point rating scale

0 = Not happened/not present

The symptom has definitely not been present in the past month

1 = Mild

Either:

i) The symptom has occurred in the past four weeks but it has been rare.

ii) Or - The symptom has occurred but has been so mild as not to cause a problem to the individual you are rating or to others.

2 = Moderate

Either:

i) the symptom has definitely been present in the past four weeks and occurs frequently but has not been present for most of the time

ii) Or – the symptom has been present and has caused a moderate degree of distress to the individual or to others.

3 = Severe

Any of the following:

i) the symptom occurs with a very high frequency and has been present for most of the time in the past four weeks

ii) The symptom is very severe and has caused considerable distress to the person you are rating or to others. It may or may not have been present for most of the time in the past four weeks.

iii) The symptom has significantly threatened the person's environment. For instance the symptom may have lead to the exclusion from a day centre, loss of relationships or has threatened the persons residential placement

iv) The symptom has caused serious danger to the person you are rating or to others.

This was the consent form that the carer and client were asked to sign to confirm that they had agreed to be approached about the research. It was copied and filed in the patient's notes as a record of their consent to be contacted.

Client and carer 'consent to be contacted' form

Client

I confirm that Dr .... has given me a client information leaflet about some research that Bridget Cryer, Clinical Psychologist is going to do. I agree that she can come and talk to me about her research. I also agree that .... can give her my telephone number (or my address so she can write to me if I don't have a telephone) This is so she can make a time to come and see me so I can find out more about the research. Then I can choose if I want to take part in the research.

Signature of client... Date..............................

Name(BLOCK CAPITALS)..

Signature of witness (if client unable to write) ....

Name (BLOCK CAPITALS)..

Carer

I confirm that Dr .... has given me a carer information leaflet about some research that Bridget Cryer, Clinical Psychologist is going to do. I agree that she can come and talk to me about her research. I also agree that .... can give her my telephone number (or my address so she can write to me if I don't have a telephone) This is so she can make a time to come and talk to me so that I can find out more about it and then I can choose if I want to take part.

Signature...Date ....

Name (BLOCK CAPITALS)..

[This form needs to be copied and filed in the patient's medical notes]

This form was adapted from the standard format in view of the needs of people with learning disabilities for simplified language and aims to facilitate informed consent

PATIENT CONSENT FORM

"Exploring the personal meaning of 'voices' and dreams for people with learning disabilities"

The person who is doing the research is Bridget Cryer

Please read the patient information leaflet before you sign this consent form. If you have any questions talk to your carer or keyworker.

I agree to take part in the research project as written about in the patient information sheet.

I know that I can change my mind at any time and say I don't want to talk any more. I don't have to say why. This will not change the way my doctor helps me. It won't stop me seeing a psychologist if I need help in the future.

I know that people who are doing the research might want to look at my medical notes, but that all the information will be treated as private and confidential. They will not tell other people my name.

I understand that the interview will be taped and that when the project is finished and written up, I can have a copy of the tape. Any other copies of the tape will be wiped so the words are gone.

I understand that medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I have read the patient information leaflet or .... has read it to me. I have been able to talk about the leaflet with ....and ask questions about it. They have told me what is going to happen and what I will be doing if I decide to help with the research.

Signature of patient... Date...............................
(Name in BLOCK LETTERS)...

[Where patient is not able to write:

I confirm that (name) .... has agreed to take part in the research study under the terms outlined above.

Signature of witness .... Date ....
(Name in BLOCK LETTERS) ....
Relationship to patient...]

I confirm I have explained the nature of the research, as detailed in the patient information leaflet, in terms, which in my judgement are suited to the understanding of the patient.

Signature of Investigator .... Date ....
(Name in BLOCK LETTERS) ....

This leaflet was made user friendly to meet the needs of people with learning disabilities for simplified language and shorter sentences. They also had a chance to talk to me if they had any questions about the leaflet.

Client Information Leaflet.

" Exploring the personal meaning of 'voices' and dreams for people with learning disabilities"

Investigator: Bridget Cryer

Contact details:
Clinical Psychology department
Groby Road
Leicester
LE3 9QF

Telephone number – 0116-2255330

Who am I?

My name is Bridget Cryer and I work at Leicester Frith Hospital. I am also doing a course at college. It is supervised by Dr Nigel Beail. As part of my course I have to do a research project. Research is when you try to find out something that no one knows yet. You can do research in different ways. I am going to ask some questions to see what people say. It is not a test and there are no right or wrong answers. I want to know what different people say.

The research is not part of my work as a psychologist. If you say yes or no to my research, it will not change whether I see you later on if you need help.

What do I want to know?

I would like to find out more about dreams people have and 'voices' they hear. These are the voices that you hear when other people say they don't hear them or there's no one in the room with you.

I have tried to find out about these in books but I couldn't find anything about it. It would be good if you could help me by talking about them. This is so I can find out what you say. I will ask some other people too. If we find out new things we can find new ways to help people.

What do I want you to do?

I would like you to talk to me about your dreams and voices for a few minutes. I will ask some questions but you can talk as much as you want to and I will listen. It might take a few minutes or a bit longer. It depends how much you want to tell me.

What if you don't want to talk?

You can stop as soon as you want to. It's ok if you don't want to talk. If you say yes and then change your mind, it's ok. You only have to talk if you want to. After you talk to me you can change your mind and ask me not to use what you have said.

What will happen next?

I will come and tell you more you about the research and answer questions about this leaflet. I will also ask your carer or someone who knows you well, some questions about you. Then I will ask if you want to help with the research.

If you want to talk to me, you need to write your name on a piece of paper. This is so people know you want to help. If you don't write, you can ask someone else to write that you have said yes. Then I will make a time to see you at the hospital arrange for you to get here. You can ask me questions if you want to. I will ask you some questions too and listen to what you say. We can stop for a while if you want a break. You can come back another day if you get tired.

If I come to see you, you can still say you don't want to talk to me.

What happens if things go wrong?

If you get upset or worried when we talk, we will stop straight away. Then you can ask to talk to another psychologist if you want.

"Medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs"

If you helped with the research and you got hurt when something went wrong , you might be able to ask for some money to make up for the mistake. You can only ask for money if it happened because I was not careful enough.

What will happen after we talk?

For my project, I need to remember what you tell me. This is so I can write about it. Some of the things you say might be in my project but I will not write your name. This is so people will not know who you are or that you talked to me. So that I can remember what you say, I will use a tape recorder and I might write some words down. I will listen to the tapes later and write the words down. Then the tapes will be wiped clean or you can have them to keep if you want.

Your psychiatrist will need to write in your notes that you have told him that it is OK for me to come and tell you about the research. If you do agree to take part, I will not tell them the things you say in the interview.

If you want to know any more or you have any questions, you can telephone me. My phone number is 0116-225530.

Bridget Cryer
Clinical Psychologist

This questionnaire was used to check the client had understood the information leaflet and could make an informed decision

Information questionnaire

To find out if you want to help with my research, someone told you about it. This is to check you know what it's about.

1. What do I want to talk about?

2. What do you do to say yes or no?

3. What happens if you change your mind?

4. What am I going to do?

5. What do I want you to do?

6. What happens if you get upset or want to stop talking?

7. What will happen after I see you?

Bridget Cryer
Clinical psychologist

This is the form that relates to the carers consent to participate in the completion of the Vineland ABS communication subscale and the Mini-passadd schedule in relation to the client's behaviour.

CARER CONSENT FORM

"Exploring the personal meaning of 'voices' and dreams for people with learning disabilities"

Name of principle investigator: Bridget Cryer

This form should be read in conjunction with the carer information leaflet

I agree to take part in the above study as described in the carer information leaflet.

I understand that I may withdraw from the study at any time without justifying my decision and without affecting the client's normal care and medical management.

I understand that medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS. i.e. compensation is only available if negligence occurs.

I have read the carer information leaflet on the above study and have had the opportunity to discuss the details with Bridget Cryer and ask any questions. The nature and purpose of the tests to be undertaken have been explained to me and I understand what will be required if I take part in the study.

Signature of Carer .... Date ....
Name (BLOCK CAPITALS) ....

I confirm that I have explained the nature of the research, as detailed in the carer information leaflet, in terms, which in my judgement are suited to the understanding of the carer.

Signature of investigator .... Date ....
Name (BLOCK CAPITALS) ....

This is the form that was given to staff (paid carers) prior to me visiting to ask for consent, when they also had the opportunity to discuss the research

Staff (paid carer) information leaflet:

Title: **"Exploring the personal meaning of 'voices' and dreams for people with learning disabilities"**

Name of principle investigator: Bridget Cryer

You may contact her at:

Clinical psychology department,
Leicester Frith Hospital,
Groby Road,
Leicester.
LE3 9QF.

Telephone: 0116-2255330

1) What is the purpose of the study?

There is very little research carried out about psychological therapies with people with learning disabilities, although the results that have been published have been hopeful. I am a qualified clinical psychologist working in the learning disabilities services in Leicestershire. I am also doing a post-qualification doctorate course at Sheffield University and am supervised there by Dr Nigel Beail. As part of the course I hope to carry out some research that seeks to explore how people with learning disabilities experience their dreams and 'voices' they hear. This aims to increase the understanding about the way they can tell what is real or not real in their day-to-day lives. This is to help improve the way that psychological therapies are used for people with learning disabilities with mental health problems.

2) What will be involved if your resident takes part in the study?

- For your resident?

I will talk to them for approximately 30-60 minutes at the mansion house, Leicester Frith hospital. The exact time will vary depending on how long they want to talk. If they get tired we can have a break or they can come back another day. I have some open-ended questions to ask them about dreams and voices, but they can say as much or as little as they want. I will tape the interview so that I can remember what is said. These tapes will be wiped at the end of the project or they may wish to keep them as a memento.

- For you?

Before meeting them, I will come and talk to you for approximately 20-30 minutes so I can find out about their communication skills and mental health symptoms. This to help me check that they match the type of people needed for the research. If you agree to participate in this, you will need to sign a form so people know you have consented. I will bring this with me when we meet.

3) Will information obtained in the study be confidential?

Yes. All information collected (including the tapes) will be coded so that no one can trace the participants name and records will be kept locked away. When the research is written up, it will not contain any names. However it may include some anonymous quotes from the interviews. Their psychiatrist will need to record in their notes that they have agreed to be contacted by me, but will not find out what has been said in the interviews.

4) What if your resident is harmed by the study?

In the unlikely event that the person becomes distressed, the interview will be stopped immediately. They will be offered the chance to talk to another clinical psychologist who will be in the building at the time of interview.

Medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

5) What happens if your resident does not wish to participate in this study or wishes to withdraw from the study?

If they do not wish to participate in this study or if they wish to withdraw from the study they may do so without justifying their decision and their future treatment will not be affected.

It is important that they have the chance to talk about the idea of taking part in the research and that they feel able to say no. This is because people with learning disabilities often agree to do things because they think they have to.

6) What happens if your resident decides they wish to participate?

If after reading the patient information leaflet or you talking to them about it, they decide they would like to find out more about taking part in the research project, please ask your psychiatrist to let me know. There is a form for you both to sign to say you have agreed for me to visit to discuss the research. I will then arrange to visit you both to answer any questions they/you have. If they wish to participate in the research they can sign the consent form. You may need to witness that they have agreed to this if they are not able to write their name. I will then telephone them to arrange a time to see them here for the research interview at Leicester Frith hospital. I can collect them if they need transport. Even if they sign the form, they can change their minds at any time and withdraw from the study.

If you need further information or have any questions, please do not hesitate to telephone me on the number above.

Thank you in advance for your help

Bridget Cryer
Clinical psychologist

This was the form that was given to carers(relatives) prior to me visiting to ask for consent, when they also had the opportunity to discuss the research

Carer (relatives) information leaflet:

Title: **"Exploring the personal meaning of 'voices' and dreams for people with learning disabilities"**

Name of principle investigator: Bridget Cryer

You may contact her at:

Clinical psychology department,
Leicester Frith Hospital,
Groby Road,
Leicester.
LE3 9QF.

Telephone: 0116-2255330

1) What is the purpose of the study?

There is very little research carried out about psychological therapies with people with learning disabilities, although the results that have been published have been hopeful. I am a qualified clinical psychologist working in the learning disabilities services in Leicestershire. I am also doing a post-qualification doctorate course at Sheffield University and am supervised there by Dr Nigel Beail. As part of the course I hope to carry out some research that seeks to explore how people with learning disabilities experience their dreams and 'voices' they hear. This aims to increase the understanding about the way they can tell what is real or not real in their day-to-day lives. This is to help improve the way that psychological therapies are used for people with learning disabilities with mental health problems.

2) What will be involved if your relative takes part in the study?

- For your relative?

I will talk to them for approximately 30-60 minutes at the mansion house, Leicester Frith hospital. The exact time will vary depending on how long they want to talk. If they get tired we can have a break or they can come back another day. I have some open-ended questions to ask them about dreams and voices, but they can say as much or as little as they want. I will tape the interview so that I can remember what is said. These tapes will be wiped at the end of the project or they may wish to keep them as a memento.

- For you?

Before meeting them, I will come and talk to you for approximately 20-30 minutes so I can find out about their communication skills and mental health symptoms. This to help me check that they match the type of people needed for the research. If you agree to participate in this, you will need to sign a form so people know you have consented. I will bring this with me when we meet.

3) Will information obtained in the study be confidential?

Yes. All information collected (including the tapes) will be coded so that no one can trace the participants name and records will be kept locked away. When the research is written up, it will not contain any names. However it may include some anonymous quotes from the interviews. Their psychiatrist will need to record in their notes that they have agreed to be contacted by me, but will not find out what has been said in the interviews.

4) What if your relative is harmed by the study?

In the unlikely event that the person becomes distressed, the interview will be stopped immediately. They will be offered the chance to talk to another clinical psychologist who will be in the building at the time of interview.

Medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

5) What happens if your relative does not wish to participate in this study or wishes to withdraw from the study?

If they do not wish to participate in this study or if they wish to withdraw from the study they may do so without justifying their decision and their future treatment will not be affected.

It is important that they have the chance to talk about the idea of taking part in the research and that they feel able to say no. This is because people with learning disabilities often agree to do things because they think they have to.

6) What happens if your relative decides they wish to participate?

If after reading the patient information leaflet or you talking to them about it, they decide they would like to find out more about taking part in the research project, please ask your psychiatrist to let me know. There is a form for you both to sign to say you have agreed for me to visit to discuss the research. I will then arrange to visit you both to answer any questions they/you have. If they wish to participate in the research they can sign the consent form. You may need to witness that they have agreed to this if they are not able to write their name. I will then telephone them to arrange a time to see them here for the research interview at Leicester Frith hospital. I can collect them if they need transport. Even if they sign the form, they can change their minds at any time and withdraw from the study.

If you need further information or have any questions, please do not hesitate to telephone me on the number above.

Thank you in advance for your help

Bridget Cryer
Clinical psychologist

Interview schedule – principle questions to be used

Dreams:

- **Tell me about a dream you had last night**

Prompt: What was it about? What happened? How did you feel? Did you do anything? Where were you? What dreams can you remember?

- **Tell me about another dream**

Prompt: Do you remember any dreams? What are they about? When do you have them? What's in the dream?

- **What is a dream?**

Prompt: Where do they come from. What are they for? Who else has dreams?

Reality:

- **Tell me what you did yesterday (this morning)**

Prompt: What then? How did you feel? Where were you? Were other people there?

- **What else did you do**

Voices:

- **Tell me about the voices you hear**

Prompt: What was it about? What happened? How did you feel? Did you do anything? Where were you?

- **What is a voice?**

Prompt: Where do they come from. What are they for? Who else has voices?

- **Tell me a bit more about dreams and voices**

What are they like?

Appendix iv. Information to support an audit trail for the analysis

- Transcript excerpts
- Thematic grid

furniture layout

Elvis

I yeh

A maybe it goes slanted like that, watch tele. that way, but it's no good putting Elvis there cos people take me, take me, they'll take, D and E will take my Elvis and that if they come in one day

I your Elvis?

A well if I get it cos that's something else I seen

future sight

I yeh

I just see it all

A you know, I just see it all there

I what, you say see it, where do you see it?

A no I can't explain it

it's as if it's happened before in reality

future is as if it's already happened, like past experience

I is it like in your head or?

A it's just, as if it's happens real before

I right

A that it's all laying there, I mean to think I've been in this room before, as if it's all happened

as if it's all happened

I yeh

A you know I can't be carrying this I want to live the way I want to live now. So I'm just carrying on.

rejection of burden

need for self-choice

- I can't be carrying this
- I want to live the way I want to live now.

I (P) I remember when I came to see you in your flat you talked a bit about that didn't you, and you said sometimes you dream about your flat

A oh yeh, uhm,

I can you remember any dreams that you've had?

A uhm, like what sort of dreams?

I I don't know, whatever you have

Dreams = negative
Dream of future

– I dreams that I'll go missing

A I dream, dreams that I have, I have a dreamt that I'll go missing cos that's part of the future and the cat runs outside with the dog cos the cat is used to the dog so it chases the dog, and I get them and say that's my dog you know. Before that happened, it's his dog, he was cruel to, cruel to the animals

– cos that's part of the future

jumping around

dog + cat escape

I who's that?

Dream re gipsy taking animals back

A this man, a gypsy, and I said to L and B, don't tell him my address, I knew when I see him, I see L, I says don't you tell him my address you know, I got a feeling that G comes into it by taking them down the tip, Are you alright? No he's not alright! Because then he finds out where I live and takes the dog when I'm on me own and I'm not having it cos he's cruel, he says I'll ring the police then, and all I can do is put a junction on him

future fear

I right

A if it come to it

I right

A and I don't know how, say he's not done nothing wrong but I can't help you but, see what the police are like! But that's all in the future

future dreams

all in the future

I right so you worry that that's going to happen

A yeh, cos I've looked after that dog, I have I've looked after him, he loves me to bits he plays with me, he's a lovely dog, cos I brought him like that. We bought him, I mean I know G teached him to obey and he had to train him and he did - out there, go toilet! Not on the carpet! If he goes in the passage and the toilet it's alright because then you can just clean it up, but the carpet I just won't accept, but he knows now so, he's known a long time, oh, I thought I was going to get a pain

Relationship c̄ pets

Ordinary life

– he's a lovely dog

– he loves me to bits

I are you alright?

A yeh,

I so you have some dreams about some things you're worried about

A yeh, it oh yeh

I yeh, so what would you do if you had a dream like that?

Dream about holiday in Italy

A see I had a dream about going on holiday to Italy, and I seed J arguing with his ex-wife and L there as well, she gets in there, she comes on the train with us, and he

Dreams – foreign trips

sees his ex-wife, Oh it's got nowt to do with, you know he had to explain all this to,

?

Confusion

then he had another wife, he had to all explain it, he says to L who's this K? K's a friend, but then when he sorted me out and so on, he says who's this L then, who is

Man sorts her out

she? In the end I think B, I think A had to take me, uhm to his sisters while he sorts the problem

I right

elaborate drms of future

A And I was sat there worrying, are you coming back, then on the way there, or back, I mean B don't like hoovercroft, cos everybody's sick on the hoover croft, and uhm,

Clarifying for interviewer

I've never been this is future

future

I've never been this is future

I right

A so anyway, we got there on the hoovercroft, I said I don't want to go back on the hoovercroft, so we go on the ship and I was wondering whether it would be any easy journey, I mean the trains, she don't like the train, I don't know

I is L, is she a friend?

we die

A but I feel as we's all treading water and we just die, yes cos I just don't like it under the water; I feel as if it's going to crash or

as if she's experiencing it all.
Story very real to her, caught up it in.
Contrasts to telling the difference of Vs earlier

emergent themes Excerpt 05 Important phras

325. I yeh

326. A they were talking, I think they were like whispering; I thought they were talking 'bout me and I get confused whether to or not

feeling persecuted

confused

327. I the voices were talking about you?

328. A me sister and L

329. I Your sister and L

sister + L talkin about him

330. A They were talking behind my back, that's how I felt trapped, I thought 'what are they saying? Are they saying anything about me or what?'

trapped

felt trapped

Doubts re whats really happening

are they talking about me or not

331. I uhm

332. A then the voice comes in me head

voices come in my head

Reaction to confusion = voices

333. I uhm

334. A "look out they're talking about you"

look out they're talkin about me!

L Vs express thoughts??

335. I right, uhm

336. A and they're like, whispering and it says "come and listen to them talk"

come + listen to th talk

337. I the voice tells you to go and listen?

asks S+L if talking ab him

338. A yeh, right, and then I come out with it, "are you talking about me?" They say "no we ain't talking about you", ...(?) then the voice comes and says "yeh, they are talking about you"

Vs contradict what people tell him

Voice says they're talkin about yo

Dialogue c̄ Vs

339. I they are ?

careful what they talk about

340. A "careful what they talking about", then I go "no, no, they aren't talking bout me at all, sure they're not"

I say they're not

Doubts?

341. I uhm

342. A and then I come in the living room and they were talking, then when I went in the bathroom to go toilet it's like whispering again "they're talking about you again". I go "no they ain't" , "yeh they are, they're talking

Go to toilet and V whispers again

Persistence of Vs

they

(doesn't know whether to believe Vs or not, tries not to but gets pulled in)

- felt scared

bout you” and I felt scared, why, you know, why they talking bout me, asking questions inside me head

- why they talking about m
- asking Qs inside head

fear

343. I Yeh

It hurts to hear it ins

Get more conf

344. A you know, it hurts me to hear it inside, that person inside say ‘do something about it’ and I go ‘ I can’t do anything about it’ and you get more confused

'it' person
helpless
confused

345. I cos the voices tell you to do something and you’re arguing with it and

346. A yeh

347. I and you say, ‘no I won’t’

coping?
response to confusion

348. A yeh

349. I what do you get confused about?

feel like hurting myself

350. A it’s like, I feel like hurting myself,

feel like SIB
becos fed up

351. I you feel like hurting yourself?

352. A yeh

I'm fed up, c̄ it telling me what t do

353. I uhm

jumping about

354. A cos I’m fed up, telling me things to do, not to do and uh, it’s a bit scarey, frightening, even though I felt; in my dreams, I woke up this morning and I said to L I had a dream, a dream about someone was after me with knives and it were going to catch up with me and I keep turning corners and that

it's a bit scarey
frightenin

Dream of persecution

it

had dream that someone w after me c̄ knives and it going to catch up c̄ m

355. I you keep what?

356. A turning corners

try + avoid, get awa from them

357. I turning corners, yeh

avoid pursuers in dream

358. A try and avoid them, get away from them

359. I yeh

hurting me in dream

360. A And it's like they're come to me and they're hurting me — they like come and are hurting me with a knife

361. I yeh with a knife

knives

362. A with a knife yeh

363. I sounds frightening

L said it's only a dream

364. A yeh and uh, I told L that and she said, it's only a dream A, but I felt trapped — but I felt trapped

Support - only a dream

Trapped

365. I you felt trapped in your dream?

366. A yeh

Sometimes my drea
Can come true

367. I can you remember any other dreams you've had?

Clairvoyance - dreams can come true

368. A sometimes my dreams can come true

369. I right

evidence for his beliefs

370. A in the past, when I was with me dad, me grandad came back from Canada to come and live , dad went to see him, this is in the car, this is in me dream, uh, I said to him, I said me dad went up yesterday to see him in the car and uh, me sister looked at me and that, we had a big row in the car and that, I got out the car and then I said I wish me grandad were dead — this in me drea — I said I wish granda was dead

371. I uhm

he died following day

372. A and he died the following day

373. I right

Guilt

374. A and I felt guilty — I felt guilty

375. I yeh

376. A and I said ....(?)

377. I so did you have a dream about

the dream came true

378. A it was; the dream came true

379. I so in the dream, you were in the car with your sister and you had a row

380. A yeh

381. I but he did die?

Telling the difference

382. A yeh

383. I and was that a dream or..?

dream that came true

384. A it were a dream that came true

It were a drea
that came tr

385. I once the dream stopped you found your grandad had died

386. A yeh

387. I right, how did you feel about that?

hurt + guilty (belief that his dream caused real death)

388. A hurt

hurt
and guilty

389. I hurt

390. A and guilty

391. I and guilty, did you do anything?

told sister

support?
matter of fact response

392. A well I went to me dad and I think I told me sister about it when I went back in the car, and me sister said "yeh, well you can't do owt about it"

393. I you can't do owt about it?

394. A no

Flashbacks

395. I can you remember any other dreams that have come true?

Raped as child

a no, I get flashbacks from when I was about ten, I've been raped

396. I right

flashbacks whe
10yrs I've been ra

Story (telling the story)

397. A cos I went down X park catching fish and this bloke comes from nowhere ……………..(?) and he got me like (action arm round his neck) like that gripping me throat.

398. I yeh

childhood trauma
support?

went to me m
filthy

399. A I got hurt and I went to me mum and dad and I felt filthy and worry about that,

400. I umm, and that was when you were ten

Excerpt 05.

emergent themes

Important phr

457. I trying to think about voices and flashbacks and dreams and how they're different or the same?

Voices at night

alot at night

458. A the same?, some same some different, uh, a lot at night time, happens then, then I forget

Forget some

then I forget

459. I what happens at night time?

If Vs tten go to family (support)

go to nieces/broth

460. A well, then, I go down nieces or go down brothers'

461. I sorry you said it happens at night time, what happens?

462. A the voices come in me head

voices come in m
head at night

463. I right

- afternoon

Battle, try + fight Vs

464. A and sometimes it happens in the afternoon, like when I go in town or go on bandits and uh, I try and push me mind away but generally they get stronger, it's when I got the money, it happens then

- I try + push mind a
- generally they get str
- it's when I got mon
- terrible bad things
- the voices were wro
aga

money = trigger temptation

465. I right

466. A I told L, I tell her …….(?) done terrible thing, bad things and she said "it's your own fault" and I thought, the voices were wrong again

Vs real to him

As it's part of him that expresses desires but denies responsibility
Vs fault. They're wrong again.

467. I uhm, what about the flashbacks then, where do they happen or when do they happen?

morning/night/middle of afternoon

468. A happens, uhm, like this morning and at nighttime or middle of afternoon

469. I in the afternoon

470. A yeh

471. I and you said this morning

triggers for flashbks = others talking about him.

472. A yeh

473. I right

if someone talks about me and that, I get em that way.

474. A it's like, if someone talks about me and that, I get em that way

as if:

475. I right, when someone talks about you

- a recorder in yr bedrm

tape recorder spying

476. A it's like someone's got a recorder in your bedroom, uhm, coming to spy on me, felt trapped and I thought, how they spy on you-

- spying on me

felt trapped

I thought 'how they spy on you'? -

Trapped

477. I as if they've got a recorder

he questions how: 'theories'

478. A yeh a recorder

479. I what, like this (points to tape on tqable) or?

480. A yeh like this

481. I or like a video?

482. A no, not video, smaller

Communication finding right words

483. I like a tape recorder

484. A yeh, like a tape recorder, small

485. I walkman?

486. A yeh

487. I so it's like someone's get a recorder in your room, spying on you

488. A yeh

489. I is that when, (pause), the flashbacks, when do they? What sets those off?

- set off by a row

- get confused + hurt

Rows trigger FBs

Confused/hurt

490. A set off by, when a row or it's like you do this, and I get confused by them and hurt by them and someone telling me I'm talking in my head, nonsense

- someone telling me I'm talking in my head

- nonsense

Fluidity Vs+FBs

491. I <u>you</u> are?(emphasis)

492. A yeh, and owe people money, I pay them; well I've got to pay them, but I hear a voice saying "ooh, no! leave it until another time!"

V 'ooh, no, leave it until another time'

Vs tempt him

493. I yeh

no will
Control =>
orders/his
instructions

- like I've got no will
- it's like a robot ~~the~~ contr
- turn this way/that way

494. A it's something like I've got no will, well I ain't got a will, it's like a robot that controls

495. I uhm

496. A turn this way, turn that way

497. I uhm, like you're being controlled

498. A yeh

499. I what's that feel like?

feelings

horrible

500. A horrible

501. I horrrible, uhm, right

502. A you know what we were talking about in the car, I can't drive but I could drive, but caught by coppers

503. I you got caught by the coppers?

self doubt

504. A yeh, pulled up, I didn't know if I was doing the right thing or the wrong thing then. Cos I helped out this lady I know, that's who I took for cos she can drive herself but she ain't got a licence, got it took off her

believe ∴ is so

505. I oh right

506. A she ain't got a full licence, she told me so and I believe her

507. I yeh

Emergent themes

08 transcript

important phrases

15. A – yeh

16. I – what we were going to talk about was dreams as well as voices

17. A – yeh yeh yeh and nightmares and dreams, nightmares

18. I – yeh

nightmares + dreams

nightmares + dreams
nightmares

19. A – nightmares

20. I – what kind of nightmares?

shouting in sleep

behaviour during

21. A - shouting in sleep, shouting in sleep shouting in sleep

22. I – shouting?

23. A – in sleep, yeh in sleep

in sleep

during sleep

24. I – when you're asleep?

25. A -yeh

repetitions

26. I – and you shout?

27. A – yeh

28. I – right. What happens in the nightmares?

29. A - Carry on carry on

carry on

relentless / persistence of experience (nightmare)

30. I – the nightmare carries on?

31. A – yeh (nodding)

32. I – and you shout

shout in my sleep

33. A – shout yeh in my sleep

34. I– so what is it you dream about, what's the nightmare about?

fluidity (Dms + Vs) (Dms about Vs)

35. A – about voice, hear voices

about voices,
hear voices

36. I – about hearing voices, right.

37. I – can you remember a dream you had last night?

38. A – yeh

39. I – can you tell me about it?

man talking in my head

[illegible]

40. A – urrh, about man, man talking in my head, man talking in my head, hit me,

hit and shout

hit me + shout

Physical location of V

attacking

41. I – men were talking to you in your head?

hit myself

42. A – yeh and hit myself

SIB

(hits self when man in dream hits him)

43. I – really! You do that in your sleep?

44. A – yeh A –(Sound of man clearing throat outside window) (looks up at window)

45. I – someone's got something in his throat!

46. A – yeh (both laugh)

47. I – ok

48. I – so what were they talking, what were they saying?

49. A – you've got to kill yourself, cut it here (gestured on wrist), think I'll cut it here

- you've got to kill yourself
- cut it here (wrist)

Control

malevolence

50. I – they were telling you to cut your wrists? - think I'll cut it here

51. A – yeh

52. I – right

They order - he considers?

53. A – and kill yourself

54. I – and kill yourself

kill yrself

55. A - Yeh

56. I – right

57. I – so how did that make you feel?

feelings

58. A - awful

repetition

59. I – yeh I bet

feel awful

60. A – awful

awful

61. (A drinks his tea and gulps)

62. I - how often do you have those dreams?

daily

63. A – every night

64. I – every night

dreams every night

65. A – yeh

66. I – and what do you do?

67. A – get up and get dressed, go down stairs

get up + get dressed
go downstairs

Coping

68. I – yeh so you wake yourself up, get up and get dressed

69. A – yeh

70. I – yeh, ok, what do you do then

71. A – watch TV

watch TV

72. I – watch TV yeh

73. I – can you remember any other dreams?

74. A – no, same sort of dreams, same sort

no other dreams,
same sort of dreams

All dreams =
same

75. I – sorry say that again

76. A – same sort of dreams, same sort, same sort of dreams

77. I - so do you only have the nightmares, you don't have other dreams?

communication
difficulties

78. A – no, only --?--- dreams ---?------

79. I – in the dreams, when the men are telling you, talking to you in your head, can you see them or?

80. A – at home ----?--

81. I – not in your dreams?

Shadow on the walls
Black shadows

82. A – in dreams, no, Shadow walls, shadow on the walls, black shadows walls

83. I – what's going through the walls? Sorry!

repetitions to emphasise
point

84. A – shadows! Black shadows

Black shadows

85. I – black shadows!

Communication difficulties

86. I – so can you tell me what, what is a nightmare? nightmare = scream + shout

87. A – shout and scream, shout and scream, scream and shout, scream and shout

repetitions

88. I – you scream and shout, yeh, that's what you do when you have a nightmare

nightmare = his behv (concrete)

89. A – yeh

90. I – do you know what a nightmare is? DK what nightmare is

91. A – (big shrug) no

92. I – wonder where it comes from?

93. A – comes from the back of my head Comes from back of my head

94. I – from the back of your head? down there

Physical origin 95. A – yeh, down there (points to base of back of head), I hear voices now I hear Vs now

96. I – you're hearing voices now?

Current experience of Vs 97. A - Back there Back there

98. I – what are they saying now?

99. A – that you've got to kill yourself, You've got to kill yrself

100. I – right, uhm, do they ever say anything else?

101. A – uhm, yeh, go away we don't want to know you Go away we don't want to know you

persecution

102. I – they don't want to know you, you or me?

unpleasant rejecting 103. A – no, me! me

104. I – you, right. And how does that make you feel?

Feelings (awful) 105. A – awful awful

106. I – yeh, yeh. [P] How often do you hear the voices?

107. A – ooh, every night hear Vs every night

108. I – what about in the day?

109. A – every daytime yeh, every daytime every daytime

110. I – you get them in the daytime too?

111. A – yeh in the daytime

hear them all day

112. I – and is that all day, or are there times you don't hear them?

relentless – continual

113. A – all day, I can hear them now

I can hear them now

114. I -- what other things do they say then?

rejecting

115. A – go away, we don't want to talk to you

go away, we don't want to talk to you

116. I -- they don't want to talk to you

117. A – yeh

118. I -- what do you want to do? (looks over and gestured at the tape recorder)

Control of interview

119. A – play it for me

play it for me

120. I – do you want to listen to it again?

121. A – yeh please

Click

122. A –thank you

(wonder if he wanted to see if Vs were on tape?)

stage 3 emergent themes.

	50s	Very Young	40s	50s	30s	Very Young	30s	60s		
themes	01	02	03	04	05	06	07	08		
Explanations purpose + origins (theories of).	✓	✓	✓	✓	✓	✓	✓	✓		physical locations.
telling the story	✓	✓	✓	✓	✓	✓		✓		
feelings	✓	✓	✓		✓	✓	✓			
Coping strategies	✓	✓	✓	✓	✓	✓	✓	✓		
Confusion (theirs)	✓	✓	✓	✓	✓		✓			
Contradictions	✓				✓	✓	✓			
Treatments + the system	✓		? as part coping							coping?
Fluidity (Vs, Drms, flashbks, visions).	✓	✓	✓	✓	✓	✓		✓		
magic/religion/metaphysical/extraterrestrial	✓	✓			✓	✓	✓	✓		part of theories?
sharing experiences	✓		✓							helping others
Control/power	✓	✓	✓	✓	✓	✓	✓	✓		
Relationship with 'it'/phenomena	✓	✓	✓				✓			
Resignation/acceptance/neutrality	✓		✓	✓						part of coping?
Clarity	✓		?							characteristics
Visual impact		✓								- characteristics of?
Sentient it them he/Personality	c ✓	✓		✓	✓	✓	✓	✓		?
~~Malevolen~~ce of 'it'		✓			✓			✓		

Malevolence

ones experiences

?

themes	01	02	03	04	05	06	07	08		
fear of disclosure / others reactions		✓			✓					
'it' expresses their fears / ~~thoughts~~		✓			✓		?			
Triggers / antecedents		✓	✓	✓	✓	✓	✓	✓		
Universality of dreams (as an experience)		✓	✓							
effects of phenomena on ~~[illegible]~~ interviewee		✓	✓		✓	✓	✓	✓		include feelings.
Film characters / celebrity / television		✓					✓			characteristics of phenomena.
* Concreteness		✓				✓	✓	✓		
* Telling the difference	✓	✓	✓	✓		✓	✓	✓		~~[illegible]~~
Uniqueness of Vs		✓					✓			
fear of loss of positives			✓							(c̄ fear of disclosure ?)
helping others cope			✓							
Then + now	✓		✓			✓				telling story / chronology
Independence / freedom			✓	✓						normality
Everyday life			✓	✓	✓	✓	✓			(part of coping?)
Support networks										Part of coping.
effects of treatment	✓			✓						

~~8~~

themes	01	02	03	04	05	06	07	08		
Characteristics of phenomena		✓	✓	✓	✓		✓	✓		
Jumping around			✓	✓	✓					(c̄ confusion? fluidity?)
Telling the future			✓		✓					
Conflict + violence		?✓			✓			✓		
Death + bereavement	~~✓~~			✓	✓		✓			
Persecution/paranoia			✓		✓			✓		malevolence
Victim (I'm not responsible).					✓					
Learning disabilities (Qs confuse me, words get muddled)					✓	?	✓			(links to confusion?)
Belief in a just world - why me?					✓					
Hopes for the future			✓		✓					
making sense of experiences	✓	✓	✓			✓	✓			- theories
Invention (not real, can be invented ∴ understand real/not real)	✓		✓	.	✓?		✓			~~check back~~ *
? Acceptance of different but real experience		✓	✓	✓	✓	?✓	✓	✓		entity?
Confused interviewer		.	✓	✓	✓	✓	✓	✓		
~~Belief~~ Concrete acceptance (± believe = it is real)		✓	✓	✓		✓?	✓			concreteness ~~check back~~ *
Repetitions		✓		✓				✓		→ Telling story
Variety of phenomena	.	✓	✓		.	✓	✓	✓		- Characteristics

themes	01	02	03	04	05	06	07	08	
Current experience (in interview)				✓		✓		✓	
communication difficulties in interview					✓		✓	✓	
poor Q of L								✓	

communication / Confusion in interview

everyday life?