Psychology, Health & Medicine, 2013
Vol. 18, No. 2, 242–249, http://dx.doi.org/10.1080/13548506.2012.701753

Routledge
Taylor & Francis Group

Challenging stereotypes and changing attitudes: Improving quality of care for people with hepatitis C through Positive Speakers programs

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(*Received 19 December 2011; final version received 7 June 2012*)

Positive Speakers programs consist of people who are trained to speak publicly about their illness. The focus of these programs, especially with stigmatised illnesses such as hepatitis C (HCV), is to inform others of the speakers' experiences, thereby humanising the illness and reducing ignorance associated with the disease. This qualitative research aimed to understand the perceived impact of Positive Speakers programs on changing audience members' attitudes towards people with HCV. Interviews were conducted with nine Positive Speakers and 16 of their audience members to assess the way in which these sessions were perceived by both speakers and the audience to challenge stereotypes and stigma associated with HCV and promote positive attitude change amongst the audience. Data were analysed using Intergroup Contact Theory to frame the analysis with a focus on whether the program met the optimal conditions to promote attitude change. Findings suggest that there are a number of vital components to this Positive Speakers program which ensures that the program meets the requirements for successful and equitable intergroup contact. This Positive Speakers program thereby helps to deconstruct stereotypes about people with HCV, while simultaneously increasing positive attitudes among audience members with the ultimate aim of improving quality of health care and treatment for people with HCV.

Keywords: positive speaker programs; hepatitis C; public health; stereotypes; stigma

Introduction

Positive Speaking typically involves the use of individuals diagnosed with an illness as a "professional public education resource" (Finn & Sarangi, 2009, p. 48). A key benefit associated with Positive Speaking is learning about the speaker's experience of the illness thereby reducing ignorance about the disease (Paxton, 2002). This is particularly relevant to stigmatised illnesses such as HIV/AIDS or hepatitis C (HCV). Stigma has been defined as an attribute that is "deeply discrediting" (Goffman, 1963, p. 12), whereby the undesirable attribute or stereotype is linked to the stigmatised group (Jones, Scott, & Markus, 1984). People who are stigmatised are often labelled as different and structures put in place to protect the majority from

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this perceived negative attribute (Gilmore, 1996; Parker & Aggleton, 2003). Hepatitis C (HCV) is an illness that attracts a large amount of stigma because of the legal and moral trepidation associated with injecting drug use (Earnshaw & Chaudoir, 2009). It is possible that Positive Speaking could help to dilute stereotypes associated with HCV by putting a human face to the illnesses.

Previous research investigating the effect of Positive Speakers can be understood by examining the Contact Hypothesis or Intergroup Contact Theory. The rationale behind Intergroup Contact Theory is that under appropriate conditions, interpersonal contact is one of the most effective ways to reduce prejudice between majority and minority group members (Allport, 1954). This theory suggests that if the majority of group members have the opportunity to communicate, and learn sufficient new information about the minority this will result in a greater appreciation of the minority and ultimately lead to positive attitude change (Pettigrew, 1998). However, for such dissonance between "old prejudices and new behaviour" to be sufficient motivation for revising attitudes, contact must generate an affective tie towards minority group members and also meet particular optimal conditions of equal group status, common goals, inter-group cooperation, and authority support (Amir, 1976; Pettigrew, 1998). If these conditions are not met, prejudice between majority and minority group members may not vary (Pettigrew, 1998). The majority of research on Intergroup Contact Theory has focused on interracial prejudice and discrimination (Bullock, 1978; Deutsch & Collins, 1951; McKay & Pitman, 1993). However, there has also been some research on other stigmatised groups (Herek & Capitanio, 1996; Werth & Lord, 1992). Bermingham and Kippax (1998) found that discriminatory behaviours by general practitioners decreased as contact with people with HIV increased. Hence based on the premises of Intergroup Contact Theory, Positive Speaker programs may be an important mechanism to change stigmatised attitudes but may only be effective if the required optimal conditions of intergroup contact are adequately met.

The stigma associated with HCV and injecting drug use has been found to have implications for the well-being of people with HCV (Segerstrom & Miller 2004), their access to health care (Brener, von Hippel, von Hippel, Resnick, & Treloar, 2010; Link & Phelan, 2006) and their treatment outcomes (Brener et al., 2010). Hence is it important to develop strategies to reduce this stigma especially within the health care sector. The *Ceen & Heard* (*C&H*) Positive Speakers program provides a service in which trained speakers talk about their personal experiences of living with HCV to audiences such as health care, community, youth and corrective services workers. The service aims to deepen the understanding of the reality of living with HCV; improve attitudes and decrease discrimination towards people with HCV and increase the quality of life of people with HCV. The program is marketed as a Hepatitis C Education Program with a Positive Speakers component. It began in 2002 and currently has 14 speakers. Speakers attend two days of training facilitated by experienced speakers using a peer education model, and then have ongoing training and support by Hepatitis NSW. Each session consists of an education component and then a talk of approximately 20 minutes by a Positive Speaker followed by an opportunity for questions. The speaker is accompanied by a Hepatitis NSW staff member who often conducts the education session part of the program but is also there for support, debriefing and facilitation.

The current research aims to qualitatively assess the perceived influence of the Positive Speakers program on audience members from the point of view of both the

speakers and the audience. Further the research aims to establish whether attending a Positive Speakers session was perceived by speakers and audience members as providing contact which met the optimal conditions of Intergroup Contact Theory to promote positive attitude change among audience members towards people with HCV.

Methods

Sample

Nine *C&H* Speakers, six female and three male, were interviewed. Their mean age was 49 (range 35–58 years). The majority of speakers had been involved since the program's inception and had been Positive Speakers for over eight years.

The audience sample consisted of 16 people who had attended a *C&H* Education Session within the three months between March and May 2011. Audience participants were 12 women and four men, with a mean age of 44 (range 25–61 years). They occupied various positions from nursing ($n = 6$), health promotion ($n = 3$), Aboriginal health ($n = 3$), youth worker ($n = 2$) and dentistry ($n = 2$).

Procedure

Speakers were informed of the study and all contacted agreed to participate. Interviews focused on knowledge and experience of stigma and discrimination and experiences of being a *C&H* Speaker. Questions were framed around concepts relating to optimal intergroup contact, by addressing what speakers felt contributed to their ability to impact on the attitudes of the audience. Interviews lasted approximately one hour were audiotaped and transcribed verbatim. The transcripts were de-identified, checked for accuracy and pseudonyms were assigned. Speakers were reimbursed AU$60 for their involvement the study.

Five of the nine speakers had recently spoken at an education session and audience members were chosen to be interviewed from these sessions, to ensure recent experience and to assess the reports of speakers in relation to their audience members. At the end of the education session, the audience was notified of the study and asked to provide their contact details should they be willing to participate. Sixteen audience members were interviewed between March and July 2011. Interview questions were framed to elicit issues reflecting Intergroup Contact Theory especially around the conditions that make contact optimal for attitude change. The interview also focused on establishing changes in attitudes after listening to the speaker and lasted approximately 30 min. Interviews were audiotaped, transcribed verbatim and the transcripts were checked for accuracy and de-identified. Pseudonyms were assigned to participants. Audience members were sent a gift voucher of AU$30 to thank them for their participation. This research was approved by the Human Research Ethics Committee at the University of New South Wales.

Data analysis

The researchers conducted close readings of the transcripts using Intergroup Contact Theory to frame and guide identification of key themes related to the perceived impact of the Positive Speakers program on both audience members and speakers. Results are themed around the impact of the *C&H* Program in changing the attitudes

of audience members through contact between speakers and audience members based on the premises of Intergroup Contact Theory – that speakers and audience are of equal status, that speakers are seen by the audience as skilled educators, that speakers are perceived of as similar to audience members and that the audience is receptive to the speaker's messages. The results and discussion section will highlight how these factors contribute to speakers' successful attempts to deconstruct stereotypes and challenge the stigma associated with HCV.

Results and discussion

The impact of Positive Speakers on attitudes towards people with HCV

Audience members acknowledged that their experience at the *C&H* session had an impact on their attitudes and opinions by making them more aware of stereotypes and how these may impact on their clients. Attending the Positive Speaker session appeared to encourage attendees to reflect on their own attitudes and behaviours towards their clients with HCV, and they suggested that this would make them more sensitive to the way they interact with these clients

> ... I think every time you have to stop and think about what it is you're doing, how you are presenting yourself to these patients, it's got to be a good thing if its making you have a thought as to how you're wording questions, how you are approaching them, whether you are maintaining their confidentiality, which of course everyone is supposed to, but. ...we know that it just doesn't always happen and so I think just when people are being made to think about it, it's a good reflection on practice. (Amy, sexual health nurse)

Later in the interview Amy, a sexual health nurse at a correctional facility, goes on to give a particularly poignant example of the impact of the Positive Speakers in promoting a change in attitude towards people with HCV and how such changes may impact on quality of care offered to people with HCV,

> ... to a large extent, these people get tainted with the notion that they are just a junkie, that's how you got your hep C just from drug using, so you're not really a very good person kind of thing... A lot of staff just regard patients as that, just junkies and 'why are you bothering having treatment because you are only going to re-inject and re-infect yourself?' So it's very hard to get over those mental attitudes. Positive speakers can really do that I think. (Amy, sexual health nurse)

For speakers that their talks could result in any potential changes in audience members' attitudes was very meaningful to them. Being able to discuss their own experiences in the health care sector and highlight stigma and discrimination while simultaneously presenting themselves as skilled and professional educators gave these speakers a real sense of being able to make a difference however small, as Sarah states

> ... if I can change the way they treat their patients, if it's only one, I've achieved something. I have had very bad treatment from some doctors and also from some registrars and some nurses. And if I can stop one patient from being treated like that, you know if it takes me 100 or 200 talks, if I can stop one being treated like that, then I've achieved what I set out to do. (Sarah, speaker of eight years)

Being a positive speaker allowed speakers to feel that they could play a role in improving the quality of health care afforded to people with HCV. Speakers mentioned how empowered they felt at having the opportunity to provide honest

information about themselves and their experiences to audience members so that the impact that HCV has on the lives of those affected was properly understood. Similarly, audience members felt that they attended these sessions to acquire more information about HCV which would enable them to work better with their client group. Many audience and speaker participants felt that it was ignorance about the disease that fuelled fear and prejudice amongst health care workers. Humanising the experiences of people with HCV, by challenging stereotypes and presenting it as a complex chronic and debilitating disease, was thought by speakers to aid audience members to better understand the hardships faced by people with HCV and ultimately improve quality of care.

Conditions for optimal intergroup contact

Speakers as skilled educators

That speakers were presented as professional, skilled and very knowledgeable about HCV was seen by audience members and speakers alike to contribute to deconstructing the stereotypes associated with people who acquired HCV. As Jessica says:

> It was just the most wonderful experience cause I got to talk about my experience from both sides of the story, as an educator and as someone who lives with it and got to say how I'm exhausted and get nauseous and sick and to put across that, you know, people who are quite often looking for some support in terms of financial benefits, are actually really ill but they mightn't... look really ill... I remember the Centrelink guy [audience] going 'Oh my god, I'd never thought of that. I just thought they were lazy old junkies' (Jessica, speaker of nine years)

In one reported instance, a speaker was able to directly confront the negative attitude of an audience member. Sarah, who prior to conducting her positive speaking session was sitting in the audience during the HCV education discussion, was confronted by an experience of prejudice from an audience member. She expressed satisfaction at having the opportunity to ''expose'' herself as a Positive Speaker and hence challenge stereotypes held by the audience member:

> We were discussing testing when they come into a prison environment, testing for hepatitis C and he [audience member] said 'they all should have it tattooed across their forehead' and he said this to me and one of the other educators, ...the look on her face ....she was horrified, she was like 'oh my god, what's Sarah going to do?' She didn't know if I was going to run screaming from the room, and I said to him 'why should they have it tattooed on their forehead, what's with that', and he said 'because they're all infectious' and I went 'oh really?', so I made sure then 15 seconds later, when I started my presentation, I started it right in front of him, slammed my hands on the desk and said 'when I was diagnosed ...' and he shrunk down in his chair and you could see that 'I just want to die look on his face'. (Sarah, speaker of eight years)

Sarah stated that she felt that being able to directly and immediately address this audience member's prejudicial attitudes in a very an open but supportive environment, would hopefully lead to a reappraisal of his beliefs about people with HCV.

Similarities between speaker and audience

Speakers felt that they were able to address stigma and discrimination by presenting themselves as similar to the audience. This often entailed making the audience aware

that a person with HCV could be their relative or friend so that the audience could identify with the speaker.

> I think that because there's a face that they can connect to the reality of the disease rather than just say 'oh it's people who inject drugs and we don't like them, you know, for a whole range of reasons'. I think actually having a person who could be their daughter or who could be their mother or who could be their dad .... I think when a group hears someone they can relate to in a way they can know who the person really is, it's not just a figure on the paper it's actually a real person sitting in the room with them who's brave enough to tell their story. I think it suddenly becomes real in a very different way for an audience. (Renee, senior health promotion officer)

Connecting with the audience also involved playing on similarities between speakers and audience members by presenting issues in relation to their jobs, their children or families so that audience members would be able to identify with them. For Rebecca, a nurse at a correctional facility, it was seeing this Positive Speaker and connecting them with a family and broader life circumstances that helped to reframe her perceptions of people with HCV.

> Well it's actually seeing the person. I mean, she didn't look like a junkie, she didn't speak like one, she was quite you know ....she knew what she was talking about, her experiences, she had a family. You know, these aren't just street people, they've got families and things and she's come out of the situation that she was in and she's changed her life. (Rebecca, nurse)

Audience receptiveness

Speakers felt that their experience of being a *C&H* Speaker was very empowering because their courage to tell their story was recognised and valued. Part of the benefit was that speakers developed confidence to speak about their experiences in front of a largely receptive audience. Audience members echoed these feelings by noting the courage and strength displayed by speakers to tell their story in front of an audience.

Kate reflected on the dual dynamic between speaker and audience as contributing to audience engagement and successful outcomes:

> ... but it was all the health care workers, which were all very willing to learn and they were very interested. They asked a lot of questions and yeah, very interested in how ....you were coping from day to day and how I feel in my life with family and friends and all of that, ...and they all seemed they really wanted to help the [prison] inmates try to adjust and help them with discrimination and settling into the community and everything. So again, it was positive because they were really interested and asked a lot. (Kate, speaker of nine years)

Similarly, all audience members interviewed noted that they wanted to attend the presentation and thought the experience was very valuable. The audience members generally felt that the speakers were very knowledgeable, competent and skilled. They perceived speakers to be open and honest about their experiences and as a result were receptive to audience questions.

Conclusions

The data above illustrates the significant impact that this Positive Speakers program is reported to have on the audience by both speakers and audience members. Speakers set out to challenge stereotypes and reduce stigma and audience members acknowledge the impact that these talks have in changing their understanding of

people with HCV, increasing compassion and ultimately improving quality of care. Despite the limitation in this study of the inherent bias in the self-selected audience sample, the *C&H* program demonstrates success at the very least with this group of audience members. Although research on Positive Speaker programs for those with a stigmatised illness is scant, previous studies do suggest the effectiveness of this approach in reducing stigma and increasing positive attitudes towards people living with a stigmatised illness (Bermingham & Kippax, 1998; Herek & Capitanio, 1996; Werth & Lord, 1992). To the authors' knowledge, this study is unique in capturing both speaker and audience views of the Positive Speaker program, hence providing greater insight into the aspects of this program that have contributed to its success.

As proposed by Intergroup Contact Theory, the contact afforded by this Positive Speakers program meets the optimal conditions of equal group status, common goals, intergroup cooperation and authority support (Pettigrew, 1998; Schiappa, Gregg, & Hewes, 2005). A key element in determining the success of the program is that speakers are viewed by audience members as trained professionals of equal status, well supported by Hepatitis NSW. Hence, their level of skill as a speaker and their knowledge of HCV as educators is trusted and valued by their audience. Speakers' stories are structured through their training in such a way so that audience members are able to identify with the speaker, making experiences of stigma and discrimination more real to the audience. Audience receptiveness to attending the program and to the speaker is also crucial in understanding the success of the program. It would be difficult to change the attitudes of people who do not want to attend these talks or who do not recognise speakers as experts in their own right. Ultimately, by choosing to attend these workshops, the audience members are working towards the same goals as the speakers, promoting good quality of care for people with HCV (Pettigrew, 1998). Additionally, these audience members work in environments where they have on-going contact with people with HCV. This prolonged contact and continuing care for their clients with HCV affords the opportunity to develop affective ties between workers and their clients, a further essential component to positive intergroup contact (Pettigrew, 1998; Rothbart & John, 1985); although an important addition to this study would be to assess audience attitudes towards people with HCV over time. The data in this study would also have been well supplemented with the use of a quantitative measure of attitudes pre and post the *C&H* session in order to provide a more quantifiable reflection of attitude change.

Nonetheless, the qualitative data from this study provides sufficient evidence to suggest that it is through this experience of intergroup contact with Positive Speakers, that audience members report being better able to understand the experiences of people with HCV, reflect upon their attitudes; and hopefully provide better quality health care to people living with HCV. Positive speaking may, therefore, be viewed as a dynamic and interactive mechanism to decrease stigma and effect attitude change, especially within health care contexts through the experience of positive intergroup contact. As this research shows, such a favourable outcome is most likely with receptive audience members encountering skilled and well-trained members of the stigmatised group in an encouraging, supportive and well-managed context.

Acknowledgements

Funding for this research was provided by Hepatitis NSW. The researchers would also like to thank all of the study participants who gave their time to take part in this research.

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