

The barriers and facilitators of supporting self care in Mental Health NHS Trusts

Executive Summary for the National Institute for Health Research Service Delivery and Organisation programme

April 2010

prepared by

Steve Gillard

▪Division of Mental Health, St George's, University of London

Christine Edwards

▪Kingston Business School, Kingston University

Sarah White

▪Division of Mental Health, St George's, University of London

Rachel White

▪Division of Mental Health, St George's, University of London

Katie Adams

▪West Yorkshire NHS Research and Development Consortium

Lucy Davies

▪School of Health Sciences, University of Southampton

Katherine Green

- Hampshire Partnership Foundation Trust

Trevor Kettle

- School of Health Sciences, University of Southampton

Judith Lathlean

- School of Health Sciences, University of Southampton

Mike Lucock

- Huddersfield University and South West Yorkshire Partnerships
NHS Foundation Trust

Stephen Miller

- South West London and St George's Mental Health NHS Trust

Virginia Minogue

- North East Strategic Health Authority

Christine Nugent

- School of Health Sciences, University of Southampton

Lucy Simons

- School of Health Sciences, University of Southampton

Kati Turner

Division of Mental Health, St George's, University of London

Address for correspondence

Dr Steve Gillard

Division of Mental Health

St George's, University of London

Cranmer Terrace

London

SW19 0RE

E-mail: sgillard@sgul.ac.uk

Executive Summary

Background

The Department of Health has prioritised the need to support individuals in the care they take to maintain their own mental health (2005). Research on the effectiveness of a variety of self care interventions has been reviewed (DH 2007). Challenges to changing from a culture of 'doing for' to 'doing with' have been identified (Wilson 2005). We use a theoretical framework derived from organisational research to explore how health service organisations change (Edwards 2004), complemented with a strong focus on service user involvement in the research process (Faulkner 2002).

Aims

- To identify barriers and facilitators to providing self care support in Mental Health NHS Trusts
 - To compare learning about self care support across health service areas
-

About this study

A mixed method cohort study design was used to investigate how self care was supported in three case studies in contrasting Mental Health NHS Trusts. Case studies comprised a range of projects: Wellness Recovery Action Planning; peer support groups for people with Personality Disorder; creative arts projects provided by voluntary organisations.

Demographic and service use data was collected from service users who were new to self care projects, and again nine months later. Service users also completed standard measures of outcomes associated in the literature with self care (e.g. empowerment) and qualitative interviews about their expectations and experiences of self care. Informal carers (partners, family members) were also asked about their experiences, as were staff working in the self care projects. Strategic managers in the case study Trusts were asked about organisational issues around implementing self care policy.

Analysis of co variance was used to identify variables that might be associated with self care outcomes. A thematic analysis of qualitative interview data explored experiences of self care from a range of stakeholder perspectives. Quantitative findings were further explored through synthesis with qualitative interview data. Online survey was used to consider how findings might generalise to Mental Health NHS Trusts nationally.

Limitations of the study

Analysis of change in outcomes was exploratory in nature and was used to identify factors that might impact on change. We selected contrasting self care initiatives that served varied populations so that we could identify a broad range of barriers and facilitators of supporting self care. Given the heterogeneity of our samples, this approach does mitigate against generalising our findings to specific populations, and any conclusions should be read with this proviso in mind.

Findings

We report here the most interesting findings indicated by statistical analyses of the data. Although in most comparisons change in outcomes were non-significant, in one site we noted significant reduction of 35% ($p=0.005$) in A&E attendance, and significant improvement in empowerment and mental health confidence of 3.9 (95% CI 0.8 - 7.0) and 0.5 (95% CI 0.2 - 0.8) points respectively. A second site also showed significant improvement in mental health confidence of 0.3 (95% CI 0.0 - 0.6) points. Choosing to take medication as prescribed was associated with both empowerment and mental health confidence ($p=0.007$ and $p=0.055$). A higher level of clinical severity at baseline was associated with higher satisfaction with the self care project ($B=0.01$: 95% CI 0.00, 0.01). A higher quality of life at baseline and more highly rated collaboration with the member of staff participants had most contact with were associated with staying engaged with the self care project ($p=0.047$ and $p=0.020$ respectively). Following synthesis of quantitative and qualitative analyses we drew conclusions in a number of areas:

Services supporting self care

Peer support groups and personal plans were strongly indicated as facilitators of self care when well supported. Service users developed strong positive identifications where projects focussed on 'wellness'.

'Timing' support for self care was crucial, with service user control over when to access support for self care (self referral) and how to use that support (flexible; ongoing) fundamental to effective support for self care.

Control over engagement in self care support is more important than amount of engagement: support for self care cannot be 'dosed'.

There can be no 'discharge' to self care: service users were concerned about being 'abandoned' by the Trust without a route back at times of crisis.

Self care and risk

Engaging in self care often required the individual to confront difficult issues: self care involves a degree of 'positive' risk for service users and

service provider. Overcoming those issues offered rewards (empowerment).

The relationship between medication and support for self care was complex: some individuals incorporated medication into their self care while some made a decision to come off medication.

Self care and the service user-staff relationship

All projects were characterised by a change in the staff role – from provider to enabler – and a change in the service user-staff relationship.

Relationships were informal and non-judgemental of the service user, but where relationships were 'too relaxed' service users could lose confidence in the ability of the service to provide clinical support at times of crisis.

Employment of service users as staff on self care support projects offered clear benefits for service users, service user employees and their professional colleagues. However, there were transactional costs of training and supporting service users as staff.

Self care and social networks

Carers were positive about self care support and the benefits it offered, but self care impacted on their relationships and could be a source of conflict.

Social networks were strengthened through self care, especially where support was given in settings away from the Mental Health Trust and where new, non-mental health identities were nurtured.

Self care and the Trust

Trust staff working in self care support were often highly motivated, expressed high job satisfaction and felt well supported in their teams. They also experienced low morale where they felt job security was low.

Professional resistance to a culture change - delivering services 'with' rather than 'for' service users - was in evidence, but not widespread. Lack of a strategic approach was a more likely barrier to imbedding change.

The sustainability of some innovative projects was best achieved by bringing them into the Trust as part of mainstream service provision. However, some beneficial features could be lost through mainstreaming.

Self care and partnership working

Where support for self care was provided outside of mainstream services there were advantages of innovative and flexible ways of working. However, externally provided initiatives were vulnerable to loss of funding.

Many qualities of self care support aligned well with other policy initiatives (e.g. recovery) and social care priorities (e.g. personalisation), facilitating cross-sector support.

Self care policy implementation

Communication with the other SDO self care research teams indicated that many features of self care support were common across health service areas: e.g. commissioning challenges, culture change.

Recommendations

We recommend that Mental Health Trusts should

- Enable service users to access self care support, including peer support groups, through properly informed self referral
- Give control over how support for self care is used to individual service users through supported personal (self care) planning
- Ensure that clinical and crisis support remains accessible to those who are engaged in self care
- Embrace 'positive risk' at the heart of self care strategy, personal planning, and risk management policy and procedure
- Incorporate joint service user-clinician decision making around medication into personal self care plans
- Provide dedicated training (co-facilitated by service users) to staff teams supporting self care
- Ensure service user employees are effectively managed and supported under appropriate contractual terms and conditions
- Support carers in their changing role, reaching out to those partners and family members who do not identify as carers
- Demonstrate strategic support for self care in order to recruit and retain the best staff in self care support roles
- Enable self care leaders, staff teams and service users to become agents for change through championing their good practice
- Work with commissioners, local authorities and voluntary sector partners to ensure to the sustainability of the best projects
- Consider whether projects supporting self care best deliver health and social care objectives from within, or outside of the Trust

We recommend future research in order to

- Determine, through controlled studies, the effectiveness of specific self care interventions, incorporating detailed process evaluations where interventions are complex in nature
- Understand the extent to which innovation is driven by policy and/ or by initiatives originating from service user-practitioner partnerships, innovative teams and charismatic leaders
- Investigate the impact of changing staff roles and staff-service user relationships on the staff team, including the integration of service user employees into clinical teams
- Explore the cost effectiveness of supporting self care in order to better inform commissioning decisions
- Identify when and how support for self care for physical health issues is appropriately provided through the Mental Health Trust and/ or in partnership with other providers
- Develop community driven solutions to supporting self care that specifically target people from a range of ethnic groups
- Explore how support for self care might be best provided in specialist mental health settings
- Understand how service user involvement in research impacts on the collaborative research process, shapes findings and facilitates the mobilisation of research into practice

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.