

## Treatments can focus on resources rather than deficits of patients

Diseases in medicine are commonly characterised by a deficit, i.e. by something in the organism that is not functioning as it should be. Treatments target – directly or indirectly – that deficit so that the patient is cured or at least not impaired by the deficit anymore. The history of psychiatry has been dominated by the same focus on deficits as the rest of medicine. Mental health treatments have been developed to remove a presumed deficit, even if – for most mental diseases – there has been hardly any evidence on what the precise deficit may be. Yet, the deficit focus applied to all sorts of treatments. Pharmacological treatments claim to address transmitter disturbances in the brain that are assumed to be behind the diseases. Psychological treatments such as psychoanalysis or cognitive behaviour therapy aim to solve underlying conflicts or to change maladaptive thinking and behaviours that according to their models are the problems causing depression or other diseases.

This focus on deficits has led to various treatments that are currently used in mental health care. However, it also has a number of limitations. It may strengthen a negative image of the patient and has produced, at best, limited progress in developing more effective treatments since the 1980s. New perspectives might help to advance treatments and develop novel and more effective ones.

Not all treatment models in psychiatry however have been developed to target deficits. Instead, a number of very different treatments aim to tap into the strengths of patients and utilize their positive personal and social resources. Such models can be considered as 'resource-oriented'. Eventually, they may indirectly affect the symptoms of a defined disease, but their primary target is patients' resources, rather than deficits.

Resource-oriented models have been described by a large body of literature and have been more or

less widely used in practice. In the literature, they are usually treated separately without considering their shared resource-orientation. A recent conceptual review published in the *British Journal of Psychiatry* (Priebe, Omer, Giacco & Slade) provided a synoptic view of resource-oriented models and analysed their commonalities and differences. The review focused on therapeutic models for patients with severe mental illnesses, as the traditional core group of patients in psychiatry. Yet, the review obviously did not specify diagnostic groups as conventional diagnoses in mental health care reflect assumptions of deficits of patients, not their strengths and resources.

The review identified ten distinct resource-oriented treatment models which were further analysed:

Befriending schemes, Client-centred therapy, Creative Music Therapy, Open Dialogue, Peer Support Workers, Positive Psychotherapy, Self Help Groups, Solution Focused Therapy, Systemic Family Therapy, and Therapeutic Communities. On each of these models, there is a large body of literature, and they have been more or less widely used in practice.

Six resources are utilized in such models: social relationships, patient's decision making ability, experiential knowledge, patient's individual strengths, recreational activities, and self-actualising/-

correcting tendencies. However, there is only one theme that all models have in common: all of them utilise social relationships in one way or another. The type of the relationships varies. In some treatments, these relationships are with professionals, in others with peers, friends and families or a combination of these. The nature of the relationships is mostly unidirectional, i.e. the patient receives help from someone else, although some are more reciprocal, i.e. the patient is valued as someone who also has something to give. Finally, most models suggest that the expertise lies with the patients, either the patient in question or peers who have had similar experiences.

The review concludes that these resource oriented treatments are a very promising basis for further developments. They provide a range of possibilities of how exactly resources are mobilised, and what precisely their beneficial effect is. In particular, they point to the importance of exploring helpful factors across social relationships and how they can be used in different therapeutic contexts. Considering them in synopsis rather than separately opens up new perspectives and underpins the helpful potentials of different social relationships.

Utilising patients' social relationships appears to be the most effective way to strengthen their resources so that they can overcome their mental distress. Research in East London is at the forefront of studying this systematically and developing novel models for interventions.



■ Half empty or half full?



# SUGAR Wins National Public Engagement Award

Researchers at City University London in partnership with East London NHS Foundation Trust have won a national award for their mental health public engagement work.

SUGAR – Service User and Carer Group Advising on Research – was recognised for successfully developing community engagement and collaborative working in mental health nursing research.

It was the winning project in the Health and Wellbeing category from over 230 entries.

The project is facilitated by Professor Alan Simpson from the School of Health Sciences at City University London.

The competition is run by the National Coordinating Centre for Public Engagement (NCCPE).

SUGAR was funded as part of a research grant from the National Institute for Health Research (NIHR).

Established in 2009 and facilitated by Professor



■ SUGAR members Jagdish Jha (left) and Richard Humm (centre) receiving the award, with BBC Horizon presenter and Professor of Public Engagement in Science Alice Roberts. Photo by Alex Freeman Photography

Simpson, the 13-member group consists of mental health service users and carers recruited via East London NHS Foundation Trust and local organisations. Members of the group receive education and training. They are provided with honorary university contracts, access to the library, computers and facilities, and are remunerated for involvement.

The group and academics meet monthly to collaborate on all aspects of a programme of mental health nursing research.

The group has been a great success with

consultations with service users and carers resulting in changes and improvements in research funding applications. Members have also helped to address ethical issues; refined and tested research instruments; analysed and interpreted findings; and helped disseminate results. Due to its impact, the model has also been adapted by a team of academics working with patients and carers in kidney care, including haemodialysis and transplants.

The researchers received the Awards in a ceremony on 11 June 2014 at the Natural History Museum.

# Carers' Involvement in Acute Mental Health Treatment

By [Aysegul Dirik](#), Research Assistant, Unit for Social and Community Psychiatry

The term "carer" refers to, "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Carers.org). Anyone can become a carer when someone they are close to becomes unwell. The use of the term "carer" is still debated in the field of mental health and some people prefer not to use it, as it can imply a one-sided relationship based on dependency. However, the term can also be a very useful way of identifying the individuals that make up a patient's support network, as these individuals often have unrecognised and unsupported needs of their own. Using a general term such as "carer" can allow clinicians, researchers and policymakers to focus on the experiences of those supportive individuals and to identify any common issues that occur.

People with mental health problems can be supported by their carers in a number of ways. Perhaps the most obvious comes in the form of practical support: carers can help with every day tasks such as managing medication and organising appointments. Emotional support is more complex; it has more potential to present difficulties to carers and the amount of time spent on it can fluctuate greatly depending on the patient's emotional state. Carers can also be involved in a patient's care by taking part in "family interventions" provided by professionals. These can vary depending on the need and service but can include a variety of components such as psychoeducation, consultation, communication training and family therapy. Decades of research evidence indicates that involving carers in patients' care can result in improved clinical outcomes, including fewer admissions, shorter inpatient stays as well as better reported quality of life.

## Acute Mental Health Treatment

A particularly stressful time for both patients and carers is when the patient is hospitalised. As well as the patient, carers themselves may become increasingly distressed in the process of waiting for support and trying to manage the situation at home. Interviews conducted with carers suggest that once inpatient admission takes place, they experience complex feelings of relief mixed with guilt and worry. Other difficulties can then arise related to the inpatient process itself. Carers commonly report feeling as though clinicians do not listen to them and that they are excluded from having involvement when important decisions are made about the patient's treatment. This can be particularly frustrating as they may feel that they could provide a useful perspective on the patient's situation. Moreover, if carers are going to continue supporting the patient once they are discharged from hospital, it would be helpful to have them "on board" in care planning at every stage. From the patient perspective, surveys suggest that the majority of patients do want some information to be shared with

their significant others, as this often means that they will be able to provide them with better support.

Whilst acute treatment can have the aforementioned complexities, it may also be seen as an opportunity to engage with carers and to understand the needs of the patient better. The benefits would potentially be wide-ranging. Being updated about the patient's condition could alleviate some of the carers' worries about the patient's wellbeing and give them a clearer understanding of what their support needs will be when they return home. Allowing carers to share information about the patient's situation when they were becoming unwell could provide clinicians with a better understanding of the patient as a person and what their early warning signs are. As a result, patients' clinical outcomes and experience of care would potentially improve.

Many challenges exist to involving carers in treatment, such as clinicians having busy caseloads, practices being focused on the patient-only and unclear guidelines existing around confidentiality. The latter is a complex issue and can often prevent staff members from engaging with carers altogether for fear of breaking patient confidentiality. Conversely, local and national policies and guidelines explicitly encourage the involvement of carers in treatment. Overall, despite the abundance of evidence pointing to the benefits of family involvement in mental health treatment, it is largely under-implemented in the United Kingdom.



## Research Project

The Unit for Social and Community Psychiatry (USCP) undertook an initiative within the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames aimed at improving carers' experiences and involvement in the treatment of severe mental illness.

Initial principles for the project have been developed:

- Involving carers early on in the admission process (within 3 hours)
- Providing information to carers on treatment and on confidentiality procedures
- Developing a shared understanding of the crisis and identifying early warning signs
- Working together on a treatment plan, including discharge planning

As a starting point, the team have conducted a systematic review into the barriers and facilitators of

family involvement worldwide, hoping to learn from the difficulties as well as good practice shared by others. Additionally, when developing the intervention the needs of patients, carers and staff will need to be well understood and incorporated into the design. The initial phase of the study therefore includes focus groups with staff, patients and carers across the boroughs of East London NHS Foundation Trust.

Focus groups involve group discussions guided by a facilitator, who asks specific questions on a particular topic and allows the participants to interact, reflect and respond to comments made by others. This allows individual participants to develop and refine their ideas in light of the discussions and provides researchers with a large amount of qualitative information, which can then be analysed using established methods. Five focus groups with 6-10 participants in each will be held to obtain a variety of perspectives. The groups of participants will be as follows:

- Patients only (with experience of being admitted to hospital within the past year)
- Carers only (with experience of caring for someone who was admitted within the past year)
- Mixed patients and carers (as above)
- Clinical staff
- Senior Managers

The focus groups will be audio recorded and transcribed, omitting any identifiable information.

The transcripts will then be analysed using Thematic Analysis. Based on these findings, the researchers will develop a more detailed plan for the programme. These procedures will then be repeated with two further mixed focus groups later on in the year. This will enable the researchers to continuously develop the project and refine the procedures with the views of patients, carers and staff accounted for.

As well as the focus groups study, existing carer and patient

groups in Newham, Tower Hamlets, the City and Hackney are being visited by the researchers to maintain engagement and keep the public aware of the project's progress. If you would like the researchers to visit your group, or to find out more about the focus groups, please get in touch using the contact details below.

## Patient and Public Involvement

The active involvement of patients and carers in the development of the project is anticipated. Patient and carer representatives will be recruited for a quarterly steering group and a Patient and Public Involvement (PPI) plan is being developed with the input of existing patient and carer groups. If you would like to become involved please contact either Ayse Dirik (a.dirik@qmul.ac.uk / 020 7540 4380 ext. 2331) or Domenico Giacco (d.giacco@qmul.ac.uk / 020 7540 4380 ext. 2319).

# Changes to booking and submission of NHS RECs

In order to improve its service and make the booking and application process more straightforward for researchers, as of May 2014, the HRA changed the processes for applying to NHS Research Ethics Committees (RECs). The key changes are as follows:

## NEW Central Booking Service (CBS) for applications to NHS RECs

A new national Central Booking Service (CBS), with a single number, to cover all bookings for RECs in the UK has replaced the previous Central Allocation System (CAS), Proportionate Review Allocation Systems (PRAS) and Local Allocation Systems (LAS). It will result in a more efficient allocation of applications across meetings. Researchers will still be able to book to the REC of their choice for full applications when using CBS.

Phase 1 studies may be booked via CBS or direct with the NHS REC.

## NEW Introduction of electronic submission to NHS RECs

All forms created in IRAS for submission to NHS RECs (except notices of substantial amendment, which should be submitted by e-mail) must be submitted electronically from IRAS.

The NHS REC form (including GTAC, Social Care REC, Research Tissue Bank and Research Database variants) and non-NHS Site Specific Information (SSI) forms and their associated supporting documentation must also be electronically submitted by the applicant from IRAS to the REC system thus removing the need to submit hard copies.

Electronic submission must be completed on the same day as the booking is made. So applicants must ensure that their application is ready to submit (i.e. form checked, supporting documents attached and electronic authorisations in place) before phoning to book their application. Any pre-submission advice should continue to be sought from local HRA REC Offices.

Notice of substantial amendment forms are still created in IRAS but they are not electronically submitted; submission of these forms continues to be via email.

## Keeping up to date

The webpage, <http://www.hra.nhs.uk/research-community/booking-submission-changes-spring-2014/>, is regularly updated.

## Upcoming Events

### Research Training Sessions

The Academic Unit at the Newham Centre for Mental Health holds fortnightly training sessions on a variety of topics of interest to those undertaking research in the NHS. The training is held from 11:00-12:00 on a Wednesday in the Lecture Theatre; for more information, contact Hana Pavlickova by email at [Hana.Pavlickova@eastlondon.nhs.uk](mailto:Hana.Pavlickova@eastlondon.nhs.uk)

Date	Title	Presented by
17 September	<i>Developing a protocol</i>	Vicky Bird
8 October	<i>Digital storytelling</i>	Rose Thompson
29 October	<i>Searching and Assessing Eligibility</i>	Vicky Bird
12 November	<i>Meta-Synthesis</i>	Vicky Bird
3 December	<i>Thematic Analysis</i>	Sima Sandhu

# Understanding conduct disorder: The ways in which mothers attempt to make sense of their children's behaviour

By [Rhiannon M Lewis](#), [Victoria Petch](#), [Naomi Wilson](#), [Simone Fox](#) and [Catrina E Craig](#)

Dr Naomi Wilson from the Trust's Institute of Psychotrauma was part of a qualitative research project with Dr Rhiannon Lewis at the University of Surrey that explored parental views regarding the origins of their children's 'disruptive' behaviour. The study highlighted the important role of loss and trauma in the development of externalising behaviours and was recently published in *Clinical Child Psychology and Psychiatry* (Lewis et al., 2014).

'Disruptive behaviour disorders' are often cited as the most common reason for referral to CAMHS and present a significant challenge to services. They are associated with negative long-term outcomes including poor educational attainment, criminality, substance misuse, and employment problems.

Parenting style, parental conflict, exposure to physical abuse and parental separation are all thought to play a key role in the development of antisocial and oppositional behaviour in children. Current treatment guidelines focus on parent-training programmes but families are often described as difficult to engage. Parental attributions regarding the origins of their children's behaviour, attitudes towards help-seeking, stigma, shame and practical barriers to accessing services have all been proposed as factors influencing engagement.

The study aimed to explore the processes and methods that parents utilise to try and make sense of their children's behaviour from their own perspective rather than imposing a pre-existing framework of understanding onto their experiences.

Participants were recruited through CAMHS in South London and semi-structured interviews were carried out with six mothers of children (aged 8-13 years) identified as having 'significant conduct problems'. The majority of the interviews captured mother-son relationship and participants came from White British, European, and Black Caribbean backgrounds. All of the participants reported significant financial stressors, were living in social housing and were dependent on benefits for at least part of their income. Two participants reported a history of domestic violence towards themselves.

Interpretative Phenomenological Analysis (IPA) revealed four master themes: 'Understanding the Emotional Child', 'The Emotional Parent', 'Getting Help' and 'The Journey'. See Figure 1

## 'Understanding the Emotional Child'

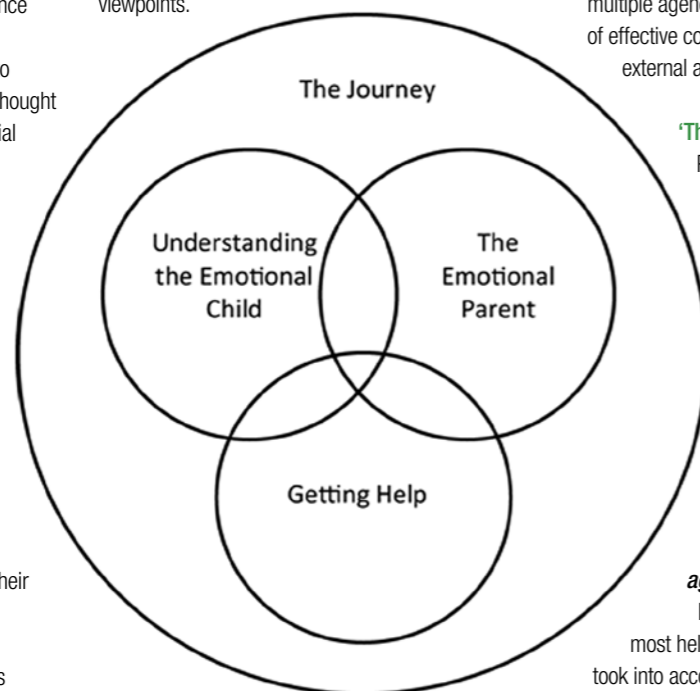
Participants offered a variety of explanations in their attempts to make sense of their children's behaviour. A recurring theme was the view that the behaviour was a result of their child struggling to deal with complex

emotions. Notably, the impact of loss and trauma within relationships played a fundamental role in mothers' understanding of their child's internal world.

Participants' attributions appeared to oscillate, from viewing their children's behaviour as 'intentional and directive' on one end of the spectrum to 'uncontrollable' on the other. Mothers' descriptions of their children were also conflicting, with children described as 'manipulative' on one hand and 'vulnerable' on the other.

*"... it's like there's two of them, and all it takes is a switch to flick from one to the other, does that make sense?" (Ellie\* 48, son aged 13)*

These shifting perspectives appeared to be associated with strong emotional responses, with participants finding it difficult to integrate the conflicting viewpoints.



■ Fig 1, Interpretative Phenomenological Analysis (IPA)

## 'The Emotional Parent'

Parents' own emotional wellbeing appeared to play an important role in how equipped they felt to manage their children's behaviour. Mothers described feeling overwhelmed and emphasised the multiple pressures in their family lives, including violence, conflict and financial pressures in addition to their child's behaviour.

*"And I was like in the middle of it, you know, like maybe I'm not doing this right, I'm not good enough so that was a really bad time." (Fiona\* 41, son aged 12)*

The role of relationships was central to survival and making sense of experiences. Parents used family and peer networks as sources of emotional and practical support and there was an emphasis placed on the importance of speaking to people who shared similar experiences.

## 'Getting Help'

In some cases, support from external agencies was framed as being helpful in aiding understanding, normalising parents' experiences and improving confidence in addressing challenging behaviours.

*"... it was like someone's actually listening to what we were saying and not just assuming that we were bad parents." (Alison\* 48, daughter aged 10)*

However, help-seeking was also associated with feelings of shame and stigma, and external agencies were often experienced as invalidating, inconsistent and disempowering. For some, this seemed to echo experiences of loss and abandonment in their personal relationships. Mothers reported significant difficulties in accessing services and confusion regarding the multiple agencies involved, highlighting the importance of effective co-ordination and collaboration between external agencies.

## 'The Journey'

Participants' understanding of their own role in the development and maintenance of their children's behaviour varied. Their hopes and expectations for the future were influenced by the perceived effectiveness of strategies employed to try and manage the behaviour thus far.

*"But it had been that long since I'd been in control... that I had lost the confidence to do what I knew I had to do." (Ellie\* 48, son aged 13)*

Participants described some of the most helpful interventions as those which took into account their own emotional needs and utilised systemic theory and practices to inform the intervention.

## Implications for clinical practice

### Improving access

Participants reported considerable difficulties accessing services and navigating the multiple agencies involved in their children's care. Clearly there is more work to be done in ensuring parents have access to the necessary support services, including early intervention programmes which provide targeted support to vulnerable groups. The study also highlighted a lack of clarity about different services, their function and how they relate to one another.

The mothers interviewed spoke about multiple pressures and stressors in their family lives, which emphasises the importance of recognising parents' needs and helping parents to access additional support services as needed, for example, by signposting to housing, education and adult mental health services.

## Promoting engagement

Participants' experiences of engaging with services were varied; the findings highlight the importance of a collaborative, non-judgemental stance so that parents feel listened to and understood. Participants used a range of concepts and ideas in their attempts to understand their children's difficulties. This would support a collaborative, formulation-based approach which makes use of these existing frameworks to help parents develop an integrative and individualised understanding of their child's difficulties and explains the rationale for targeted interventions. Participants reported difficulties in implementing parenting strategies in the home, which were quickly dismissed as being ineffective. This highlights the importance of delivering information about behavioural strategies in a more experiential format that does not assume knowledge per se will necessarily result in change.

## Recognising loss and trauma

The study highlighted the important role of loss and trauma in the development of externalising behaviours. This draws attention to the need for an in-depth and thorough assessment, including paying particular attention to documenting trauma histories, including domestic violence, parental conflict and significant losses within the family. This also adds further support to systemic interventions which pay particular attention to issues around attachment and loss. There are also important implications to consider for service delivery; several parents reported being referred for multiple, brief interventions which were framed as being ineffective and are likely to have added to the feelings of failure and rejection in the midst of a stressful family context. This highlights the need for services to consider the role of attachment and loss in influencing engagement and be pro-active in 'stepping-up' care at the appropriate points, rather than run the risk of perpetuating this negative cycle.

## Final thoughts

For the authors this study highlighted the complex task of trying to make sense of children's behavioural difficulties and the importance of frequently re-examining assumptions about the basis of these behaviours. Much of the existing literature does not adequately capture the emotional conflict that parents experience in trying to understand their child or the intensity of the child's emotional experiences. The relationship to loss and trauma was essential in understanding children's behaviour, and the underlying themes of shame, blame and fracture in relationships were mirrored in parent's experiences of trying to access help. This highlights the importance of qualitative research in ensuring that an individual's emotional experiences do not get lost among the clinical descriptions of 'disordered' groups.

\* Pseudonyms have been used to protect confidentiality

# Serious Gaming in Forensic Mental Health

By [Aili Nidsjo](#), research coordinator

Serious games provide virtual environments to explore role-play and problem-solving. Researchers of forensic mental health care from City University London [CUL] School of Health Sciences (Lisa Reynolds, Alan Simpson, Aili Nidsjo, and Jacqueline Davies) are collaborating with experts in serious gaming from CUL School of Informatics (Paul Hodge and Neil Maiden) and professionals in the East London Foundation Trust [ELFT] (including Bradley Mann, Simon Tulloch, Ryan Wczasek and Nikki Wood) to design a serious game for forensic mental health service users. Serious games are increasingly used as a tool in mental healthcare settings. In 2012 a study showed serious games to be a successful therapy component to improve self-control and emotional regulation; and a systematic review of evidence on games based learning and their use linked to a range of positive cognitive and behavioural outcomes.

Forensic mental health services are charged with the duty to rehabilitate service users who pose a risk to the public; a risk that limits opportunities for them to practice appropriate responses

to the difficult situations they may come across upon discharge, and acquire the skills needed to live in the community.

Developing a serious game for forensic mental health could therefore enable service users to engage with risky scenarios in a virtual world that may happen in the real world following discharge; giving service users the opportunity to reflect upon their responses to these scenarios within the security of the therapeutic setting.



■ Head and shoulders of avatar for the serious game designed by Paul Hodge

This serious gaming project is a small scale pilot study investigating the usability and acceptability of a serious game to support existing programmes which prepare service users for discharge back into the community. The research process is guided by service user advisors

from forensic services and in the study itself, the research team and a group of forensic mental health service users are working collaboratively in order to design a game with realistic scenarios, environments and characters. The game, once completed, will be tested by another group of service users, who are in the stages of preparing for their discharge. The testing will be followed by an evaluation group, focusing on the acceptability and feasibility of the game. Administrative healthcare providers along with clinicians that facilitate role play and therapeutic activities will be interviewed individually in order to explore their thoughts and opinions on the use of a serious game in forensic mental health. The study will run over approximately seven months and participants will be provided with the opportunity to help disseminate and present findings.

This is the first time a serious game has been tested in a forensic mental health rehabilitation context, and if found useful by service users, further iterations and developments will be considered.

For further information about the CUL/ELFT forensic mental health serious gaming project please contact Dr Lisa Reynolds at [l.reynolds@city.ac.uk](mailto:l.reynolds@city.ac.uk)

## OTHER NEWS

### Research in East London – Save the Date!

Are you interested in the latest research taking place in the Trust? The Twelfth Annual East London Mental Health Research Presentation Day will be held from 14:00 to 17:00 in the Robin Brooks Centre at St Bartholomew's Hospital, in the afternoon of Wednesday, 1 October 2014. There is no need to register in advance and we hope to see many of you there.

### Research Governance to be reviewed

The HRA, which has taken responsibility from the Department of Health for issuing guidance for research in England, has committed not to just update the Research Governance Framework (RGF), but to fundamentally review the whole framework with an ambition to having a single framework for research across the UK.

A UK wide steering group, led by the HRA, is managing a number of projects which will contribute to the development of a new document. Before a formal consultation takes place on the new framework, the steering group has agreed to circulate the reports and recommendations from the relevant individual projects for comment. The first project is 'What research can the NHS support?' and you can download their report from <http://www.hra.nhs.uk/documents/2014/03/best-support-educational-research-nhs.pdf>

### EU good news for All Trials

MEPs have voted overwhelmingly in favour of the new EU law that will require all drug clinical trials in Europe to be registered and their results reported in a public database. The regulations are due to come into effect in 2016 and you can read more including reactions to the news on <http://www.alltrials.net>

# Adverse events and deterioration reported by participants in a trial of therapies for chronic fatigue syndrome

By **Dr Dominic Dougall**,  
Consultant Psychiatrist,  
Newham Centre for Mental Health

Health problems occurring during clinical trials are often attributed to the treatments given in a trial. However, the attribution of new health problems to a treatment could be misleading when the illness is remitting and relapsing. In a trial such health problems may be recorded as adverse events, may be considered clinically serious or not, and may be considered a reaction to a trial treatment or not. To date there have been few studies which have looked to examine associations and predictions of adverse events in clinical trials. Our study explored this issue in patients with chronic fatigue syndrome (CFS) who participated in the PACE trial (White et al, 2011). This was a multicentre four arm randomised trial which was designed to compare the efficacy and safety of cognitive behaviour therapy (CBT), graded exercise therapy (GET) and adaptive pacing therapy (APT), each added to specialist medical care (SMC), against SMC alone. CBT and GET were designed to be rehabilitative whilst the goal of APT was to optimise adaptation to the illness by planning and pacing activities to avoid or reduce fatigue. Measures of safety included systematic assessments of adverse events (AEs), serious adverse reactions (SARs) and serious adverse events (SAEs). The PACE trial found that both CBT and GET were more effective than adaptive pacing therapy (APT) when any of these therapies were added to SMC, and also were more effective than SMC alone.

Our paper (Dougall et al, 2014) reported the more commonly reported non-serious adverse events (NSAEs). We compared their frequency between treatment arms, and also examined baseline factors that might be associated with reporting larger numbers of NSAEs. On the basis of the previous literature, we hypothesised that NSAEs would be associated with female sex, a larger number of physical symptoms at baseline, and both depressive and anxiety disorders present at baseline.

AEs were defined as 'any clinical change, disease or disorder experienced by the participant during their participation in the trial, whether or not considered related to the use of treatments being studied in the trial'. They were recorded on three occasions at 12, 24 and 52 weeks over one year in 641 participants. At each time point a research assistant asked participants if a new illness or health event had occurred since the last assessment. For example if a participant had visited their GP, attended hospital or had commenced medication. Spontaneously reported AEs were also recorded.

In our analysis we compared the numbers and nature of AEs between the four treatment arms. We examined associations of AEs with baseline measures such as demographic characteristics, depression and anxiety scales and a standardised psychiatric interview, physical symptom scales and measures of chronic fatigue. We also compared the proportions of participants who deteriorated by clinically important amounts, defined a priori.

We found that serious adverse events and reactions were infrequent, whilst non-serious adverse events were common. The median number of NSAEs



per participant over one year was 4, and was not significantly different between the treatments. A greater number of NSAEs were associated with recruitment centre, baseline physical symptom count, body mass index, and depressive disorder. Deterioration in physical function was significantly different across the treatment arms. In those who received APT 25% deteriorated, 9% after CBT, 11% after GET, and 18% after SMC. There were no significant differences in worsening fatigue.

## Substantial variation

Our most unexpected finding was the substantial variation in the number of reported NSAEs between centres. After we had explored alternative explanations, such as the small differences between centres in baseline factors, we concluded the differences were likely due to variation in ascertainment. I.e. research assistants may have asked questions about the occurrence of NSAEs and their thresholds differently. This appears to have occurred despite the use of a standard trial protocol.

Other findings were more expected, such as having more symptoms at baseline, particularly those

associated with CFS, predicting subsequent NSAEs in general and also NSAEs attributed to CFS. Our finding that a diagnosis of a depressive disorder at baseline predicted increased reporting of NSAEs is also consistent with previous studies that found negative affect was associated with NSAEs specifically and having somatic symptoms in general.

However, unlike some previous studies, we did not find an association with anxiety, although at least one other trial has also failed to find an association between anxiety and adverse events. We also found that a higher BMI was associated with more NSAEs

in general. Previous research has found that obese people generally report more physical and mental health related problems, although our finding may also have been due to our sample having a relatively high number of participants who were morbidly obese. We were unable to support our hypothesis that female participants are more likely to report adverse events.

In conclusion, we found no important differences in the frequencies of any of the adverse events between treatment arms, and no excess associated with either CBT or GET, which are both treatments that some patient groups have expressed concerns about, in terms of efficacy and safety. Clinically important deterioration occurred least often after the active rehabilitation interventions of CBT and GET and more often with the more adaptive APT. Our finding that the reporting of non-serious adverse events varied by recruitment centre has implications for the design of future trials. We have therefore suggested that research assessors require clear manualised guidance on the definitions of adverse events, and both training and supervision in the implementation of assessments. That baseline symptom count, having a depressive disorder and BMI were significantly associated with a greater number of NSAEs, independently of the treatment arms, also has both research and clinical implications for clinicians running trials, particularly those including patients with CFS. Adverse events in trials may more accurately reflect fluctuations in a condition, rather than reactions to interventions.

## Upcoming Events

### Autumn/Winter Research Seminars in the Unit for Social & Community Psychiatry

The S&CP regularly holds seminars to present to work of its members. These seminars are free, open to the public and held from 14:00-15:00 in the Lecture Theatre, Academic Unit, Newham Centre for Mental Health. For more information, call Carolanne Ellis on 020 7540 4210.

Date	Title	Presented by
15 September	<i>Group music therapy for acute adult psychiatric inpatients</i>	Catherine Carr
22 September	<i>Carer involvement in the treatment of psychosis</i>	Aysegul Dirik
29 September	<i>COFI – Comparing functional and integrated systems of mental health care</i>	Victoria Bird
6 October	<i>EPOS – findings from the trial</i>	Serif Omer
13 October	<i>VOLUME – Existing volunteering schemes</i>	Joyce Siette
20 October	<i>FIAT – The follow-up on financial incentives for adherence to medication in non-adherent patients</i>	Hana Pavlickova
27 October	<i>Development of a mobile health intervention using positive psychology for common mental health disorders</i>	Sophie Walsh
3 November	<i>Recruitment to trials and mental health care</i>	Paulina Szymczynska
10 November	<i>Immediate social networks in people with psychosis</i>	Domenico Giacco
17 November	<i>Group processes in therapeutic groups</i>	Stavros Orfanos
24 November	<i>Built environment and mental health</i>	Nikolina Jovanvic
1 December	<i>Video clip study and treatment expectations</i>	TBC
8 December	<i>QuEST – Quality and effectiveness of supported housing services for people with mental disorders</i>	Sima Sandhu
15 December	<i>Friendship in Befriending</i>	Rose Thompson
22 December	<i>FIAT – Financial incentives for adherence to medication in non-adherent patients experiences</i>	Katie Moran
<b>Holiday Intermission</b>		
5 January	<i>Comparing functional and integrated systems of mental health care – management of the COFI programme</i>	Domenico Giacco
12 January	<i>NESS – findings from the body psychotherapy for the treatment of negative symptoms trial</i>	Mark Savill
19 January	<i>EPOS – findings from the trial</i>	Eoin Golden
26 January	<i>Review on religious leaders involvement in mental health</i>	Victoria Bird

## Studies recruiting in your trust

*Has your brother or sister been affected by psychosis?*

*Has your sibling's illness had an impact on your life?*

*Would you like more information and support to cope with your sibling's illness?*

*If so, the E-Sibling Project could help you!!!!*



### The E-Sibling project is...

An online resource for brothers and sisters of people who are affected by psychosis. The website <http://siblingspsychosis.org/> provides peer support and information on psychosis, coping and management strategies for common symptoms and ways to look after yourself.

We want to find out whether it works in improving the sibling's wellbeing and coping using a research design commonly called a trial.

### What does it involve...

Using the online resource for 10 weeks. You'll have access to the resource 24/7 and can use it whenever and however you like. You will also be asked to fill in some questionnaires online to see how you are feeling at the start, the end of and after 20 weeks of using the resource. We'll also invite some participants for an individual interview. Participants will be paid £10 for their time and entered into a draw to win one of three vouchers for £100

### Who can take part...

- A brother or sister of a person who developed psychosis within the last 3 years
- Aged over 16 years
- Have a good understanding of spoken English
- Have daily access to the internet
- Have weekly contact with your brother or sister (includes texts, phone calls, facebook etc...)
- Based in England

### If you'd like to join or find out more...

- <http://siblingspsychosis.org/>
  - Contact the study team – Tara Harvey 07872850393 or [tara.harvey@nhs.net](mailto:tara.harvey@nhs.net) or [tara.harvey@eastlondon.nhs.uk](mailto:tara.harvey@eastlondon.nhs.uk) OR Jacqueline Sin – [Jacqueline.sin@kcl.ac.uk](mailto:Jacqueline.sin@kcl.ac.uk)
- Follow us @ESiblingProject or <https://www.facebook.com/Esiblingproject>

## Recent Publications

Notification of the following publications has been received since circulation of the last newsletter. *Don't be shy!!* Please send copies of papers or reference details to the Research Office (ResearchOffice@eastlondon.nhs.uk) so they can be included in this list and made available to interested staff.

■ Ajdukovic D, Ajdukovic D, Bogic M, Franciskovic T, Galeazzi GM, Kucukalic A, Lecic-Tosevski D, Schutzwahl M & Priebe S (2013) *Recovery from posttraumatic stress symptoms: a qualitative study of attributions in survivors of war*, **PLoS One** 8(8):e70579.

■ Barnicot K, Savill M, Bhatti N & Priebe S (2014) *A Pragmatic Randomised Controlled Trial of Dialectical Behaviour Therapy: Effects on Hospitalisation and Post-Treatment Follow-Up*, **Psychother Psychosom**, 83(3):192-193.

■ Barregard L & Stansfeld S (2014) *Medication use as an outcome variable in environmental (noise) epidemiology*, **Scand.J Work Environ.Health**, [Epub ahead of print] doi: 10.5271/sjweh.3426

■ Basner M, Babisch W, Davis A, Brink M, Clark C, Janssen S & Stansfeld S (2014) *Auditory and non-auditory effects of noise on health*, **Lancet**, 383(9925):1325-1332, doi: 10.1016/S0140-6736(13)61613-X.

■ Bhui K, Ullrich S & Coid JW (2014) *Which pathways to psychiatric care lead to earlier treatment and a shorter duration of first-episode psychosis?*, **BMC.Psychiatry**, 14(1):72, doi:10.1186/1471-244X-14-72

■ Bhui K, Warfa N & Jones E (2014) *Is violent radicalisation associated with poverty, migration, poor self-reported health and common mental disorders?*, **PLoS One**, 9(3):e90718.

■ Bhui K (2014) *Preventing the tragedy of railway suicides*, **Ment Health Today** 24-27.

■ Bird V, Leamy M, Tew J, Le BC, Williams J & Slade M (2014) *Fit for purpose? Validation of a conceptual framework for personal recovery with current mental health consumers*, **Aust.N.Z.J Psychiatry**, doi: 10.1177/0004867413520046

■ Bird VJ, Le BC, Leamy M, Williams J, Bradstreet S & Slade M (2014) *Evaluating the feasibility of complex interventions in mental health services: standardised measure and reporting guidelines*, **Br.J Psychiatry**, 204:316-321, doi: 10.1192/bjp.bp.113.128314

■ Copeland J, Thornicroft G, Bird V, Bowis J & Slade M (2014) *Global priorities of civil society for mental health services: findings from a 53 country survey*, **World Psychiatry**, 13(2):198-200, doi: 10.1002/wps.20133

■ Dougall D, Johnson AL, Goldsmith KA, Sharpe M, Angus B, Chalder T, White PD (2014) *Adverse events and deterioration reported by participants in the PACE trial of therapies for chronic fatigue syndrome*, **Journal of Psychosomatic Research**; 77: 20-6.

■ Giacco D, Matanov A & Priebe S (2014) *Providing mental healthcare to immigrants: current challenges and new strategies*, **Curr Opin Psychiatry** [Epub ahead of print]

■ Giacco D, Luciano M, Del VV, Sampogna G, Slade M, Clarke E, Nagy M, Egerhazi A, Munk-Jorgensen P, Bording MF, Kawohl W, Rossler W, Zentner N, Puschner B & Fiorillo A (2014) *Desire for information of people with severe mental illness*, **Soc Psychiatry Psychiatr Epidemiol**. [Epub ahead of print] doi: 10.1007/s00127-014-0901-5

■ Gonzalez RA, Kallis C, Ullrich S, Zhang T & Coid JW (2014) *The protective role of higher intellectual functioning on violence in the household population of Great*

*Britain*, **Pers Indiv Differ**, 61-62(0):80-85 <http://dx.doi.org/10.1016/j.paid.2014.01.012>

■ Hirani SP, Beynon M, Cartwright M, Rixon L, Doll H, Henderson C, Bardsley M, Steventon A, Knapp M, Rogers A, Bower P, Sanders C, Fitzpatrick R, Hendy J & Newman SP (2014) *The effect of telecare on the quality of life and psychological well-being of elderly recipients of social care over a 12-month period: the Whole Systems Demonstrator cluster randomised trial*, **Age Ageing**, 43(3):334-341, doi: 10.1093/ageing/af1185

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■ Korszun A, Sarker SJ, Chowdhury K, Clark C, Greaves P, Johnson R, Kingston J, Levitt G, Matthews J, White P, Lister A & Gribben J (2014) *Psychosocial factors associated with impact of cancer in longterm haematological cancer survivors*, **Br.J Haematol**, 164(6):790-803.

■ Leamy M, Clarke E, Le BC, Bird V, Janosik M, Sabas K, Riley G, Williams J & Slade M (2014) *Implementing a Complex Intervention to Support Personal Recovery: A Qualitative Study Nested within a Cluster Randomised Controlled Trial*, **PLoS One**, 9(5): e97091, doi: 10.1371/journal.pone.0097091

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print] doi: 10.1177/1359104514538040

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■ Morina N, Wicherts JM, Lobbrecht J & Priebe S (2014) *Remission from post-traumatic stress disorder in adults: A systematic review and meta-analysis of long term outcome studies*, **Clin Psychol Rev**, 34(3):249-255 [Epub ahead of print] doi: 10.1016/j.cpr.2014.03.002.

■ Mulder CL, Ruud T, Bahler M, Kroon H & Priebe S (2014) *The availability and quality across Europe of outpatient care for difficult-to-engage patients with severe mental illness: A survey among experts*, **Int J Soc Psychiatry**, 60(3):304-310, doi: 10.1177/0020764013485941

■ Nickerson A, Priebe S, Bryant RA & Morina N (2014) *Mechanisms of Psychological Distress following War in the Former Yugoslavia: The Role of Interpersonal Sensitivity*, **PLoS One**, 9(3):e90503, doi: 10.1371/journal.pone.0090503

■ Pavlickova H, Turnbull O & Bental RP (2014) *Cognitive vulnerability to bipolar disorder in offspring of parents with bipolar disorder*, **Br.J Clin.Psychol**, [Epub ahead of print] doi: 10.1111/bjc.12051.

■ Priebe S, Omer S, Giacco D & Slade M (2014) *Resource-oriented therapeutic models in psychiatry: conceptual review*, **Br.J Psychiatry**, 204:256-261, 10.1192/bjp.bp.113.135038.

■ Rukat A, Musisi S, Strohle A & Mundt AP (2014) *Prescription Patterns of Psychotropic Medications for the Treatment of Psychotic Disorders in the Largest Mental Health Institutions of Uganda*, **J Clin. Psychopharmacol**. [Epub ahead of print]

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■ Wang MJ, Mykletun A, Moyner EI, Overland S, Henderson M, Stansfeld S, Hotopf M & Harvey SB (2014) *Job strain, health and sickness absence: results from the hordaland health study*, **PLoS One**, 9(4):e96025, doi:10.1371/journal.pone.0096025

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