

EFFIP (E-support for Families and Friends of Individuals affected by Psychosis): A randomized controlled trial of a co-produced online intervention for carers

Aims of the research

This research project aims to develop and evaluate an online intervention providing peer support, information, and coping strategies to promote the wellbeing of families and friends of individuals affected by schizophrenia and psychosis.

Background to the research

Psychoses including schizophrenia are very common mental illnesses affecting at least 1% of the population. Psychosis results in a range of distressing symptoms including hallucinations, delusions and paranoia which often lead to significant secondary difficulties, such as anxiety, depression and social isolation. The outlook and prognosis for individuals can be significantly improved by having caring support from family and friends. Informal carers are invaluable for increasing social opportunities and providing meaningful relationships for their loved ones, which can in turn promote their engagement and confidence in undertaking regular daily activities. Total savings contributed by carers to the NHS and social care systems are estimated to be £1.24 billion per annum.

While there are clear advantages to family members supporting each other, several research studies have found that informal caregiving for people with psychosis can lead to very high levels of stress, distress, anxiety and depression in carers. Also, research findings indicate that carers often lack information about psychosis and management strategies for symptoms. Carers are not necessarily provided with appropriate resources and support which can make their distress and feelings of helplessness worse. Lack of information and support for carers can also hamper their capacity to care for their loved ones leading to poorer outcomes for service users and the whole family.

There have been some, albeit limited attempts to develop interventions for carers of people with psychosis. Interventions most often researched have comprised individual and group formats. However, the success of these approaches has been affected by factors such as: accessibility, time constraints and competing demands associated with the caregiving role. The implementation of the Care Act stipulates a legal requirement for carers to be provided with support. The E Sibling Project (<http://siblingpsychosis.org>) showed that an interactive online intervention for siblings of individuals with psychosis was feasible. This strongly suggests that an online (e- health), carers-focused intervention might address those support needs.

Design and methods used

This research project utilises a mixed methods study design based on the UK Medical Research Council's framework for the development and evaluation of complex interventions. The project comprises three phases. First, in order to map out the design and content of the intervention, reviews of relevant research and focus groups with families, service users and mental health professionals will be conducted to identify the best approach for developing an

e-health intervention specifically for carers. Second, the intervention prototype will be tested for usability with 30 carers. This feasibility stage will inform any further development. Third and finally, the effectiveness of the intervention will be evaluated using a randomised controlled trial. The intervention will be compared with a non-interactive information-giving website (which represents the best available current treatment provision). Questionnaires about carers' mental wellbeing, their caregiving experience, quality of life, and family relationships will be collected at three time points over a 40-week period to establish if the EFFIP intervention works better than the comparison website.

Patient and public involvement

PPI activities are embedded in this project to ensure that the intervention is relevant and usable, and that the research design and conduct is acceptable to families and service users. A Project Reference Group (PRG) comprising service users and carers, clinical and voluntary sector representatives will be established at the outset to oversee and advise on the project throughout its course and to input into every aspect of the research design. To help develop the intervention, an Expert Advisory Group (EAG) comprising at least eight service users and carers in addition to mental health, carer-workers and ICT experts, will be established to provide consultation on the design and implementation of the intervention and to advise on sourcing, selecting, and screening materials for it.

Dissemination

A major output of the project is a dedicated website which not only hosts the EFFIP intervention but will also be used to share all relevant information and findings of the project. Throughout the course of the project, study findings will be disseminated to the scientific community as well as the wider health and social care arena. In order to reach families, carers, professionals and commissioners cost-effectively, various forms of media will be used, including peer-reviewed publications, conference presentations, carer organisations' e-newsletter and social media.