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inside this edition:

**meaningful day care in Services for
People with a Learning Disability**

relapse prevention planning

**a CAMHS perspective on Obsessive
Compulsive Disorder**

decision-making analysis

Carers & Users Expectations of Services

and more.....

Advancing Practice in Bedfordshire

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As randomly selected by the editorial group, the following authors of two articles published in APB Edition 3 will each receive a free book:

Terri Dorman—Practice Development Nurse, Services for People with a Learning Disability

Kay Stokes—Sheridan Day Hospital Manager, Mental Health for Older People

Editorial:

Maggie Nicholls

Welcome to edition 4 of the Journal of Bedfordshire & Luton Community NHS Trust. It doesn't seem possible that it is almost a year since the journal was re-launched, as so much has happened in this time, *not least the Trust's review by the Healthcare Commission in November 2004 about which we will talk more in edition 5*. We hope that you will agree with us that the contents of this edition are just as stimulating and varied as ever and give some indication of the level of interest and expertise of staff employed by the Trust.

Jane King and Claire Sostacenko work in Services for People who have a Learning Disability (SPLD) and have a remit to develop day activities for clients in one of the assessment and treatment units of the service. Their paper details how they went about initially developing ideas for the service and the connections they made, both with colleagues in the Trust and with another NHS Trust. They also discuss processes they have instigated and how they are implemented within their own home in an article that may be very useful and informative for other services of the Trust that are looking to develop their own day activity programmes.

Editha Butler and John Butler provide a review of some key literature on structured relapse prevention planning for depression, together with a brief account of the key stages involved in developing relapse prevention plans collaboratively with service-users. The potential value of this care component is highlighted—this is also emphasised within the Trust's Care Programme Approach Policy.

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P. Ganeson and Uttom Chowdhury provide an article that focuses on Obsessive Compulsive Disorder (OCD) in relation to children and adolescents, describing what they feel may be a unique approach within community based primary care services. They report on the most common obsessions that are presented and how they manifest themselves in the behaviour of young people, as well as the incidence rates and associated demographic factors. Gani and Uttom go on to discuss the focus that the Child and Adolescent Mental Health Service (CAMHS) take when working with young people who have OCD, that includes a discussion of suitable medications as well as the psychological, family, social and educational interventions that the service currently undertakes and plans for the future.

In a powerful and passionate paper, David Robinson evaluates an approach to the everlasting and difficult area of allocation of health resources, as conducted at national policy level. The article discusses decision making analysis: a model which is proposed to facilitate decisions on which treatments or health related areas that are likely to

be most beneficial are based. He argues that this is an inappropriate model for health related issues. Using experiences from his own nursing career, David brings to life the potential consequences that using utilitarian decision making methods could bring to people in need, particularly in mental health services.

Under the heading of quality improvement in this edition is an audit report of a project investigating waiting times within SPLD. This project was identified as a priority by the directorate because of concerns that service-users might be waiting for an unacceptable time to commence treatment following timely initial assessments. Furthermore, it was thought that there would be many cases of inappropriate or repeat referrals, all of which would have a negative effect on waiting times. In a very concise report, the authors, Linda Hiscott and Mandy Quarmby, show how a focussed project idea can provide a wealth of information, and results that are not always as expected. We will not spoil the 'ending', but would recommend this article to those of you who are not sure of the importance of audit in helping

to improve the care we provide to our service users and, indeed, our own working lives.

Finally, Debbie Buck shares her experience of using the CUES (Carers & Users Expectations of Services) satisfaction questionnaire within the Trust's rehabilitation services. As a consequence of this work, she proposes a set of recommendations for practice.

We hope that you will enjoy the contents of this edition and find the entries thought provoking and useful and we would very much like to encourage all Trust staff to submit articles for this journal. Perhaps you would like to send a review of a publication, new tool or process that might be of interest to colleagues, or perhaps details of projects or other work that you are involved with. We know that excellent work is being undertaken throughout local services and this journal is an ideal opportunity to share that knowledge and shout about what we are doing so well! You can find our contact details on page 2—we look forward to hearing from you!

**Advancing Practice
in Mental Health & Services for People with
a Learning Disability:
developments in practice, education & research**

**a one-day conference
at Silsoe Conference Centre, Silsoe, Bedfordshire
on Wednesday, June 15th, 9.30AM—4PM**

see page 34-35 for further details

Creating and Establishing Meaningful Day Care at The Spinney

Jane King & Claire Sostacenko
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THERAPEUTIC CARE

Introduction

The Spinney is one of the in-patient areas within Services for People who have a Learning Disability (SPLD). One of the objectives of the service is to provide rehabilitation to patients before they return to the community, following a period of treatment in one of the other in-patient areas.

This short paper will demonstrate how meaningful day-care has been established with the patients at the Spinney.

The Process

In the summer of 2003, the Spinney advertised two Day Care Officer posts, for which we both applied. At the time, Claire worked as an Acting Day Care Officer and Jane was a Senior Support Worker at the Spinney. We were both very involved in supporting the patients with their day time activities.

In November 2003, we both commenced our posts as Day Care Officers at The Spinney. We had very similar ideas on how day-care should be set up and implemented.

Initially, we had a meeting with the Clinical Nurse Manager at the Spinney to discuss the ideas we had and how this could be taken forward within our resources. A further meeting was held, which included the Lecturer Practitioner in Learning Disabilities, to discuss and formulate a framework for day-care reports on individual patients.

A network was set up between the Spinney and Bradlaugh House at St Andrew's Hospital in Northampton. This included exchange visits, whereby we shared ideas and good practice in day-care. We found this to be very beneficial.

As we became established in our new roles, we continued to have monthly meetings with the Clinical Nurse Manager and Lecturer Practitioner in Learning Disabilities. We planned the day-care service according to the patients' needs, which were identified to be activities associated with daily living skills and education—for example: literacy and numeracy.

When patients leave the Spinney, some go on to live in supported living accommodation, where they become more independent.

We formulated a weekly timetable of activities as a general guide for patients and staff. Each patient has individual needs and so this work was provided in accordance with their needs—some patients required individual support from staff. It was agreed that each patient would have their own individual day-care folder, for which they would be responsible. Each folder would contain their work on different subjects and copies of their day-care reports, which are written for their Care Programme Approach (CPA) Meetings.

As we felt it was important to evaluate each session of day-care, we devised and implemented a form which gives both the patients and staff the opportunity to reflect on how the session went. We use this information to help us with planning future activities.

Each session of day care is planned on a weekly basis with the patients, who have their own individual planning sheets for the week, which are kept in their folder. Lessons are planned beforehand to assist other staff to facilitate each session. Use is made of community facilities in order to develop independent living skills. This includes using the public library, personal shopping and using public transport.

Once all activities and patients' folders were agreed with the Clinical Nurse Manager, a staff meeting was arranged to present the new day care-package.

The patients have a meeting on a monthly basis. The topic of day-care was discussed at one such meeting.

The new folders were given to the patients and each session was explained in full. The patients were invited to give their views of the day-care package. All patients who expressed an opinion were very agreeable to the planned changes in day-care activities.

At present, day-care at the Spinney is progressing well and being maintained by all staff working towards the same aims. We have received positive feedback from internal and external sources, including visitors from Hertfordshire Partnership Trust and our internal Multi-Professional Team. This has led to us receiving referrals for patients in need of structured day-care, which we would like to further develop in the future—this may then generate income for the service.

In the short term, our next aim is to implement structured individual assessments with patients, that relate to day-care.

Conclusion

Day-care has now been implemented at the Spinney in a structured format by two Day Care Officers, who are both employed on a permanent basis. The activities have been designed in order to meet patients' needs with regard to their rehabilitation into the community.

Day-care is continually reviewed with patients and is deemed to be successful by patients and staff alike.

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The Effect of Structured Relapse Prevention Planning on Attitudes to Recovery from Depression: a review of the literature and programme planning

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LITERATURE REVIEW

Introduction

In this paper, we will highlight issues relating to the management of depression and the prevention of relapse—this will include: a definition of terms; a summary of findings from key studies on relapse prevention planning; a short review of the impact of relapse prevention planning on clients with depression; the key aims and principles involved in conducting structured relapse prevention planning; and, a brief outline of the stages involved in developing relapse prevention plans with clients.

Defining the Terms

Most authors define depression, the main phases of treatment and recovery, and treatment components such as relapse prevention planning, to suit the purpose of their particular study. It is first worth considering these terms for the context of this paper, with reference to the available literature.

Depression

The term depression describes a spectrum of mood disturbance ranging from mild to severe and from transient to persistent (Peveler et al 2002). Around 2.3 million people experience depression in the UK at any time, 1:5 people who seek help in primary care have psychological problems, and 1:10 suffer from depression. Females are about twice as likely to experience depression as men (Simon et al 2002).

Depression has been classed as one of the most important diseases of our time (Pereira Gray 1992), with the prevalence of major depression being reported as 5 - 10% of people seen in the primary care setting (Geddes et al 2003). It is a serious illness in that it severely affects the individual's quality of life and is associated with a worrying number of deaths from suicide. However, depression is usually treatable and can be

efficiently managed in primary care. Some may respond to conventional doses of antidepressant drugs and many have benefited from psychosocial interventions, such as cognitive behaviour therapy (CBT) and relapse prevention planning.

Many studies have indicated that poor compliance with medication has been the cause or result of a relapse of mental illness and have recommended the use of CBT as an adjunct or alternative component of treatment.

Remission, Recovery, Relapse & Recurrence: phases of treatment and recovery

The treatment of depression can be explained as progressing through three phases: acute, continuation and maintenance phases. Acute treatment ends when the patient experiences a full *remission* of symptoms. However, it is very important to encourage the patient to continue the treatment that works for them in reaching *recovery*, which means maintaining their progress, a full remission of symptoms, for at least six months. If the patient experiences further symptoms before this time, then this is known as a *relapse*. If symptoms occur again after this period of remission, this is known as a *recurrence* of the depressive illness (Scott 1999).

In a study carried out in the USA and other parts of the world involving depressed primary care patients who were receiving antidepressant treatment, Lin et al (2003) reported that more than two-thirds had a history of recurrent depression, and about 20% experienced a chronic course of their depressive symptoms. Over one-third of these patients experienced a recurrence in the year that medication had been initiated, and the earlier that medication

was discontinued, the greater was the likelihood of relapse occurring.

Risk of Relapse

The risk of relapse or recurrence increases with the following (Angst 1999, Anderson 2003):

- the more severe the initial episode;
- the longer the duration of the initial episode;
- the longer the time since the last episode;
- the total number of previous episodes;
- the presence of residual or persisting symptoms;
- a lack of self-confidence; and,
- greater disruption to family and study / work.

Angst (1999) added that: recurrence after recovery from the initial episode of major depression is an important practice issue, with over 50% of patients experiencing a recurrence within three years. He recommended that those patients at increased risk of recurrence should receive long-term preventative treatment.

Effective Treatment Approaches

Many clinical studies and reviews have demonstrated that antidepressant drug therapy is an effective treatment for moderate to severe major depressive disorder, often as the first step in treatment, and that cognitive behaviour therapy is an effective treatment for mild to moderate depression and an effective adjunct to antidepressants in moderate to severe major depression (NICE 2004).

Enright (1997), in his review of the

clinical application of CBT, concluded that CBT is the treatment of choice for many mental health disorders including depression. In addition, four randomised controlled trials (Paykel et al 1999, Blackburn & Moore 1997, Fava et al 1998, Teasdale et al 2000) found that CBT based preventive interventions sequenced after a full or partial response to antidepressant medication provided significant protection against relapse or recurrence.

Scott et al (1997) studied the application of brief cognitive therapy in primary care, suggesting a potential benefit in the treatment of depression: the results provided encouraging evidence of health gain as a consequence of the intervention. King et al (2002) suggested that CBT is as effective as pharmacotherapy for treating depression in general practice, with the added benefit of reduced rates of long term relapse.

Segal et al (2002) produced a highly commended book to help patients gain an awareness of their problems / symptoms. An integrated programme of mindfulness and cognitive therapy, this offers an innovative method for breaking the cycle of recurrent depressive episodes, which help patients recognise and manage future relapse episodes.

Therefore, CBT undoubtedly has much in its favour. It is an attractive, efficient therapeutic approach and produces good results in many instances. It has been described as the therapy to beat, and this has sharpened the minds of psychotherapy researchers worldwide (Holmes 2002).

CBT & Relapse Prevention Planning

Thase et al (1994) made comparisons

between male and female people with depression who were treated using cognitive-behaviour therapy. They found that whilst males attended significantly fewer therapy sessions, each group showed comparable responses to therapy, and patients with higher pre-treatment levels of depressive symptoms, especially females, had poorer outcomes.

With regarding to the risk of relapse following cognitive-behaviour therapy for depression, Thase et al (1992) compared relapse rates for fully recovered and partially recovered out-patients over a 12-month follow-up period following a 16-week, 20-session treatment protocol. They found that the following factors were correlated with an increased risk of relapse: history of depressive episodes; higher levels of depressive symptoms; higher levels of dysfunctional attitudes; a slower response to therapy; and being unmarried.

Key Relapse Prevention Study 1

Fava et al (1998) conducted a two stage sequential randomised study in which 45 consecutive out-patients, in remission from diagnosed recurrent depressive disorder following successful treatment with an anti-depressant, were randomly allocated to two groups: cognitive-behaviour therapy for residual symptoms; or, standard clinical management. Anti-depressant medication was gradually tapered off and discontinued for all clients within the 20-week treatment phase of their study. Of the original 45 clients, 5 were excluded from the study, as discontinuation from anti-depressant treatment was not possible, leaving 20 clients in each group. The experimental group received 10 sessions of CBT, which was supplemented by lifestyle

modification (education and daily scheduling) and well-being therapy (belief modification and relapse prevention strategies), as a result of the clinical challenge presented by these clients. Clients were followed up for two years, being independently re-assessed by a psychologist on eight occasions using the Paykel Clinical Interview for Depression, which was regarded as useful for assessing sub-clinical symptoms of depression.

Comparing the outcomes for the two groups, Fava et al (1998) reported that there were no statistical differences on any socio-demographic or clinical characteristics between the groups, that there was significant improvement in residual symptoms only in the CBT group, that 25% of the CBT group compared with 80% of the Clinical Management group had relapsed at two years, and that CBT was highly significant in delaying recurrence of depression at two years. They concluded that an amelioration of symptoms may reduce the risk of relapse in depressed out-patients by stopping the progression of residual symptoms into relapse prodromes.

Whilst a very favourable study for both the value of CBT and relapse prevention planning, their study had a number of limitations: their sample size was small; they used a naturalistic design, as patients were initially treated with different types of anti-depressant (tricyclics or SSRIs); there was no placebo-controlled withdrawal of medication; all of the treatment was provided by only one psychiatrist, with expert experience in affective disorders and CBT – the results may have been very different with multiple, less experienced therapists; and, it was unclear to what extent the results were

due to CBT, lifestyle modification or well being therapy.

Fava et al (1998) also raised some important issues:

that residual symptoms hinder lasting recovery (Fava et al 1998);

that the presence of residual symptoms after the completion of drug or psychotherapy treatment has been correlated with poor long term outcome (Fava et al 1996);

that the definitions used for recurrent depressive disorder (RDD) and for relapse differs between studies: Blackburn et al (1997) defined RDD as having had at least one previous episode of depression, whilst Frank et al (1990) & Fava et al (1998) defined RDD as having had at least three previous episodes of unipolar depression, with the immediately preceding episode being no more than 2.5 years before the onset of the current episode – this highlights the need to define and be clear about the key terms.

Similarly, in a study of 386 patients, who were randomised into two groups of a low intensity relapse prevention programme or usual primary care programme, Katon et al (2001) showed that those in the intervention group who were taking an antidepressant, with a high risk of relapse / recurrence, significantly improved. These primary care patients had a greater adherence to adequate doses of an antidepressant and had fewer depressive symptoms.

They recommended that there is a need to develop effectiveness models of continuation and maintenance treatment of primary care patients with recurrent or chronic depression and that primary care systems need to begin to adapt services to improve the care of patients

who experience recurrent and chronic medical and psychiatric illness. They concluded that a relapse prevention programme targeted to primary care patients with a high risk of relapse / recurrence who had largely recovered after antidepressant treatment showed significantly greater antidepressant adherence and fewer depressive symptom outcomes.

Key Relapse Prevention Study 2

Lin et al (2003) conducted a randomised trial of the prevention of depressive relapse in primary care patients who were at high risk of recurrent depression by evaluating the effects of a brief psycho-educational intervention on medication attitudes and the self-management of depression.

Of 702 eligible patients, recruited from four participating primary care clinics, 480 completing a baseline interview, of whom 386 were randomised to either the intervention group (N = 194) or to a control group of 'usual care' (N = 192). All of these patients demonstrated a substantial improvement of their index depression episode and had a high risk of relapse (= 3 or more lifetime depression episodes).

Over a 12-month period, the intervention group were offered: two sessions with a depression prevention specialist, who provided a manualised intervention following initial training and with ongoing weekly supervision; three scheduled telephone sessions; and, four scheduled personalised letters to monitor progress, remind and motivate patients to continue their self-care and follow their relapse prevention plan. The intervention involved each patient in writing and implementing their own relapse prevention plan, and also included evidence-based pharmacotherapy,

integrated cognitive-behavioural and motivational interviewing approaches, psycho-education on the prevalence and course of depression and its treatment, giving explanation about the high risk of relapse, a discussion of evidence that highlighted the value of maintenance pharmacotherapy in preventing relapse, individualised approaches for managing any medication side-effects, and enhancing self-efficacy for preventing relapse through self-management behaviours, such as monitoring depression symptoms and scheduling pleasant activities.

Following a face-to-face baseline interview, patients were given blind telephone interviews at 3, 6, 9 & 12 months. This involved monitoring their medication usage, attitudes towards medication, confidence in managing side-effects, and depression self-management. Attitudes to antidepressant medication were assessed by the use of a 12-item questionnaire rated on a 5-point likert scale (Katon et al 1996); a 0 – 10 scaling technique was used to measure patients' ratings of confidence in managing side-effects; and, self-management was assessed on five brief measures – participation in pleasant activities and social activities, monitoring depression symptoms, checking their early warning signs of depression, and planful coping (anticipating and planning to manage stressful situations).

88% of patients in the intervention group completed all assessments, which was significantly higher than the 76% for the usual care group. Whilst the baseline clinical characteristics for each group were very similar, intervention patients consistently reported more favourable attitudes towards taking medication, had a significantly higher level of confidence

in managing side-effects, were significantly more likely to self-monitor their depression symptoms, check for early warning signs and apply planful coping, and were more likely to continue their antidepressant and receive an adequate dose of antidepressant compared to the usual care group at 12-months follow-up. The symptom checklist depression score was significantly lower for the intervention group.

A very positive study for the use of brief relapse prevention planning, their study findings may however not generalise to populations with a more diverse ethnic or socio-economic mix, or to patients who choose not to participate in such a study. Furthermore, their study was limited by an over-reliance on self-report measures, even if these measures were practical and useful. It is also worth noting that the intervention effects on medication attitudes and confidence in managing side effects were only of a small to moderate strength.

Equally, in comparison with other authors' research of different mental disorders, Tait et al (2002), in their study of relapse prevention using a cognitive approach for clients who have schizophrenia, reported results that indicate a high adherence rate and suggest that continuous individualised early signs monitoring could be an effective tool in predicting relapse and facilitating early psychological intervention with clients who have schizophrenia.

Wright et al (2000), in their study of a relapse prevention programme delivered via bibliotherapy in the treatment of individuals with panic attacks, found that those who received the relapse prevention programme exhibited

significant reductions on measures of frequency of panic attacks, panic cognitions, anticipatory anxiety, avoidance and depression. The relapse prevention group seemingly attained a 'clinically significant change' in comparison with the controlled 'wait list' group.

Relapse Prevention Planning Approach: the process

Scientific studies indicate that problems like depression, anxiety and psychosis are not conditions that suddenly appear. As with other life conditions, such as diabetes or asthma, there is often a 'run-in time', and early intervention is always more effective. These problems provide plenty of clues that they are developing. Noticeable changes in thoughts, feelings and behaviour are good indicators, which can be viewed as early warning signs. These changes usually occur in the weeks or months before a return of the troublesome symptoms of these conditions (Wright et al 2000).

Relapse prevention planning can be described as a collaborative therapeutic activity programme with three principal aims:

To develop an individual relapse picture that helps to identify 'at risk' mental states.

To develop a relapse plan (= relapse drill). This will provide an opportunity to promote engagement with services, closely working in collaboration with the client towards the mutual goal of relapse prevention.

To promote the client's understanding and self-control over re-occurring problems / symptoms.

The ultimate aim of relapse prevention planning is to help individuals make radical shifts in the management of their depressive symptoms (Segal et al 2002, Williams 2001). This therefore involves teaching patients how to learn, understand and manage their 'early warning signs', reinforcing personal responsibility and personal action planning. Even if this does not prevent relapse, it should help to reduce the impact and shorten the duration of the relapse.

Six Step Process

Relapse prevention planning is best achieved through a series of structured steps:

1. Engagement: using the client's own way of explaining things, to gather information that will help in becoming clearer and understanding what happened leading up to their most recent relapse
2. Identifying early warning signs: working collaboratively with the client to identify signs associated with relapse (as distinct from merely listing symptoms of the illness)—workbooks (Uttoxeter Mind 2003), practical worksheets (Scanlan & Minocki 2003) and card sort exercises (based upon: Birchwood, Spencer & McGovern 2000) can be used with the individual and their family to facilitate this
3. Timeline: *what happens when*—thinking about the last relapse, to establish which early warning signs occur first
4. Clarifying the relapse picture with the client and his/her family
5. Developing the relapse plan: being creative, to help the client and his/her family to identify personal coping strategies, a

pathway for gaining support and service interventions that are likely to help in minimising the risk of relapse

6. Checking understanding: to write up the relapse prevention plan and to rehearse it with the client

It is helpful to form a very individualised personal signs self-monitoring tool for use by the client, using their own list of early warning signs—as shown in Fig. 1. The client can use such a tool to monitor the frequency and degree to which their early warning signs are beginning to occur: a simple 0—3 rating scale can be used to indicate how much each sign is occurring and/or how bothersome this is becoming.

The client should be actively involved in developing a realistic personal action plan, incorporating strategies that s/he can continue to use or recommence in managing their early warning signs, as they begin to occur—as shown in Fig. 2 (an excerpt from a client's plan).

Summary & Conclusion

The value of RPP with depression has been extensively discussed and highlighted in many research studies, and identified as a valuable part of CBT intervention. Leading CBT experts have strongly advocated and recommended relapse prevention planning (RPP) to be included as a component part of CBT.

There is strong evidence in the literature reviewed of its effectiveness, and many leading CBT specialists are much in favour of structured RPP and acknowledge the significance and importance of its application. Relapse prevention strategies will certainly provide clients with skills that will allow them to manage their own affective

Fig. 1: Personal Signs Self-Monitoring Tool

My personal early warning signs	My ratings for each day of the week						
	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Difficulty sleeping							
Broken sleep pattern							
Not eating regularly							
Boredom							
Feeling frustrated & irritable							
Feeling full of energy but having nowhere to channel it							
Spending increasing periods of time alone							
Smoking more cigarettes – up to 20 cigarettes per day							
Thinking that things are pointless							
Thinking that nothing seems enjoyable							

Fig. 2: Excerpt from the personal action plan of a Relapse Prevention Plan

My personal early warning signs	Actions that are likely to help
Feeling frustrated & irritable	To try getting involved in various activities: physical exercise; television; listening to music; practising guitar; talking to friends, if they're available
Boredom	To remind myself that: <i>'the less you do, the less you feel like doing & the more you do, the more pleasurable things are likely to be'</i>
Feeling full of energy but having nowhere to channel it	To plan a variety of activities, which could include: playing football once / week; playing golf; going fishing; practising guitar
Smoking more cigarettes – up to 20 cigs. per day	To set myself some limits about my smoking
Thinking that things are pointless	To set myself realistic and achievable goals To try balancing things up – to remind myself of things that I've done well
Thinking that nothing seems enjoyable	To make a list of things that I find enjoyable – <i>some ideas are listed above</i> To rate how enjoyable different activities actually are To make a list of even small achievements as a way of encouraging myself

states in the absence of ongoing treatment and, therefore, empowering clients in the self-management of their depressive symptoms.

An important component of the cognitive-behavioural approach, relapse prevention planning presents both a valid and complementary method for enhancing the effectiveness of this approach. Providing structured RPP should result in helping clients to achieve the long-term aim of relief from depression and facilitating the acquisition of skills to prevent its recurrence.

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Obsessive Compulsive Disorder: a child & adolescent mental health perspective

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SERVICE DEVELOPMENT

Introduction

Obsessive Compulsive Disorder (OCD) is a distinctive and frequently disabling condition characterised by unwanted thoughts or images (obsessions) and unwanted repetitive acts and rituals (compulsions). Many people have OCD symptoms and are reluctant to seek help or share their concerns for fear of being ridiculed or stigmatised. In order to make a clinical diagnosis, there needs to be a degree of impairment in terms of time consumed with OCD symptoms, and distress or interference in functioning (American Psychiatric Association 1994). Common obsessions and compulsions are listed in Table 1.

It used to be thought that OCD was a condition that affected adults only, but studies in the last 15 years have shown that the condition is prevalent in children, occurring in 1 in 100 children (Valleni-Basile et al 1994, Heyman et al 2001). It is still debatable as to whether OCD in childhood is exactly the same condition as that in adulthood. The similarities are that both age groups share relatively the same clinical phenotype and both respond to the same pharmacological intervention. However, recent studies (Geller et al 1998) show that childhood OCD is associated with a unique peak age of onset indicating a bimodal incidence of the disorder (peak age of onset is 10 and 21 years). In the early-onset age group, there is a male preponderance and a distinct pattern of comorbidity with attention deficit hyperactivity disorder and tic disorders. This is in keeping with other neuro-developmental disorders.

The Child and Adolescent Mental Health Service (CAMHS) in Luton and Bedfordshire provides out-patient, clinic-based, community services in four locations: Dunstable, Luton, Bedford and Mid-Bedfordshire. Each clinic is staffed by a multi-disciplinary team that provides assessment and treatment for emotional and behavioural difficulties in children, adolescents and their families. Patients are normally seen up to the age of 18. Referrals can be made by various

Table 1: Common obsessions and compulsions

OBSESSIONS	COMPULSIONS
CONTAMINATION	WASHING/CLEANING
AGGRESSIVE	CHECKING
SEXUAL	REPEATING
HOARDING	COUNTING
MAGICAL THOUGHTS	ORDERING
SOMATIC	ARRANGING
RELIGIOUS	HOARDING

professionals, including general practitioners, nurses, social workers and special educational needs coordinators.

What do we feel is of interest/distinctive about the Service?

We are not aware of any other community-based primary care service with a special interest in providing care for children with OCD. The OCD clinics we are aware of are national tertiary referral centres. We are aware that we are probably dealing with a slightly different population to a specialist centre in that the patients we see will present earlier and may therefore have symptoms that are not yet entrenched.

This has implications for our interventions in terms of possible outcome—better outcomes are usually associated with early intervention. We have also tended towards a 'chronic care' model, which basically accepts that OCD is a life-long condition that one does not cure entirely. The patient will therefore need ongoing support to prevent relapse. This is at variance with current trends in the NHS that look towards short-term work.

Assessment:

In order to develop consistency across the service, we developed local guidance for assessment and management based on a number of international guidelines and protocols and the evidence base in relation to children (American Academy of Child and Adolescent Psychiatry 1998, Rapoport and Inoff-Germain 2000). The National Institute of Clinical Excellence (NICE) Guidelines on OCD is due to be published later this year (October 2005) and we anticipate that our guidance will be similar. We did not wish our guidance to be long and detailed as we felt this may put clinicians off from using them. We thus highlighted some of the areas that we felt need to be asked in addition to standard history and examination (Table 2).

We are keen that clinicians recognise and ask about co-morbid conditions that occur with OCD, such as tic disorders and depression. The prevalence of co-morbid mood disorders ranges from 20% to 73% (Flament et al 1990, Geller et al 1990). However, many professionals still do not recognise or

Table 2: Assessment

Define the problem: what symptoms are present, when do they occur, where do they occur, what are the precipitating factors etc...
What coping mechanisms are used?
What is the level of distress / impairment?
Is the child / adolescent depressed?
Any evidence of tic related disorders?
Any evidence of other neuro-developmental disorders?
Are the obsessions / compulsions developmentally appropriate?
Is school work affected by OCD?
How is the family coping? Are family members caught up in the rituals? Does the family provide support?

acknowledge that depression can affect young people.

In addition to the above questions, we also suggest that it is good practice to use a rating scale, such as: the children's version of the Yale Brown Obsessive Compulsive Disorder Scale (Scahill et al 1997); the Children's Obsessive-Compulsive Inventory (Ch-OCI) (Shafran et al 2003); or, the children's version of the Leyton Obsessional Inventory (Berg et al 1986). This gives a measure of severity as well as acting as a baseline to monitor progress, should treatment commence. We also routinely use, with every patient, the Strengths and Difficulties Questionnaire (Goodman 1997) and the Health of the Nation Outcome Scales (Gowers et al 1998).

Intervention:

Psychoeducation

This is an important part of the treatment that is offered. The more one knows about OCD, the more one feels in control, hence we give a brief

explanation of the biological basis for OCD. This helps to stop the child being labelled as 'naughty' by their parents. We also give the family a copy of a fact sheet, 'OCD in Young People', written by the Royal College of Psychiatrists (see: 'sources of further information'), which explains, in lay terms, what OCD is. In some cases, the child and family are reassured within the first session with a full explanation of OCD and require no further intervention. We also send the referring GPs a fact sheet on OCD and related conditions as well as our report. GPs are extremely busy people and hence basic fact sheets are often welcomed by the majority.

Family intervention

Children develop within the context of the family and thus a treatment package should reflect this. Family members often get caught up in the rituals and routines surrounding OCD and may contribute to the maintenance of symptoms (Waters and Barrett 2000). Family focussed interventions on psychosocial factors are also likely to be more effective and durable than

interventions that target the child. It has also been shown that high levels of hostility and criticism have been associated with poor treatment outcome and relapse in adults (Chambless and Steketee 1999). Another reason for involving the family is that the rates of OCD in family members is higher than the general population and thus helpful interventions for the targeted individual may have secondary benefits to other potentially vulnerable members (Waters et al 2001).

Family interventions include:

- Exploring the effect of OCD on the family
- Improving coping strategies
- Improving communication skills
- Psychoeducation
- Reducing parental involvement in the symptoms
- Increasing positive family interactions

The family is encouraged to become part of the 'expert team' that helps the child fight OCD and thus can prove to be a useful source of support away from the clinics.

Individual work with children and adolescents

The individual work is based on protocols developed by March and Mulle in their book, 'OCD in Children and Adolescents: a cognitive behavioural treatment manual' (March and Mulle 1998). The techniques for individual work include: externalisation of OCD; the development of cognitive tactics and coping strategies (a cognitive 'toolkit') to assist with exposure and response prevention—for example, positive self talk; increasing self efficacy; generating a hierarchy of obsessions and compulsions to tackle

(with the child); the use of exposure and response prevention on targets chosen by the child (usually in vivo), and usually with some support from their parents.

Some clinicians feel that the cognitive element is not really necessary and that it is 'purely' the 'exposure and response prevention' component of the treatment approach which is most effective. Although we have not formally researched this, we feel that both elements are necessary, together with relapse prevention.

Another useful book is 'Think Good-Feel Good –a Cognitive Therapy Workbook for Children and Young People' by Paul Stallard (2002), which contains useful summary worksheets that children find helpful.

We acknowledge that there needs to be a degree of flexibility when following a protocol and the therapist should adapt the session to suit the child's pace and personality.

Medication

Although there has been a lot of controversy about Selective Serotonin Re-uptake Inhibitors (SSRIs) in the media in relation to young people and suicide in those prescribed anti-depressants for depression, SSRIs are considered by many clinicians to play a useful part in the treatment and management of OCD. SSRIs such as sertraline (recently licensed for use in children with OCD) and fluoxetine are the drugs of first choice. It is important to discuss potential side effects that may occur so that the family and child do not lose trust in medication should these occur.

Evidence base:

The actual clinical evidence base in

relation to CBT and medication in children is small. However, the majority of clinical practice seems to rest on extrapolations from adult research which supports work based on exposure and response prevention (Hollander 1997). One may thus say that in terms of evidence based practice in OCD, the inclusion of exposure and response prevention is the key factor or something you may have to explicitly justify not using (for reviews, see Shafron 1998 & Emslie et al 1999).

Liaison with schools and other services

OCD can often have an impact on the child's functioning in the classroom and with homework. For instance, children with checking rituals will often re-read a line in a text book several times until it is 'just right' or a child may need to perform a counting ritual in the classroom before s/he can sit down. If the child's education is affected, we often, with the child and parents permission, talk to the child's teacher and give a brief explanation of the difficulties. This prevents the child being unfairly treated. We sometimes write letters asking for the child's condition to be taken into account during examinations, which can be a particularly stressful time. This is only done with the child's and parents consent. Children with OCD are also vulnerable to being bullied. If there is associated depression, then the consequences may be devastating for the child. Addressing these issues with teachers and making sure that schools implement their anti-bullying policy is essential.

Other services that we liaise with include general practitioners, paediatricians and adult mental health clinicians.

OCD Support Group

Parents:

When we see parents at the initial consultation, we are often aware of the huge amount of stress that parents of children with OCD are under. As a result of this, we decided to hold a meeting for parents to see whether any of them would be interested in attending a parent support group. We sent letters to six of the parents whose children were currently attending the Dunstable clinic. Only two sets of parents replied. One set of parents said that they supported the idea but could not come to regular sessions due to other commitments. The other set of parents said that they also supported the idea of a support group but their adolescent son with OCD did not want his illness talked about in any way with others and thus they felt they could not attend. There were no other replies. Given our assessment of parental stress levels at consultation we were initially surprised by the poor response to the idea of setting up a parents group. One possible explanation is that the people we wrote to had children that were in the middle of or near the end of their treatment. The need for parental support may not be as intense as when first presenting to the clinic. We may decide to revisit the idea of a support group in the future, should there be demand from parents across the service.

Children:

Support groups for children with OCD may be a valuable way of increasing awareness and education on aspects of OCD. It can also provide much needed psycho-social support to the often isolated individual. We currently have no plans to set up a group but, if there is enough interest, we may consider

running a group or even a workshop so that children with OCD can meet others with a similar condition.

We recognise that a lot of support is needed for the child and family and therefore we provide details of the voluntary organisation, Obsessive Action—a national charity which provides information and support for families suffering from OCD (see 'sources of further information').

'Guidance' document

The aim was to develop service wide consistency. Our guidance provides recommendations in relation to assessment and treatment, linking both with evidence-based practice. We are aware that producing a document may generate all sorts of political problems within a large multi-disciplinary team. There are different ideologies within the teams, some of which take exception to the medical model ideology that our document represents. There are also potential legal issues associated with the title of the document, hence we decided to call it 'guidance' as opposed to guidelines.

Research and Audit

As we are still in the early stages of developing our service we have not yet engaged in audit or research. However potential audit areas include outcomes (including reviews using YBOCS) and record keeping. We hope to commence this once we engage a few more cases.

Conclusion

There is evidenced-based literature for the treatment of OCD. Since OCD is now recognised to occur in children (and the majority of adult cases originate in childhood), we have set up a special interest group within our CAMH Service to focus on this disorder.

Our aim is to raise the profile of OCD amongst clinicians and ensure that children and adolescents with OCD are thoroughly assessed and effective interventions are administered. We aim to improve the support networks for these children and adolescents, focusing on family work and also liaising with support agencies. In keeping with continuing professional development requirements, we also plan to set up a regular seminar on OCD / Anxiety Disorders, which will act as a forum for academic discussion and general support for clinicians.

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Sources of further information

Obsessive Action, Aberdeen Centre, 22-24 Highbury Grove, London N5 2EA Tel 020 7226 4000; email: admin@obsessive-action.demon.co.uk Website: <http://www.obsessive-action.demon.co.uk>

The **Mental Health and Growing Up** series contains 36 fact sheets on a range of common mental health problems. Available on the Royal College of Psychiatrists' website at <http://www.rcpsych.ac.uk>

The **National Institute of Clinical Excellence (NICE)** guidelines on OCD is actually published later this year (October 2005). www.nice.org.uk

Decision making analysis, QALYs (Quality Adjusted Life Years) and resource allocation in the health economy

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DISCUSSION Introduction **PAPER**

There are many ethical dilemmas in the delivery of healthcare, ranging from those that confront individuals as they search for solutions to their own health problems to those that confront national and supra national organisations as they consider how to prioritise a range of disparate needs in order to decide how best to dispose of the limited resources they possess. Decision making analysis can certainly be of assistance to individuals as they seek to marry their life objectives with the likely and varying outcomes of different treatments. It can also be of assistance to organisations who have a clear set of unambiguous objectives and who need to make a choice about the best way to achieve those objectives. However, the use of decision making analysis by national governments in order to orientate their disposal of resources is more problematic. The paper will focus on this last issue and examine the claim that this methodology can provide a way to elucidate which are the central priorities for politicians and health service managers as they determine how resources should be allocated in the field of health care.

I have been a nurse for 17 years. In the first three years of my career, I worked in a hospice where resources were lavished on people who were just about to die. For most of my nursing career I have worked on challenging behaviour units for long stay patients suffering from treatment resistant psychosis. These units were not well resourced. The following remarks are coloured by these experiences. From the perspective of decision making analysis, such 'colouring' could involve the possibility of bias, but whether decision making analysis can deliver a bias free methodology in healthcare resource allocation is precisely the issue.

Decision making analysis

Decision making analysis is a method for framing and solving problems. It is a set of intellectual techniques designed to lead the unresolved person (or persons) to the correct resolution. In order to reach this resolution, states of affairs are identified which would, if achieved, represent solutions to the framed problem. Alternative ways of achieving these desired states of affairs are weighed by perusing the likely consequences that the courses of action defined by the alternatives will bring. Roughly speaking, the course of action that is thought to be the most likely method of achieving the most desired state of affairs is then adopted. With regard to allocating resources in publically funded healthcare the problem is this: there are a range of healthcare needs and it is politically inexpedient (and economically damaging) to raise sufficient levels of tax to meet all these needs. It is therefore necessary to prioritise which healthcare needs should be met and which treatments should be adopted to meet those needs.

Decision making analysis encourages its exponents to calculate which of the identified alternative solutions to a problem is the preferred option. The calculation is made by assigning a numerical value (expressed as a fraction of one) to the likelihood of a particular consequence occurring as a result of the choice made, and then multiplying this value with another fraction which purports to represent the desirability (or usefulness) of this consequence occurring, compared to the desirability or usefulness of other consequences that may issue from the choice made. The highest numerical value attached to a consequence (or set of associated consequences) indicates to the agent faced with a choice what his choice should be. The central problem with this

method (as applied to resource allocation in health care) does not arise with regard to calculations of probability about which consequence will occur, but with the ascription of a numerical value to the utility that each consequence will bring. Research may show how likely it is that a decision will issue in a particular consequence. Research may reveal a whole series of ramifications attached to a consequence, but research cannot show per se if one consequence is more valuable or desirable than any other consequence.

Why health utilities are incommensurable

There are a number of intentions that orientate politicians and policy makers when allocating resources to health care organisations. These intentions may include among other things: the intention to relieve pain, the intention to preserve individual life, the intention to prevent infection and contagion, the intention to ameliorate the effects of economic inequality, the intention to keep the workforce healthy and therefore productive, the intention to meet international obligations, and, perhaps, the intention to control deviant behaviour (particularly relevant in the field of mental health). These intentions may complement each other but they also need to be prioritised. This process of prioritisation, over and above any considerations of political expediency that may occupy the minds of politicians hopeful of re-election, will involve a calculation about consequences. However, it will do more than this—it will necessitate foundational ethical decisions about what is valuable (Scruton 1995). These decisions will involve choosing between disparate goods. The consequences of the achieved intentions itemised above cannot be yoked with any certainty into

a single rating scale which would assign a precise numerical value to each consequence.

“Apart from the apparently insurmountable epistemological problems in knowing how specific interventions affect the lives of diverse patients and the total absence of any adequate theory of value or account of the nature of benefit that could make quantification meaningful, the task seems logically impossible since too often we are dealing with incommensurable values” (Loughlin 2000: 163)

Furthermore, even looking at one intention that orientates resource allocation—for example, the intention to relieve pain—reveals how adventitious and arbitrary is any attempt to be precise about the value of health utilities. How are we to compare the different kinds of pain associated with rheumatoid arthritis, paranoid psychosis, bubonic plague, alzheimer’s disease, generalised anxiety states, cancer of the colon or streaming colds? Ever more complex rating scales have been developed to try and assign a numerical value to different kinds of suffering and disability (McCrone 1998) but these are values drawn out of a hat. The complexity cannot disguise the suppositious and subjective nature of this enterprise. We may have a fair idea what treatments are most likely to relieve which illnesses (and how much they cost) but how can we know which kind of pain is most worthy of relief? In other words, how is it possible to have one decision making analysis process that comprehends all these diverse realities?

Resources are limited, health needs are almost limitless and so judgements are,

of course, made about which diseases, illnesses and disabilities are priorities for treatment. These judgements are influenced through a complex mixture of research findings, political expediency, custom and tradition, media pressure, sentiment, ethical conviction, pragmatism and professional pressure. Doubtless there is room for politicians and senior health administrators to be more ethical in the way in which they distribute resources—they could become less concerned with making their working lives easy, less concerned with making themselves popular when disposing of resources and more concerned with meeting real needs in an efficient and effective manner. It might also be said that they could be more rational in the way that they dispose of resources; this might be said of a health administrator who was spending money on a treatment for a particular illness which was twice as expensive as another equally effective treatment. (It would also be appropriate to say that the administrator who is acting irrationally in this way is also acting unethically because he is not conserving a limited resource so that it can be spent on another worthy cause.)

However, it makes less sense to say that a government is more ‘rational’ if, for instance, it allocates more resources to neo-natal care in Yorkshire and less resources to fighting AIDS in Uganda (or vice versa), because decisions of this kind are, in large part, derived from value judgements rather than calculations.

QALYS and the limitations of utilitarian ethical theory

There is a more profound flaw to the application of decision making analysis in the field of resource allocation in

healthcare. It is not only that the many various and disparate utilities that occur as a consequence of healthcare are incommensurable. The whole principle that resources in healthcare should be allocated to garner the maximum amount of utility is ethically questionable.

The concept of QALYs (Quality Adjusted Life years) was introduced in the 70s (Weinstein and Stason 1977) to assist policy makers in their deliberations about where resources should be allocated in the field of health care. The concept allows that other considerations apart from survival rates should be entertained when deciding how to spend money. Policy makers are also invited to consider what the quality of life is likely to be of those who receive the available treatments. The treatments that are most desirable are, therefore, those likely to offer the greatest increase in number of years lived and/or those most likely to improve the quality of life of the individuals treated. Many technical problems have been identified and addressed in the use of QALYs (Mckie et al 1998), but I wish to register in the remaining part of this paper a more generalised reservation about the use of this tool in determining how resources are allocated.

Consideration about consequences, among other things, quite properly lies at the heart of decisions about how to dispose of resources in healthcare. I have already argued that it is problematic to calculate in a comprehensive and systematic manner which consequences are most desirable in terms of utility value. However, if, for argument's sake, it were possible to calculate consequences in this way and that calculations of this kind became the commanding principle for those tasked with allocating resources (rather than

just one among several useful perspectives) then common assumptions about the value of human life would be negated. The concept of QALYs is not an ethically neutral tool developed for politicians and administrators in order to help them dispose of resources in a rational way. It represents, if swallowed wholesale, the replacement of ethical decision making by a methodology imbued with the assumptions of the production line. It is as though human beings were cars or washing machines. So, for instance, if computations about QALYs truly held sway it would cease to be 'rational' to spend much money on the care of the elderly whose minds have been affected by dementia. It would be far more 'rational' to reallocate the money spent on those with severe dementia to those sick people who are likely to make a full recovery and live long and perhaps happy lives (McKie et al 1998).

Many of us who work in mental health services believe that they are underfunded. The reasons for this underfunding (if such is the case) are multiple, but perhaps unspoken assumptions about the inability of those suffering from chronic mental ill health to enjoy a good quality of life play their part in influencing decision makers. Certainly, such assumptions about the mentally ill influence the attitudes and actions of colleagues who provide general medical care. As a charge nurse on a challenging behaviour unit, I was once comforted by the resuscitation officer from the adjoining general hospital, following the death by respiratory arrest of a patient with whom I had been working for three years (and whose life I had inexpertly tried to save). She made the observation that the patient's death was not a cause for great concern because her 'quality of life' was

so poor and likely to remain so. The asinine nature of comments of this kind serves to illuminate the deficiencies of the consequentialist (or utilitarian) ethical theory that underpins decision making analysis (McCoughlin 1999). The lady who died may well have had, by anybody's reckoning, a poor 'quality of life'. In fact she had had a terrible life, which was likely to remain terrible because she suffered from a severe treatment resistant psychosis—but it does not therefore follow that public resources should not have been spent on caring for her, or that her death should not have been lamented.

Conclusion

I have in this paper expressed reservations about the process of decision making analysis when it is used to determine how resources should be allocated in healthcare. These reservations relate, firstly, to the difficulties in computing and comparing disparate utilities in the field of healthcare and, secondly, to the unethical nature of resource allocation that is based solely on utility calculations. However, in order to secure more resources for mental health services, it is necessary to marshal arguments that will convince policy makers who are confronted by a range of pressing needs. The arguments need to have an appeal to those who do not work in the field full time. Because of the reasons outlined above, decision making analysis should have a circumscribed (rather than normative) role to play in resolving ethical dilemmas in the allocation of resources for the delivery of healthcare. The rigorous application of decision making analysis to resolve the complex dilemmas in this area, lead to the abrogation of our

ethical obligations to the severely mentally ill.

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An Audit of Waiting Lists in Services for People with a Learning Disability (SPLD)

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QUALITY IMPROVEMENT

Abstract

Waiting times for newly referred clients in the SPLD have recently been significantly reduced at the perceived expense of clinicians being able to maintain the standard of completed efficacious intervention. In order to commence a resolution of this loss of service an audit was carried out in non-medical clinical services' departments to investigate wastage due to inappropriate, repeated and duplicated referrals, consider possibilities for alternative methods of assessment and intervention so that greater resources would be available to complete detailed intervention more effectively. Three data collection tools (Referrals to the Service, Intervention Waiting Times and Completed Discharges) were designed to retrospectively analyse referrals and interventions over a 12 month period from databases of all clinicians, nurses and specialists offering out-patient services. Most professional discipline groups responded although some responding disciplines had only partial records. The data showed that some departments maintained Treatment Waitlists with long waiting times, DNA rates in most services were high (except where client attendance was ordered by the Justice system). Inappropriate referrals (referrals to a discipline that would be unable to meet the referred need) were estimated to have occurred in 8% of referrals, whilst 6% of referrals were for clients who may not have had a defined learning disability and would not be eligible for access to the service. Re-referrals of clients for identical reasons were lower than expected at 1%. These findings were discussed noting that high DNA rates, which had not been predicted, appeared more very substantially important than the anticipated problem of inappropriate referrals, such that DNA rates warrant urgent further audit. The audit process also prompted consideration of the adequacy of the referral process itself and whether staff training and other work styles could reduce the need to refer clients. A more detailed audit of DNA and cancellation rates is now underway, bearing in mind that DNAs and cancellations may reflect problems of resources and commitment for carers of people who have a learning disability rather than the identified patients themselves.

Introduction

The Services for People who have a Learning Disability (SPLD) directorate have recently been successful in reducing the waiting times for clients for an initial assessment. However, even though waiting times had been significantly reduced, there were still concerns about the length of time that clients were waiting to receive treatment. This project was identified as a priority for the directorate on their clinical audit forward plan for 2004-5.

Aims

By undertaking this project, It was hoped to increase the number of completed efficacious treatments by all community services.

Objectives

Four objectives were agreed for this project :

To reduce the number of inappropriate referrals.

To reduce the number of people who are waiting for interventions following their assessment.

To enable alternative practical options to referral (e.g. advice, information pack, staff training, pre-referral discussion).

To increase the number of efficacious treatments, which would include giving advice to staff and providing short-term interventions.

Methodology

The audit group decided to collect data from each service within SPLD.

Three data collection tools were designed: –

1. Referrals to the Service—this

involved collecting data for the last ten referrals to the service (or if less than 10 referrals were received in a month, all referrals received in the last month).

2. Intervention Waiting Times—this was designed to capture the reasons why clients on the waiting list were waiting for treatment (as of 29-7-04).
3. Completed Discharges—this involved collecting data about the number of discharges from the service, together with the number of re-referrals for the same problem (from 1-7-03 to 30-6-04).

Data was returned to the Trust's Clinical Audit Department for analysis.

Findings

A summary of the main findings is presented in Tables 1 & 2—compliance with quality standards (Table 1) and intervention waiting times (Table 2).

In some services, namely sensory and psychology, many clients were waiting for interventions when they were ready for the interventions.

The DNA (Did not attend) rates were high in some services, although this did not particularly apply to TARMO, as 80% of their clients were ordered to attend by the justice system e.g. the court / probation.

8% of referrals to services were judged to be inappropriate, which was a lower percentage than had been expected.

The majority of referrals (94%) were for clients who had a defined learning disability.

Re-referral rates to the same service for

Table 1: Summary of Findings (N=72)

Evidence of quality of care or service	Standard	Actual Practice	Exception Reporting
The referral is for a person with a defined learning disability (= eligible for a service).	100%	94%	This occurred in only 4 cases: three of these required advice only.
The referral is judged by peer review to have been sent to the appropriate department.	100%	92%	There occurred in 5 cases: three of these had an IQ of over 70 and another was not suitable for group work.
A referral is sent to different professionals for the same problem.	0%	17%	This occurred in 12 cases: three of these were referred to an Assessment & Treatment Unit; 9 were referred for Art Therapy.
An individual is discharged following the completion of treatment.	100%	83.5% overall	
An individual is referred again to the same professional with the same problem.	0%	1% overall	There were only two cases where this occurred, both being referred to psychology.

the same problem accounted for only 1% of referrals.

Conclusions

The findings showed that the perceived problems of the current referral process, which were thought to be inappropriate referrals or re-referrals for the same problem, were in fact not a significant issue.

Unexpectedly, the data highlighted that there was a significant issue around DNA rates, particularly in some areas of the directorate. High DNA rates heavily impact on the length of waiting lists, and those services with higher DNA rates had a resulting longer waiting list. Further investigation is indicated in

clarifying the reasons for these significant DNA levels.

Further discussion of the findings in the group led to questioning the effectiveness of the referral process. An analysis of the process is already in progress (even though unrelated to this project) and is expected to provide information to improve the current process. This will include areas such as the provision of advice, providing staff training or other relevant actions in response to referrals.

The peer review of referrals seemed to be misunderstood in some services, and particularly where the service consisted of only one healthcare professional in the service.

Table 2: Intervention Waiting Times for SPLD Clients (N=174)

Reasons Clients Waiting	Numbers of clients affected (%)
Client not ready for intervention	1 (50%)
Client did not attend	12 (7%)
Clinic cancelled	0 (0%)
Familiarisation sessions occurring	13 (7%)
Waiting for specialist clinic appointment	28 (16%)
Treatment booked for date in the future	34 (19.5%)
Treatment planned but waiting to provide	7 (4%)
Treatment intervention not yet planned and waiting	3 (2%)
Waiting for enough people or compatible people to form a group	2 (included in above figures)
Priority level (please state):	
High	44 (25%)
Medium	82 (47%)
Low	48 (28%)
Sensory Dept only:	
Recall clinic appointment	76 (44%)

Recommendations

To carry out a further project to discover the reasons for the high DNA rates, to enable steps to be taken to reduce this problem area and thereby reduce waiting lists.

To feedback results from this project to the SPLD Clinical Audit and Effectiveness group and the leads for each service area which took part in the project.

To liaise with NHS Lanarkshire Learning Disability Service, who have recently reviewed their referral process with good results.

For further information, or for a copy of the full audit report, please contact:

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**Advancing Practice
in Mental Health & Services for People with
a Learning Disability:
developments in practice, education & research**

**a one-day conference
at Silsoe Conference Centre, Silsoe, Bedfordshire**

Wednesday, June 15th, 9.30AM—4PM

a one day conference to:
share innovative practices and current developments,
highlight the impact of new service developments,
promote inter-disciplinary learning and partnership working

chaired by:

Paul Mullin—Chief Executive & Dr Hameen Markar—Medical Director
Bedfordshire & Luton Community NHS Trust

this conference will be of most interest to:
newly qualified and experienced health and social care practitioners
who are working in mental health and services for people with a
learning disability,
health and social care educators,
completing health and social care students

**For more information or to request an application form
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Jo Hodge—Senior Learning & Development Administrator
or the Learning & Development Team
01582-700187

Conference key note presentations:

The new role of the psychiatrist
Dr Michael Shooter (RCP President)

Valuing People: a health & social care perspective
Simon Whitehead (Valuing People Support Team)

Advances in Mental Health Nursing
Tim McDougall (Nurse Adviser, Department of Health)

a series of concurrent sessions, from which delegates will be able to participate in three sessions—to include:

Person-centred Planning in Learning Disability Services
David Roberts (Practice Educator) & Sharon Moules (PCP Coordinator)

Promoting Concordance: a practical approach
John Butler (Nurse Consultant—Acute Psychiatry)

Healthcare Records on Trial
Dr Richard Khoo (Anglia Polytechnic University)

Developments in Nurse Prescribing
Claire Saunders (Nurse Prescribing Lead)

Early Intervention: a service-user's experience
Facilitated by John Butler (Nurse Consultant—Acute Psychiatry)

Using Advance Statements / Directives
Facilitated by Alison Bass (Community Mental Health Nurse)

in addition to:

the Luton On Track Project, Autism & Learning Disability, Root Cause Analysis, Stigma in Mental Health, Crisis Resolution

& Poster Presentations

this event is supported by Wyeth Pharmaceuticals & Bristol Myers Squibb

Carers and Users Expectations of Services

Debbie Buck RMN

Team Leader—Continuing Care Team
Bedfordshire & Luton Community NHS Trust

USER SATISFACTION

Introduction

A User Satisfaction Questionnaire was developed through a collaboration between the Royal College of Psychiatrists Research Unit, the National Schizophrenia Fellowship / Rethink and the Royal College of Nursing Institute, as an aid towards care planning for service users and their carers. It has always been felt that service users should have far more involvement in developing their care plans, and this tool offers a more structured way to help service-users to focus on what they need from the mental health services. The areas that are considered within the questionnaire are: housing, money, accessing services, medication, relationships with mental health workers, and cultural and religious needs.

The format used in this questionnaire is varied: Part A provides a written description of an ideal situation against which the service-user is asked to match their current situation; Part B asks the service-user about their satisfaction with their situation; Part C asks for written comment on what they would like to change.

The introduction of the Carers and Users Expectations of Services format coincides with the Trust's move towards 'Recovery' and 'Whole Life Systems'. This promotes the empowerment of users to discuss their care, and not to be labelled or discriminated by the community or the service.

Use of the Carers and Users Expectations of Services (CUES) within Bedford rehabilitation mental health services

The mental health rehabilitation resources within Bedford were asked to complete the CUES with their users, to gain a better understanding of its potential as a resource for monitoring service-users' perception of their care and as an aid to the care-planning process.

The following service areas were involved:

Progress House—a sub-acute unit based in Bedford—eight service-users who were placed in Progress House for rehabilitation were involved in completing CUES.

John Bunyan House—a long stay unit in Bedford for people with complex needs in Bedford—fifteen (of sixteen) service-users were able to complete the CUES with the support of their key-worker.

Whicheloes Wharf—a long stay unit in Leighton Buzzard for people with complex needs—only six clients were able to complete the CUES with the support of their key worker.

Continuing Care Team—a community service that cares for clients with severe and enduring mental health problems—49 (of 152) service-users completed the CUES, whether by themselves or with the help of their care coordinator.

Methodology

As there were four teams involved in the study, it was agreed that the key workers or named staff that work with the service-users in each individual area would conduct the CUES with the service-user. It was agreed that the service-user would have the opportunity to complete the questionnaire independently, and if unable to do so, either physically or mentally, then a staff-member would help them to complete the questionnaire by reading out the statements or writing down their thoughts, or both. Within the community

team, some service-users received their questionnaires by post, being asked to complete them and post them back. Progress House had hoped to involve advocates in completing the CUES with service-users—as this did not happen, named nurses facilitated the process.

All teams were given a half hour training session during their team days. John Bunyan House had a training session with a group of staff, who cascaded this to all staff. The background of the CUES form, the rationale for using this type of format to guide care planning and the links with the recovery approach were discussed in these sessions. There was also a discussion of potential approaches and solutions in the event of service-users either being unable or refusing to complete the CUES. It was acknowledged that all clients had the right to say no, and the right to help and support if they were unable to complete the CUES themselves.

Considering the needs of the ethnically diverse community, staff interpreted the statements on the CUES form into other languages as required. However, for future studies using this questionnaire, it will be imperative that they are available in different languages, to allow service-users the opportunity to complete them in private and anonymously.

Findings

A total of 76 fully or partially completed CUES were returned, with all data being collected anonymously.

Selected findings (for six of the seventeen questionnaire statements) are summarised as a series of tables, below.

Statement 1: responses

The place you live in should meet your individual needs. You shouldn't have to worry about having to move out, and it shouldn't be too out-of-the-way. You should be able to come and go when you want, be alone when you want, and not be harassed by the people you live with, by staff or by neighbours.			
How does the place you live in compare with this description?	Residential Areas	Community Team	Total
As good as this	19	40	59
Worse than this	5	4	9
Very much worse than this			
Not completed	5	5	10
Are you satisfied with the place you live in?			
Yes	19	39	58
Unsure	2	3	5
No	7	6	13
Not Completed	1	1	2

Statement 2: responses

You should have enough money to pay bills, stay out of debt and not miss meals. You should not have to feel isolated or cut off from society because of lack of money.			
How does your money situation compare with this description?	Residential Area	Community Team	Total
As good as this	13	39	52
Worse than this	8	3	11
Very much worse than this	2	2	4
Not Completed	6	5	11
Do you have enough money to meet your basic needs?			
Yes	18	40	58
Unsure	3	6	9
No	6	3	9
Not Completed	3		3

Statement 4: responses

You should have the opportunity of spending your day in some form of regular and meaningful activity. This could be working, studying, training, and going to a day centre or to a day hospital.			
How does the way you spend your day compare with this description?	Residential Areas	Community Team	Total
As good as this	18	37	55
Worse than this	2	4	6
Very much worse than this	1	2	3
Not Completed	8	6	14
Are you satisfied with the way you spend your day?			
Yes	24	35	59
Unsure		4	4
No	4	8	12
Not Completed	1	2	3

Statement 10: responses

Doctors, nurses, social workers and other mental health workers should show you respect, be honest with you and discuss things with you in a way you can understand. They should be trustworthy and do what they say they will. They should offer regular appointments, not miss appointments and not keep you waiting. They should keep information about you confidential or ask your permission before passing it on to others. If they pass on information, it should be accurate and save you from having to repeat yourself to new mental health workers.			
How does your situation compare with this description?	Residential Areas	Community Team	Total
As good as this	13	42	55
Worse than this	6	3	9
Very much worse than this	3	2	5
Not Completed	8	2	10
Are you satisfied with your relationships with mental health workers?			
Yes	22	41	63
Unsure	4	3	7
No	2	4	6
Not Completed	1	1	2

Statement 13: responses

You should feel safe and other people should not harass, exploit, victimise or be violent towards you. You should not experience stigma or discrimination at home, at work, from the mental health workers, police or any other section of the community. People should not discriminate against you because of your race, culture, or religion, sex, sexual orientation, physical or mental disability or for any other reason.			
How do people treat you compared with this description?	Residential Areas	Community Team	Total
As good as this	20	39	59
Worse than this	1	5	6
Very much worse than this	1	2	3
Not Completed	7	3	10
Are you satisfied with the way other people treat you?			
Yes	22	38	60
Unsure	5	6	11
No	1	3	4
Not Completed	1	2	3

Statement 14: responses

Medication should only be given to relieve symptoms of mental health and to reduce your distress. All medication can have unwanted effects, but these should not cause more disruption to your life than improvement.			
How does your medication compare with this description?	Residential Areas	Community Team	Total
As good as this	17	41	58
Worse than this	2	3	5
Very much worse than this	1	1	2
Not Completed	9	4	13
Are you satisfied with your current medication?			
Yes	16	41	57
Unsure	5	2	7
No	5	4	9
Not Completed	3	2	5

Service-User Comments

Statement 1: for those in the community, general comments were made about the area in which the service-users live, the neighbours, the noise and problems with resolving these areas of concern. For the service-users in residential units, there was general frustration at the slow process of rehabilitation.

Statement 2: many service-users talked about the lack of money and feelings of being from a lower class—having to buy food from the reduced counter at Tesco and borrowing toiletries in the residential units.

Statement 4: generally, positive comments were made about the type of activities they were involved in, and the vast range available. However, there were some concerns about the poor access to Asian speaking activities as a whole, and also about the lack of 'provided for' evening and weekend activities.

Statement 10: those in residential units focused on the sharing of information—service users felt uncomfortable with this, as they felt they hadn't been consulted and didn't know who the information was being passed to. Generally, the comments from the community service users were good, although a service user had been trying to get a social worker for years, and another was experiencing some concerns about trusting their support staff after a bad experience.

Statement 13: many service-users felt that they would like to be treated with more respect by members of the public. It was generally felt that, because of the illness, they would be treated badly if they went into any employment, and

some service-users reported being taunted and verbally abused by members of the public. There were no concerns about lack of respect by staff, by fellow service-users or family members.

Statement 14: generally, people felt that their medication was helping and that this was being reviewed regularly. The negative comments related to service-users' experiencing side effects, such that some did not want to take any medication—they felt that their views had not been considered.

Interpretation of the Results

Non-completion of the CUES varied between the units: 10 from Whichelloes Wharf, one from John Bunyan House, and 103 service-users from the continuing care team failed to fill in the questionnaires. The reasons for non completion included: the frailty of some service-users; some felt happy with their care and therefore didn't want to complete the CUES; there was a poor understanding of the forms by those for whom English was not their first language; some felt unable to accept the support that was available for completing the CUES.

Recommendations

The relationship that the service has with Pilgrims Housing Association has promoted efficient communication for our service-users—more help can be given to the service-user to secure more appropriate housing than has happened in the past. Developing an accommodation forum, albeit in the early stages, will enhance this process

further, and assist in developing closer links with other housing providers. The aim must be for a more seamless service, as the users identify frustration at the slow speed of moving through 'rehabilitation' as something that they want to see changed.

Having greater access to support for benefit queries is an important area for all staff and users. All users need to be asked about their benefits within their care planning sessions to ensure that they have the opportunity to discuss any concerns.

There is a clear need to further develop course opportunities for users, such as training on budgeting skills, and to help them to access services that they need, as a priority.

Users highlighted a clear need for weekend and out-of-hours activities, which requires some creative thinking and greater use of existing community groups or workshops. There is a need for out-of-hours support to help users to access these activities—this would require some flexible working arrangements for support workers and recovery workers.

Families as carers need a greater level of support from the mental health teams, especially as they make up the majority of the unpaid carers. Specific training, especially when they first come into contact with the mental health services, needs to be made available. Supporting users to talk openly to their families may also help, together with more access to family work and confidence-building training.

Although social lifestyle is very individual, each user should have the opportunity to attain a social life that they want, and be assisted to develop

this outside of the residential unit and mental health service—this would also require flexible working arrangements in encouraging users to utilise facilities that are available within the community. Support staff within the community units could work more flexibly to encourage users to attend social activities at preferred times in the areas / facilities of their choice.

Information-giving appears to be random, and too often is not synchronised or systematic. Whilst some users experienced good information sharing, others felt that they needed to ask for information. When completing a Care Programme Approach review, it would be more beneficial if the user was given an information pack explaining their review, their level of care (standard or enhanced CPA), details of who to contact in emergencies and other relevant information. Within this pack, there could be a checklist for the service-user and staff-member to work through, in ensuring that everyone has the same opportunities for information sharing and the same understanding about the services available for all service-users.

Service-users again have experienced very varied forms of access difficulties within the service, although much fewer problems within the residential units. The service-user should be informed of the cover that would be available to him/her if their named nurse were not available.

It appears that there is a lot of inconsistency about the level of information that is made available to service-users. Although residential service-users made fewer comments about this, community users felt very unsure about what was being offered. Again, this could be addressed by

providing a pack of information at every formal review.

It is very important that all users have the same amount of access to staff as each other, whether in a residential unit or in the community. It would be helpful to have standard information material available for service-users to aid their understanding of the type of help and support that is available—for example, for meeting accommodation needs.

It is imperative that service-users are heard, acknowledged, and that their views are noted and accounted for within decision-making processes and reviews. Certainly, as Progress House implement recovery planning, which they carry out solely with the service-user in mind, s/he will become far more central to the development of their care package. It is envisaged that all areas will be developing this type of practice, in time, which could incorporate the use of the CUES.

There appears to be a great need to educate the general public, and to look closely at workplace experiences. There is a need to plan such activity in a more productive and systematic way, particularly focusing on employment and discrimination.

The continuing care team have been undertaking a lot of work recently in trying to develop a medication concordance training package for service-users and their families. This will involve educating service-users in all aspects of medication: how the medication works; identifying side effects; managing side effects; and, new treatments. There is a need for this type of course for service-users, as many are prescribed medication and feel, at times, that they haven't sufficient information to be able to ask questions or challenge

decisions. This will shortly be made available to all service-users within Bedford.

Although service-users generally felt that their general physical health was well cared for, there were concerns about receiving support for dental needs and chiropody. Both of these services require the service-user to try and access the service themselves, which is difficult for some. Finding dental services that have vacancies can be difficult, and referring to a chiropodist is also a lengthy process. There is clearly a need to look at working more closely with primary care services, ensuring that service-users are supported in accessing these services.

Concerns were raised about gaps in appointment times and physical examinations—something that is generally being noted by nursing staff, as more nurse-led clinics develop for monitoring the physical health of clients who are prescribed anti-psychotic medication. This is currently being addressed both in the community and in the residential units.

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