The simulation of hallucinations to reduce the stigma of schizophrenia: A systematic review

Shuntaro Ando [*,1], Sarah Clement [1], Elizabeth Alexandra Barley [2], Graham Thornicroft [2]

Section of Community Mental Health, PO29, Health Service and Population Research Department, King's College London, Institute of Psychiatry, De Crespigny Park, London SE5 8AF, England

ARTICLE INFO

ABSTRACT

Background/objectives: Many people with schizophrenia face stigmatisation. Several methods have been produced to simulate the auditory and visual hallucinations experienced by people with schizophrenia in order to increase empathy and understanding about the condition. However, there has been no review of such methods. This systematic review aims to determine whether and how simulated hallucinations are effective in reducing stigma, and if simulated hallucinations are safe and acceptable.

Methods: Medline, Embase, PsycInfo, the Cochrane Library, CINAHL, and Worldcat Dissertations and Theses were searched from 1980 to September 2010. Reference checking, hand-searching, and contacting of experts in the field were also performed. A narrative synthesis of quantitative studies was conducted, and qualitative studies were synthesised using meta-ethnography.

Results: Ten studies were included. Simulation tools varied in context, but consistently increased both empathy towards, and desire for social distance from, people with schizophrenia whilst findings for other attitudes were inconsistent. Participants reported physical, cognitive and emotional discomfort. Qualitative data suggest that these discomforts give participants an 'insider's perspective' which produced empathy and respect. Simulated hallucinations sometimes produced concurrent negative affect, and physical and emotional distress, but were considered a highly acceptable learning tool.

Discussion/conclusions: Simulated hallucinations have contradictory effects on stigma, increasing empathy but also the desire for social distance. They should therefore be used with caution. Further research is required to discover if there is a way of using simulated hallucination interventions that increases empathy without increasing the desire for social distance from people with mental illness.

1. Introduction

Many people with schizophrenia experience stigma. A survey in 27 countries showed that approximately half of the 732 people with schizophrenia interviewed reported negative discrimination when making or keeping friends, 43% from family members, and 29% when finding a job (Thornicroft et al., 2009). A recent postal survey examined the level of self-stigma and perceived stigma reported by people with schizophrenia or other psychotic disorders across 14 European countries. Almost half (42%) reported moderate or high levels of self-stigma and 69% moderate or high perceived discrimination (Brohan et al., 2010). In a survey of 1737 adults in the UK, it was found

that more than 70% of the general public viewed people with schizophrenia as dangerous and/or unpredictable (Crisp et al., 2000). Stigmatisation of individuals who have schizophrenia is also prevalent in medical and nursing students. A survey of medical and nursing undergraduates showed that 78% thought that patients with schizophrenia are dangerous or violent, and 40% of them rejected or felt ambivalent about accepting them in a social situation (Llerena et al., 2002).

In the field of physical disability there has been a long history of using simulated experience in attempts to increase understanding and destigmatise disability (French, 1992). In recent years simulated experience has begun to be used in the mental health field with various aims. For example interventions that simulate hallucinatory experience have been used with patients with schizophrenia as part of exposure therapy to desensitise them to their hallucinations (Tichon and Banks, 2006). However such interventions have most commonly been developed with the aim of reducing the stigma associated with psychosis. For instance the widely-used "Hearing Voices that are Distressing: A Training Experience and Simulation" developed by the National Empowerment Center, Boston (Deegan, 1996). This comprises of a 45-minute recording of benign and derogatory voices

* Corresponding author at: Department of Neuropsychiatry, Graduate School of Medicine, University of Tokyo , 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-8655, Japan. Tel.: +81 3 5800 9263; fax: +81 3 5800 6894.

E-mail addresses: sandou-tky@umin.ac.jp (S. Ando), sarah.clement@kcl.ac.uk (S. Clement), elizabeth.barley@kcl.ac.uk (E.A. Barley), graham.thornicroft@kcl.ac.uk (G. Thornicroft).

[1] To be considered as joint first authors.
[2] To be considered as joint last authors.

typical of those heard in psychosis which participants hear through headphones whilst undertaking a variety of tasks at workstations and in the local area. Further components are an audiotaped presentation about the experience of psychosis and a post-simulation debriefing discussion. Other simulations use virtual reality techniques to re-create both audio and visual illusions in the 3-dimensional environment (Radio, 2002; Banks et al., 2004), the most widely used being headphones and goggles headset developed by a pharmaceutical company (Tabar, 2007). These interventions were expected to prompt understanding and bolster empathy, therefore have been used as an anti-stigma intervention (Brown et al., 2010a). However, to our knowledge, there is limited evidence and no review investigating the effectiveness of simulated hallucinations in reducing stigma. This review aims to elucidate the effects of hallucination simulations on stigma, as well as the processes that may underlie any effects on stigma, and evidence on possible harm and acceptability among the general public.

2. Objectives

This systematic review addresses four specific research questions:

1) What is the effect of simulated hallucinations on the stigma associated with schizophrenia?
2) What processes underlie any effects of simulated hallucinations on stigma?
3) Do simulated hallucinations cause any harm or distress to those who participate in the simulation?
4) How acceptable are simulated hallucinations to participants?

3. Materials and methods

3.1. Inclusion and exclusion criteria for studies

In order to collect a wide range of relevant evidence, we used a broad set of inclusion criteria and relatively few exclusion criteria. Studies were included if they used any simulation that created the experience of auditory, visual, olfactory, and/or tactile hallucinations with the aim of reducing stigma. Included studies could be on any population including students, professionals, informal caregivers or the general public of any age. In line with our research questions, studies were required to be data-based and to include at least one of the following: (i) any stigma-related outcome, including social distance (individual's willingness to interact with people with mental illness in various situations), attitudes to mental illness or people with mental illness, behaviour towards people with mental illness, empathy related outcomes, or emotional reactions to people with mental illness, or understanding of mental illness, (ii) any harm or distress (negative reaction) caused by the simulation experience, (iii) any data about the processes that may underlie any change in stigma, and (iv) any data relating to acceptability. Eligible studies may utilise any active control (non-simulation intervention intended to reduce stigma) or inactive control (intervention not intended to reduce stigma) or none. We excluded studies if they used simulation with patients for therapeutic purposes or to understand psychotic processes.

3.2. Search strategy

Electronic and manual searches were conducted. Six electronic databases were searched from 1980 to September 2010 on 30th September 2010: Medline, Embase, PsycInfo, the Cochrane Database of Systematic Reviews and the Cochrane Central Register of Controlled Trials Register, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Worldcat Dissertations and Theses. No restrictions were applied for language or publication type. The following search terms were used: ((voice$ OR vocal$ OR hallucinate$ OR illusion$ OR

psychosis$ OR schizophreni$) AND (simulat$ OR virtual)) ($ = truncation). In addition, the MeSH terms: voice, illusions, schizophrenia and disorders with psychotic features, and patient simulation were applied.

Reference lists of included papers were checked and the journal 'Simulation in Healthcare' was hand-searched from the first publication (2006) to September 2010. In addition, citation forward checking for included studies was undertaken. Finally, the first authors of included papers, intervention producers, and other experts (International Expert Advisory Group for the SAPPHIRE Research Programme on Stigma and Discrimination in Mental Health) were contacted for unpublished studies and any additional studies that may have been missed.

3.3. Study selection

Screening of the identified titles for potential relevance was conducted by the first author (SA). Another member of the research team (SC) independently screened a random 10% sample of the titles and abstracts; agreement on potential relevance was 99% (397/400) which was calculated by counting the agreed decision for each paper. After screening, full manuscripts of potentially relevant studies were obtained. Two researchers (SA and SC) independently assessed all potentially relevant studies against the inclusion criteria, with discrepancies resolved through discussion and arbitration with a third researcher (EB).

3.4. Quality assessment

Two reviewers (SA and EB for the quantitative studies and SA and SC for the qualitative studies) assessed independently the quality of each paper using established instruments for each study design. The quality assessment tools were: the Cochrane Tool for assessment of risk of bias (for randomised trials) (Higgins and Green, 2009), the Critical Appraisal Skills Programme criteria for assessing qualitative studies (Public Health Resource Unit, 2006), and an adapted eight-item version of the 'Quality criteria for critical appraisal of observational studies' (for other types of studies) (Petticrew and Roberts, 2006). Discrepancies between reviewers were reconciled through discussion.

3.5. Data extraction

Data extraction was undertaken by the first author (SA), and also independently by one other researcher (EB for quantitative studies and SC for qualitative studies). Discrepancies were resolved by discussion and arbitration from a third reviewer (SC/EB).

In order to compare quantitative studies with a comparison group, the standardised mean difference was calculated for each study outcome (The Cochrane Collaboration, 2009). Stigma-related outcomes of the studies were divided into three categories: social distance, attitudes, and empathy on the basis of the types of stigma-related outcome found in the included studies. For quantitative observational studies without a comparison group, relevant statistical information was extracted. Data from qualitative studies were extracted using the meta-ethnographic approach (Noblit and Hare, 1988) in which concepts and interpretations in the individual studies are identified by repeated reading and extracted. Authors of the included studies were contacted to provide clarifications about issues relating to quality criteria and unclear data.

3.6. Synthesis of evidence

Characteristics of the studies and interventions were tabulated. Within each research question, synthesis of extracted data was undertaken separately for each type of study. For quantitative studies with a comparison group, due to the diverse interventions and outcome scales, synthesis of the standardised mean difference