Impact of cognitive therapy on internalised stigma in people with at-risk mental states

Anthony P. Morrison, Max Birchwood, Melissa Pyle, Clare Flach, Suzanne L. K. Stewart, Rory Byrne, Paul Patterson, Peter B. Jones, David Fowler, Andrew I. Gumley and Paul French

Background
Internalised stigma in young people meeting criteria for at-risk mental states (ARMS) has been highlighted as an important issue, and it has been suggested that provision of cognitive therapy may increase such stigma.

Aims
To investigate the effects of cognitive therapy on internalised stigma using a secondary analysis of data from the EDIE-2 trial.

Method
Participants meeting criteria for ARMS were recruited as part of a multisite randomised controlled trial of cognitive therapy for prevention and amelioration of psychosis. Participants were assessed at baseline and at 6, 12, 18 and 24 months using measures of psychotic experiences, symptoms and internalised stigma.

Results
Negative appraisals of experiences were significantly reduced in the group assigned to cognitive therapy (estimated difference at 12 months was −1.36 (95% CI −2.69 to −0.02), \( P=0.047 \)). There was no difference in social acceptability of experiences (estimated difference at 12 months was 0.46, 95% CI −0.05 to 0.98, \( P=0.079 \)).

Conclusions
These findings suggest that, rather than increasing internalised stigma, cognitive therapy decreases negative appraisals of unusual experiences in young people at risk of psychosis; as such, it is a non-stigmatising intervention for this population.

Declaration of interest
None.

Trial design
The EDIE-2 trial is a multisite randomised, controlled, single-blind (rater) study comparing two conditions (cognitive therapy plus mental state monitoring v. a mental state monitoring control). The randomisation algorithm used randomised permuted blocks with block sizes of six or eight, after first stratifying by site and gender. Assessors were masked to treatment condition and many diverse strategies were employed to achieve masked ratings. More details of the trial methodology, including a CONSORT flow diagram, are available in the primary outcome report.

Participants
Entry criteria for the EDIE-2 trial were assessed using the Comprehensive Assessment of At-Risk Mental States (CAARMS), which is specifically designed for the assessment of ARMS. The entry routes consist of individuals experiencing brief limited intermittent psychotic symptoms, attenuated psychotic symptoms
or state-plus-trait factors. Other inclusion criteria were aged 14–35 and help-seeking. Five sites were involved: Manchester, Birmingham/Worcestershire, Glasgow & Clyde, Cambridgeshire and Norfolk. Participants were predominantly identified by health professionals working within diverse agencies within primary- and secondary-care settings; our most common sources were early intervention services (34%), primary care (GPs/primary care mental health teams: 21%) and youth/student counselling services (15%). We recruited 288 participants; 144 were allocated to cognitive therapy and 144 to monitoring only.

**Measures**

Eligibility for the study was measured using the CAARMS, which provided measures of transition to psychosis, symptom severity and associated distress. The interrater reliability of the CAARMS assessments was assessed regularly over the lifetime of the trial and intraclass correlation coefficients indicated good interrater reliability (mean 0.90, s.d. = 0.03).

Internalised stigma was measured using the Personal Beliefs about Experiences Questionnaire (PBEQ; details available from the authors on request), which is a 13-item self-report questionnaire; each item reflects social and cultural beliefs/stereotypes about psychosis (for example 'I can talk to most people about my experiences'). Participants rate the degree to which they endorse statements to be true about themselves on a four-point scale (one to four): 'strongly disagree', 'disagree', 'agree' and 'strongly agree'. The PBEQ is an adapted version of the Personal Beliefs about Illness Questionnaire (PBIQ); minor revisions were made in order to make the questionnaire suitable for use with people meeting criteria for ARMS. These revisions involved replacing the word 'illness' with 'experience' and the removal of three items that were not applicable to the ARMS population. Exploratory factor analysis of the PBEQ with the ARMS population has suggested two subscales for this measure: negative appraisals of unusual experiences and the perceived social acceptability of unusual experiences. Analyses indicated good reliability for the negative appraisals subscale (α = 0.74) and acceptable reliability for the social acceptability subscale (α = 0.52), which is comparable to the reliability of the original subscales of the PBIQ. Items loading highly on the negative appraisals factor included: 'There is something strange about me which is responsible for these experiences', 'It is hard for me to work or keep a job because of my experiences' and 'There must always have been something wrong with me as a person (to have caused these experiences)'. Items loading highly on the social acceptability factor included: 'I can talk to most people about my experiences', 'My experiences mean that I should be kept away from others' and 'I am embarrassed to talk about my experiences' (the latter two items being reverse scored). High scores on negative appraisals indicate higher internalised stigma, whereas lower scores on social acceptability indicate higher internalised stigma.

All participants received assessments that included both CAARMS and PBEQ at baseline, 6 months (end of treatment) and 12 months. Our variable follow-up period meant that participants recruited in the first 14 months of the study were planned to receive 24 months of follow-up; participants recruited after that were offered steadily reducing follow-up periods, depending on time of recruitment, with a minimum follow-up period of 12 months.

**Procedure**

Participants were randomised to one of two conditions: monitoring control or cognitive therapy plus monitoring. All participants received treatment as usual plus regular monitoring (incorporating a CAARMS assessment from a research assistant), which represents an enhancement over routine care since it aimed to provide warm, empathic and non-judgemental face-to-face contact, supportive listening, signposting to appropriate local services for unmet needs and crisis management when required. In addition to this monitoring component, participants allocated to the therapy arm of the trial received cognitive therapy based on a specific cognitive model. Sessions were offered on a weekly basis for up to 26 weeks, plus up to four booster sessions in the subsequent 6 months. Cognitive therapy allows an individualised, problem-oriented approach and incorporates a process of assessment and formulation, which is manualised. The specific interventions depend on individual goals and formulations, but the range of permissible interventions is described in our published manual. Key ingredients of the approach are the development of a problem and goal list, early formulation (both longitudinal and maintenance), a focus on normalising psychotic-like experiences and an active therapy stance utilising behavioural experiments and evaluation of appraisals. The emphasis on provision of normalising information regarding unusual experiences and the evaluation of catastrophic and shame-related or pessimistic appraisals of such experiences is particularly relevant to this study. Further details regarding the trial design and primary trial outcomes can be found elsewhere.

**Statistical methods**

Analyses were undertaken in Stata (version 12) for Windows. The analysis strategy of the primary trial outcome was replicated for this investigation of changes in internalised stigma; primary analysis was by intention-to-treat. Repeated measures models with random effects were used with the summed PBEQ subscales as dependent variables, allowing for attrition and the variable follow-up times introduced by the design of the trial. This approach accounts for non-independence of measures within the same person. The use of these models allows for the analysis of all available data, on the assumption that data are missing at random, conditional on adjustment for centre and observed baseline scores. The models allowed for linear, quadratic and cubic trends in stigma scores over time, but only involved testing the treatment by linear trend interaction (i.e. based on the assumption that quadratic and cubic trends would be the same for both groups). The estimated parameters include a main effect of treatment, a linear and quadratic effect of follow-up time (months) and a linear effect of treatment × month interaction. Months of follow-up were centred on 12 months so that the main effect of treatment corresponds to the difference between the two arms determined at 12 months. We adjust for the stigma subscale scores at baseline and the site of the participant. We report robust standard errors, significance levels and confidence intervals.

In order to examine the effect of attendance at cognitive therapy, instrumental variable regression using the adjusted treatment-received algorithm was used in a two-stage least squares analysis on the 12-month outcomes. A regression model was first fitted for the effects of site and randomised group on sessions. Predicted values and residuals from this model were saved and used in a second regression model for the effects of sessions on outcome using the predicted values, allowing additionally for site and the baseline value of the stigma score. This two-stage procedure allows for missing outcomes assuming that they are missing at random.
Results

The baseline characteristics of the whole sample, and the two groups, are presented in Table 1. More detailed baseline characteristics, demographics and referral pathways for the participants are described elsewhere.27 The participants allocated to cognitive therapy received a mean of 9.11 sessions (s.d. = 6.69, range 0–26), each session lasting on average 1 h. Adherence to cognitive therapy was reasonably good, with only 9/144 (6.25%) not attending any sessions, and 108/144 (75%) receiving at least four or more sessions. Table 2 shows the results of the PBEQ subscales (negative appraisals and social acceptability) at the 6-, 12-, 18- and 24-month end-points.

The random-effects regression analysis estimates that negative appraisal scores are 1.36 points lower in the cognitive therapy group at 12 months compared with the monitoring group (95% CI –2.69 to –0.02, P = 0.047). There is an overall reduction in negative appraisals over time (coefficient, −0.18, 95% CI –0.32 to –0.04, P = 0.012), but no significant interaction by treatment arm (coefficient, 0.05, 95% CI –0.07 to 0.17, P = 0.402). Thus, a beneficial effect of cognitive therapy is observable at 12 months, but the scores of both groups reduced significantly over the whole duration of the trial.

There was no statistically significant difference in social acceptability scores between the cognitive therapy and control arms (coefficient, 0.46, 95% CI –0.05 to 0.98, P = 0.079). Social acceptability shows a small increase over time, although this is not quite statistically significant (coefficient, 0.06, 95% CI 0.00 to 0.12, P = 0.051). There was no interaction between time and the treatment group, indicating that changes in social acceptability over time do not differ between the groups (coefficient, 0.0001, 95% CI –0.06 to 0.06, P = 0.997).

With regard to the effects of number of sessions, no significant exposure effect was observed at the 12-month outcome for either negative appraisals (sessions effect, −0.06, 95% CI –0.26 to 0.13, P = 0.521) or social acceptability (sessions effect, 0.06, 95% CI –0.02 to 0.14, P = 0.132). Thus, there was no dose–response effect.

Discussion

Main findings

This is the first study to examine the effects of any treatment on internalised stigma in people with ARMS. Our study has shown that cognitive therapy for people meeting ARMS criteria does not increase, but probably reduces, their negative appraisals of unusual experiences over 12–24 months. Cognitive therapy does not significantly improve their appraisals of the social acceptability of these experiences; however, there was a strong trend in that direction (P = 0.07), which is clearly incompatible with suggestions that it may worsen concerns about the social acceptability of psychotic experiences. These results suggest that concerns that the provision of cognitive therapy to people at risk of psychosis may be contraindicated or harmful on the basis of increasing internalised stigma14 are unfounded. Indeed, it would seem that, rather than increasing stigma as an adverse effect associated with treatment, cognitive therapy tends to reduce internalised stigma as has been suggested elsewhere.16,17

This finding has implications for the likely cost–benefit ratios associated with providing specific treatments for this group, which has been identified as of crucial importance in the ethics of intervening with an at-risk population.28 It is, therefore, important that future studies evaluating treatments for ARMS should measure internalised stigma to inform the consideration of such risk–benefit ratios, as they are likely to differ significantly between treatment approaches. It has been argued that a key mechanism of action underpinning the effectiveness of cognitive therapy is the reduction of potentially harmful appraisals of psychotic experiences via the development of normalising, decatastrophising and deshaming understanding of these experiences.29,30 Our findings are compatible with such an assumption.

The non-significant increase in perceived social acceptability of experiences may reflect the possibility that changing appraisals of social acceptability is a greater challenge, since such appraisals are likely to be deep-rooted in the wider cultural context, rather than internally generated. In fact, it may be that a certain level of caution about disclosure of psychotic experiences in the current cultural environment may be adaptive, given the extent of prejudice and discrimination.29 Goffman originally described stigma as ‘an attribute which is deeply discrediting’ and as ‘an undesired differentness’, and described internalised stigma as identification with a negative stereotype.30 Psychosis is one of the most stigmatised mental health problems29,31 and stigma associated with psychosis can discourage people from seeking help.32 This may delay treatment and leads to social isolation and reduced employment and education opportunities.29 Such stigma also results in poorer physical healthcare, suicidality and higher mortality rates.33 People with psychosis report internalising stigmatising social stereotypes and experience shame and fear as a consequence.24,35 There is a strong negative relationship between internalised stigma and a range of psychosocial variables including hope, self-esteem, empowerment and adherence with treatment;36 similar associations have recently been demonstrated in the ARMS population. Therefore, a reduction in negative appraisals of unusual experiences and a trend towards increasing the perceived social acceptability of such experiences is an important finding.

Limitations

Our trial is the largest trial with an ARMS population to date, and the use of five sites should ensure the generalisability of our

<table>
<thead>
<tr>
<th>Table 1 Baseline characteristics</th>
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<tbody>
<tr>
<td>Whole sample (n = 288)</td>
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<tr>
<td>Age, years: mean (s.d.)</td>
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<tr>
<td>Comprehensive Assessment of At-Risk Mental States, mean (s.d.)</td>
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<tr>
<td>Severity, summed</td>
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<tr>
<td>Distress, summed</td>
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<tr>
<td>Personal Beliefs about Experiences Questionnaire, mean (s.d.)</td>
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<tr>
<td>Negative appraisals</td>
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<tr>
<td>Social acceptability</td>
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</tbody>
</table>
Table 2: Means and standard deviations for the negative appraisals and social acceptability subscales of the Personal Beliefs about Experiences Questionnaire

<table>
<thead>
<tr>
<th>Variables</th>
<th>6 months</th>
<th>12 months</th>
<th>18 months</th>
<th>24 months</th>
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<tbody>
<tr>
<td></td>
<td>Cognitive therapy group a</td>
<td>Monitoring only group</td>
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<td></td>
<td>n</td>
<td>n</td>
<td>n</td>
<td>n</td>
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<td></td>
<td>Mean (s.d.)</td>
<td>Mean (s.d.)</td>
<td>Mean (s.d.)</td>
<td>Mean (s.d.)</td>
</tr>
<tr>
<td>Negative appraisals</td>
<td>81</td>
<td>20.43 (5.23)</td>
<td>83</td>
<td>21.12 (4.96)</td>
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<td></td>
<td></td>
<td></td>
<td>86</td>
<td>20.07 (5.89)</td>
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<td></td>
<td>81</td>
<td>19.78 (5.04)</td>
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<td></td>
<td>35</td>
<td>18.77 (5.89)</td>
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<td>39</td>
<td>19.90 (4.66)</td>
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<td>30</td>
<td>17.77 (5.64)</td>
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<td></td>
<td></td>
<td></td>
<td>27</td>
<td>20.03 (6.34)</td>
</tr>
<tr>
<td>Social acceptability</td>
<td>82</td>
<td>10.24 (2.06)</td>
<td>83</td>
<td>10.06 (2.04)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>87</td>
<td>10.61 (2.13)</td>
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<td>82</td>
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<td>40</td>
<td>10.68 (2.62)</td>
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<td>30</td>
<td>11.13 (2.49)</td>
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<td></td>
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<td></td>
<td>27</td>
<td>10.19 (2.62)</td>
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</table>

b. Numbers of participants available for follow-up at 18 and 24 months were lower than previous assessment points because we had a decreasing follow-up period for participants recruited later in the trial.

We have demonstrated a statistically significant reduction in internalised stigma as a result of cognitive therapy. However, it remains to be seen whether the effects of cognitive therapy and monitoring are generalisable to people with a diagnosis of schizophrenia, which are significant predictors of social acceptability in the general public.

Implications

There was a significant proportion of missing data, which can introduce the possibility of bias. However, the proportions were similar for both groups and were not associated with a label such as ARMS or the attenuated psychosis syndrome proposed in DSM-5. Similarly, as we did not have a label or diagnosis, we believe the present study provided a strong test of the internalised stigma hypothesis. We should also point out that the social acceptability subscale had an alpha of 0.52; however, the original PQ subscales had an alpha of 0.32; however, the original PQ subscales had a comparable level of internal reliability that demonstrated a significant beneficial effect of cognitive therapy.

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implement and consistent with International Early Psychosis Association guidelines regarding treatment in the at-risk phase. 144

There are several other clinical implications of this study. Cognitive therapy reduces negative appraisals of psychotic experiences, which should provide direct benefit given the toxic nature of internalized stigma. Cognitive therapy aims to encourage a normalising, non-catastrophic perspective on the understanding of psychotic experiences within a collaborative framework, which may be the mechanism by which such negative appraisals are reduced. It may be that targeting the social acceptability of such experiences more directly, using methods derived from the literature on prevention of stigma and discrimination (such as contact with other service users, identification of positive role models and celebration of difference), may result in greater effects. However, it is also important to consider that, until wider societal views of psychosis and mental health problems are improved, a cautious approach to disclosure of such experiences may be appropriate. Thus, it is essential that any individual approaches, such as cognitive therapy, are delivered in a context that includes campaigns designed to influence the general public.

References


Cognitive therapy and internalised stigma


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Inanimate mechanical forces

Allan Seppänen

... and thus it came to pass ...

Inanimate mechanical forces
Rampage through the central nervous systems
Of once beautiful people

Distorting affects and salience
To such an extent
That intentional self-harm by exposure to organic solvents, hot vapours, wood preservatives
Or firearm discharge
Take place

Whether in private homes
Public administrative areas
Or institutional places of residence

Allan Seppänen is a forensic psychiatrist (specialising), Vanha Vaasa Hospital, Vaasa, Finland.
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