

Linking Stigma to Psychological Distress: Testing a Social–Cognitive Model of the Experience of People with Intellectual Disabilities

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In this study we explore the link between the social experience of people with intellectual disabilities and core cognitive process that have previously been shown to be related to a range of psychological disorders. Thirty-nine people with intellectual disabilities completed self-report scales measuring the perception of stigma, core negative evaluations and social comparison. Correlation analysis suggests that core negative evaluative beliefs about the self are positively associated with the experience of feeling different: a process that could be described as internalizing the experienced stigma. Relationships were also found between negative self-evaluations and the social attractiveness dimension of the social comparison scale. Using regression techniques stigma was found to have an impact on social comparison processes that was mediated by evaluative beliefs. These findings support a social–cognitive view of the importance of the social world to people with an intellectual disability, and the psychological damage that stigmatization can cause. We discuss interventions that integrate both social and cognitive domains. Copyright © 2004 John Wiley & Sons, Ltd.

INTRODUCTION

The evidence to support the use of cognitive behaviour therapy with people with intellectual disabilities is growing and largely positive (Kroese et al., 1997; Lindsay, 1999). It has been used to treat

a range of psychological problems, such as anxiety (Lindsay, Neilson, & Lawrenson, 1997), depression (Lindsay, Howells, & Pitcaithly, 1993; Dagnan & Chadwick, 1997) and anger (Black, Cullen, & Novaco, 1997; Benson, 1994; Black & Novaco, 1993). It has also been shown that processes that underlie psychological disorders in people without an intellectual disability can be identified in people with intellectual disabilities. For example, factors such as low self-esteem (Dagnan & Sandhu, 1999), 'negative self-concept' (Benson & Ivins, 1992), negative social comparisons (Dagnan & Sandhu, 1999), feelings of hopelessness (Nezu, Nezu, Rothenburg,

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DelliCarpini, & Groag, 1995), and poor social support (Reiss & Benson, 1985) have all been identified as related to psychological distress in people with intellectual disabilities.

As cognitive models are increasingly applied to people with intellectual disabilities it is important to consider the theoretical and clinical implications of the shift towards individual therapeutic models for people with intellectual disabilities and their services. In the past 30 years the functions of emotional and behavioural distress of people with intellectual disabilities have been searched for in the environment. It has been suggested that cognitive models (and other psychological models) tend to locate the source of distress within the individual and so run the risk of blaming the individual for their difficulties (Shakespeare & Watson, 1997). Social models of disability suggest that because of negative social constructions or restrictive social structures people with intellectual disabilities experience an increased number of negative life experiences and generally reduced opportunities to develop social networks, find rewarding work and engage in key life events such as leaving home, getting married and having children (Chappell, 1998; Chappell, Goodley, & Lawthom, 2001).

This tension between social and individual models has been recognized and there are examples of intellectual disability researchers who are beginning to integrate social factors into the individual therapeutic models that they use to understand the experiences of people with an intellectual disability (Szivos-Bach, 1993; Szivos & Griffiths, 1990; Jahoda, Pert, Squire, & Trower, 1999; Dagnan & Sandhu, 1999). For example, Szivos-Bach (1993) found that increased awareness of stigmatization was associated with low self-esteem in adolescents with intellectual disabilities. Social models suggest that the construction of intellectual disability leads to stigmatization (Goffman, 1961). A psychological perspective would suggest that when stigmatization is recognized by a person with an intellectual disability this may have negative consequences on an individual's psychological well-being. This core link between social experience and psychological well-being can be modelled from a variety of theoretical perspectives. If cognitive therapy is to be used appropriately with people with intellectual disabilities, models and interventions should emphasize the central role played by social conditions and social processes in shaping fundamental evaluations, attributions and meaning.

Cognitive theory proposes that the key cognitive processes that mediate psychological distress are

schematic or evaluative. Evaluations or 'hot cognitions' can be defined as 'preferences' (Zajonc, 1980) and are distinguished from 'inferences' in that inferences are assertions that are fundamentally true or false. A number of theorists have suggested that disturbances in emotions or behaviour are a consequence of evaluations (or appraisals) rather than inferences (Ellis, 1994; Lazarus & Folkman, 1984; Zajonc, 1980). There is also a broad consensus that the most powerful evaluations in generating disturbances in emotions and behaviour are those that are social and that concern the self (Oatley & Johnson-Laird, 1987; Ellis, 1994; Beck, 1987; Chadwick, Trower, Dagnan, 1999). Chadwick et al. (1999) suggest that person evaluations can be considered on three broad dimensions: evaluations that people make about themselves, which they label 'self-self evaluations' (e.g. 'I am a bad person'); evaluations people experience other people making about them, which they label 'other-self evaluations' (e.g. 'Other people think I am a bad person'), and evaluations made about other people, which they label 'self-other evaluations' (e.g. 'Other people are bad'). A number of writers have suggested that the evaluations people make about themselves can play a major role in the development of psychological distress (Ellis, 1994; Smith, Haynes, Lazarus, & Pope, 1993; Chadwick et al., 1999).

Cognitive theory further suggests that core evaluations are functional in determining inferences. In this paper we suggest that negative person evaluations can be demonstrated in a variety of inferential cognitive processes. In particular we are interested in social comparison as a core, socially oriented, inferential process that has been identified as applicable to people with intellectual disabilities (Dagnan & Sandhu, 1999; Szivos-Bach, 1993; Gibbons, 1985; Finlay & Lyons, 2000). Social comparison is described as a process through which people actively maintain their self-worth (Festinger, 1954). It has been found that when people's self-esteem is at risk they may make *downward comparisons* with others who perform less well on a chosen attribute or lateral comparisons with those of a similar ability (Wills, 1981). People with higher self-esteem are more likely to make *upward comparisons* with people who are more able on a given attribute in order to increase their motivation to improve their functioning in these areas (see e.g. Suls & Wills, 1991; Taylor & Brown, 1988). In a qualitative study Finlay and Lyons (2000) found that the majority of their study group of people with intellectual disabilities used

downward and lateral comparisons. They suggest that this was a process that enabled members of a stigmatized group to construct a positive sense of self.

Dagnan and Sandhu (1999) studied social comparison in relation to depression in people with intellectual disabilities using an adaptation of the Social Comparison Scale by Allen and Gilbert (1995). The Social Comparison Scale offers subscales for social comparison on dimensions of social attractiveness, achievement and group belonging. Overall significant associations were found between negative social comparisons and higher depression scores. Regression analyses showed a significant independent predictor of depression to be the social attractiveness dimension of social comparison. The process of social comparison (Festinger, 1954) has been linked to psychological distress in a number of studies (Swallow & Kuiper, 1988; Allen & Gilbert, 1995; Szivos-Bach, 1993; Dagnan & Sandhu, 1999), but as yet has not been directly related to evaluative beliefs in this population. In this study we report data describing the link between the perception of stigma, core negative evaluations and social comparison for people with intellectual disabilities. The hypotheses tested in this study predict that both the perception of stigma and negative evaluations will be associated with negative social comparisons. The cognitive model would specifically suggest that environmental experience will shape core evaluations, which in turn will shape inferential cognitions. Thus we predict that negative evaluations will mediate the effect of perceived stigma on social comparison.

METHOD

Participants

Participants were recruited from three day centres and a supported employment programme. Service users who could use and understand short sentences were identified by carers and invited to take part in a consent interview in accordance with the process outlined by Arscott, Dagnan, and Kroese (1998). Fifty-two people were approached to take part; 39 gave informed consent to take part, seven refused to take part and six were unable to fully understand the consent procedure. Twenty-one (54%) of participants were men and 18 (46%) were women. The group had a mean age of 38.0 years (SD = 9.6; range 23–65 years). Twenty-nine (74%) participants lived in their family home, five (13%)

lived in staffed houses and five (13%) lived independently. Thirteen (33%) participants attended a day centre full time, nine (23%) worked full time in some form of supported employment and the remaining 17 (44%) worked part-time and attended the day centre part-time.

Measures

Participants first completed the British Picture Vocabulary Scales—II (Dunn, Dunn, Whetton, & Burley, 1997), a measure of receptive language ability. The following measures were then administered using a Latin square structure to avoid any order effects.

1. *Stigma Scale* (Szivos, 1991; Szivos-Bach, 1993). This 10 item scale assesses participants' perceptions of their own stigmatization and was developed for use with adolescents with intellectual disabilities. Szivos (1991) reports that the scale has good internal validity with item–total correlations ranging from 0.34 to 0.62 and a scale alpha of 0.81. Alpha and item–total correlations were calculated for the present sample; standardized alpha for the full scale = 0.75 and mean item–total correlation for the scale = 0.42 (range 0.22–0.57). Szivos (1991) reports factor analysis of the scale that indicates that it has three factors, labelled as (i) Feeling Different, (ii) Anxiety and (iii) Poor In-Group Concept. In the present study the scale was administered by presenting each item on a separate A4 sheet in large print. Participants were asked to rate how much they agreed with the statements when applied to themselves, using five-point visual analogues as well as written and spoken response options. These involved drawn blocks of increasing size with the words, 'never true', 'hardly ever true', 'sometimes true', 'often true' and 'always true' underneath them. These responses were given a score from 0 to 4 with higher scores representing greater awareness of stigma.
2. *Evaluative Beliefs Scale* (Chadwick et al., 1999). This scale has not previously been used with people with intellectual disabilities. However it has a simple grammatical structure that suggests it should be directly applicable to people with intellectual disabilities. The original scale has 18 negative person evaluations that are defined as 'stable, global and entirely condemning of either oneself or another'; the three subscales are made up of negative evaluations

made of oneself (self–self), that are perceived as being made by others (other–self) and that one makes about others (other–self). In previous use with people without an intellectual disability (Chadwick et al., 1999) the ‘self–self’ and ‘other–self’ subscales were strongly related to anxiety and depression; only these two subscales were used in the current paper. The scale was presented with the same response formats as described for the stigma scale. Dagnan, Wearing, and McDowell (submitted for publication) report a psychometric structure for the two-subscale version of the scale described above based upon analysis of 75 completed questionnaires from participants with mild intellectual disabilities; the larger data set includes the participants in the current study. The analysis finds a two-factor structure, consistent with the intended scales. The self–self scale has a standardized alpha of 0.62, with a mean item–total correlation of 0.35 (range 0.25–0.63); the self–other scale has a standardized alpha of 0.80 with a mean item–total correlation of 0.55 (range 0.46–0.65).

3. *The Social Comparison Scale* (Allen & Gilbert, 1995; Dagnan & Sandhu, 1999). This six item scale assesses how participants see themselves in relation to others along three separate dimensions: (i) achievement, (ii) social attractiveness and (iii) perceived group membership. They are presented with the incomplete sentence ‘When I am with other people I generally feel’, followed by six bipolar constructs: worse than other people–better than other people; not as good at things–better at things; less friendly–more friendly; less shy–more shy; on my own–part of the group; different–the same. Each statement is presented on a single sheet of A4 paper with a 10cm visual analogue. Each participant was asked to point to where thought they lay along this line for each of the six bipolar constructs; the analogue line was divided into five 2cm segments and a score between 0 and 4 was assigned to each response on this basis. The use of this type of visual analogue scale has been shown to be an effective assessment method for people with intellectual disabilities (Dagnan & Ruddick, 1995). Dagnan & Sandhu (1999) report alpha for the scale of 0.56, with a mean item–total correlation of 0.28. Alpha and item–total correlations were calculated for the present sample; the full scale has a standardized alpha of 0.55 with a mean item–total correlation of 0.40 (range 0.81–0.50).

Table 1. Means and standard deviations for total and subscale scores for Perceived Stigma, Negative Evaluative Beliefs, Social Comparison and Self-Esteem

Variable	Mean	Std/dev.
Total Evaluative Beliefs	9.33	8.33
Self–Self Scale	4.85	4.56
Other–Self Scale	4.59	4.70
Total Social Comparison	16.82	5.39
Social Comparison: Achievement	6.49	2.25
Social Comparison: Social	8.03	3.60
Social Comparison: Group Belonging	2.26	1.90
Stigma	15.26	8.41
Feeling Different	5.56	3.54
Anxiety	5.13	3.18
Poor In-Group Concept	4.56	3.78

Information letters were sent to relatives and carers of the identified participants before they were invited to take part in a consent interview. In addition, each participant was provided with information about the research project as part of the consent procedure. A procedure for managing unexpected disclosures or distress following the interview was drawn up, and was implemented on one occasion.

RESULTS

The means and standard deviations for the total and subscale scores for the stigma Scale, the Negative Evaluative Beliefs Scale and the Social Comparison Scale are shown in Table 1.

A series of *t*-tests was carried out to examine whether there were any significant differences in these scale scores due to gender, age, or work versus day centre placement. The only significant difference was that participants who lived in staffed houses showed significantly higher scores on the Stigma Scale than those who lived with family members or lived independently; however, when BPVS scores were entered as a co-variant, this effect disappeared. This suggests that any differences in scores between settings are due to the characteristics of the people in the settings rather than a product of the setting itself.

The relationship between the Stigma Scale, Negative Evaluative Beliefs and Social Comparison were examined using bivariate correlations. These are shown in Table 2. The correlations suggest a strong general relationship between perceived

Table 2. Correlations of total and subscale scores for recognition of stigma with total and subscale scores for Negative Evaluative Beliefs, Social Comparison and Self-Esteem

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Total Stigma Score		0.79	0.83	0.79	<u>0.55</u>	<u>0.46</u>	<u>0.41</u>	<u>-0.40</u>	-0.01	<u>-0.45</u>	-0.19
2. Stigma Feeling Different			0.56	<u>0.36</u>	<u>0.50</u>	<u>0.50</u>	<u>0.41</u>	<u>-0.36</u>	-0.21	-0.31	-0.09
3. Stigma Anxiety				<u>0.47</u>	<u>0.41</u>	0.30	<u>0.42</u>	<u>-0.48</u>	-0.09	-0.52	-0.26
4. Stigma Poor In-Group Concept					<u>0.41</u>	0.31	<u>0.43</u>	-0.15	0.09	-0.26	-0.05
5. Total Negative Evaluative Beliefs						0.90	0.91	<u>-0.46</u>	-0.14	<u>-0.48</u>	-0.21
6. Self-Self Evaluative Beliefs							0.63	<u>-0.36</u>	-0.05	<u>-0.04</u>	-0.19
7. Other-Self Evaluative Beliefs								<u>-0.46</u>	-0.19	<u>-0.46</u>	-0.18
8. Total Social Comparison Scale									0.54	0.88	<u>0.51</u>
9. Social Comparison: Achievement										0.23	-0.12
10. Social Comparison: Social											0.32
11. Social Comparison: Group Belonging											

Figures in bold $p < 0.01$; figures underlined $p < 0.05$.

Table 3. Regression analyses demonstrating mediating role for Evaluative Beliefs between Stigma and Social Comparison

Regression	B	Standard error of B	Beta	t	P
<i>Dependent variable (Social Comparison) onto independent variable (Stigma)</i>					
Stigma	-0.27	0.10	-0.42	-2.80	0.008
<i>Mediator (Evaluative Beliefs) onto independent variable (Stigma)</i>					
Evaluative Beliefs	0.56	0.15	0.55	3.82	0.001
<i>Dependent variable (Social Comparison) onto both independent variable (Stigma) and mediator (Evaluative Beliefs)</i>					
Stigma	-0.14	0.11	-0.22	-1.27	0.212
Evaluative Beliefs	-0.23	0.11	-0.35	-2.03	0.040

stigma and negative evaluative beliefs and a somewhat weaker relationship between stigma and social comparison.

The social-cognitive model described in the introduction suggests that from a cognitive perspective negative evaluative beliefs are core cognitive structures and that the impact of perceived stigma on inferential beliefs, such as social comparison, can be seen as being mediated by negative evaluative beliefs.

The mediative role for negative evaluative beliefs between stigma and social comparison was tested using only the total scale scores. Following the approach described for testing mediative relationships described by Baron and Kenny (1986) and Holmbeck (1997) three regressions are calculated. The first is the regression of the mediator (Total Evaluative Beliefs) onto the independent variable (Total Stigma); the second is the regression of the dependent variable (Total Social Comparison) onto the independent variable (Total Stigma) and finally the dependent variable (Total Social Comparison) is regressed onto both the mediator (Evaluative

Beliefs) and the independent variable (Stigma). A mediative relationship is established if the independent variable significantly predicts the mediator in the first equation, the independent variable predicts the dependent variable in the second equation and the mediator predicts the dependent variable in the third equation. If the effect of the independent variable is less in the third equation than it was in the second equation then mediation is demonstrated; perfect mediation is demonstrated if the effect of the independent variable in the third equation is reduced to a non-significant level. Table 3 shows the results of these regression analyses. When Evaluative Beliefs is regressed onto Stigma, Stigma is highly predictive of Evaluative Beliefs ($F(1, 37) = 16.52$; $p < 0.001$; adjusted $R^2 = 0.29$). When Social Comparison is regressed onto Stigma, Stigma is highly predictive of Social Comparison ($F(1, 37) = 6.5$; $p < 0.01$; adj. $R^2 = 0.16$). When Social Comparison and Evaluative Beliefs are regressed onto Social Comparison simultaneously, they have a significant overall predictive effect ($F(2, 36) = 6.22$; $p = 0.005$; adj. $R^2 = 0.21$). The results

suggest that Stigma is a significant predictor of Social Comparison when regressed on its own, but this effect is reduced to a non-significant level when considered alongside Evaluative Beliefs. This suggests that Evaluative Beliefs do mediate the predictive strength of Stigma on Social Comparison.

DISCUSSION

The findings of this study support the assertion that the perception of stigma is associated with evaluative and inferential cognitive processes. The correlations presented show relationships between the subscales of the three main scales and offer important insights into the process and impact of perceived stigma. Each of the stigma scales is correlated with the other-self scale of the negative evaluative beliefs scale; however, the 'feeling different' subscale of the stigma scale is the only stigma subscale correlated with the self-self scale from the negative evaluative beliefs scale. This suggests that core negative evaluative beliefs about the self are fundamentally related to the experience of feeling different: a process that could be described as internalizing the experienced stigma. Both the self-self and other-self subscales from the negative evaluative beliefs scale are correlated with the social attractiveness scale from the social comparison scale; however, this is the only social comparison subscale that correlates with negative evaluative beliefs. These findings suggest a core relationship between recognizing oneself as stigmatized, negative self-evaluations and the social attractiveness dimension of the social comparison scale. In fact the data support the general cognitive model that suggests that inferential cognitions are functionally mediated by core evaluative cognitions. Using total scale scores, stigma was found to predict negative evaluative beliefs, which in turn were found to predict social comparison. Stigma was found to have a direct impact on social comparison processes mediated by evaluative beliefs. It should be noted that the relationships supported here do not suggest causality or exclude other models that could equally well represent the data. This study, along with others in this area, is cross-sectional and does not demonstrate causality; regression approaches very clearly only demonstrate prediction. The demonstration of causality would require either a carefully controlled longitudinal study or an experimental approach, neither of which have been attempted in studies of core

cognitive-emotional processes in people with intellectual disabilities. The analysis also only shows that the meditative relationship is one possible structure for the presented data; however, the cognitive model described in the introduction very clearly identifies core evaluations as mediative between environmental experience and inferential belief and as such other possible relationships have not been tested in this paper. It is important to note that the internal reliability of the social comparison scale as reported in this study is low. This will result in greater variance within the data set and may result in unreliable or weaker correlations. This scale requires further psychometric development.

The introduction of core evaluations into the cognitive models used with people with intellectual disabilities highlights that there are a number of cognitive schematic processes studied for people without intellectual disabilities that might be particularly important to study in people with intellectual disabilities. For example, much of the work on depression carried out by Beck and colleagues uses the concepts of sociotropy and autonomy (Beck, Epstein, & Harrison, 1983). These concepts are closely linked to notions of dependency and individuation. The experience of being identified as a person with an intellectual disability and being exposed to negative social constructions might heighten individuals' sensitivity to social processes, increasing the likelihood of developing a sociotropic rather than autonomous schema. Given that the sociotropy trait has been shown to be a risk factor for depression (Beck et al., 1983) in people without an intellectual disability, this may provide a further theoretical model for understanding the increased risk of psychological problems in people with an intellectual disability.

Clinically, this study emphasizes the importance of social processes in the psychological experience of people with intellectual disabilities. Social processes are a key part of how individuals develop negative beliefs about themselves, which in turn make them vulnerable to psychological distress. This overview provides clinicians with a coherent model for intervention at a social and individual level. At a social level, the finding that the perception of stigma can lead to negative self-evaluations and distress emphasizes that the quality of the social interactions that people with intellectual disabilities experience is particularly important for their emotional well-being. Social comparison provides a framework for social intervention. A buffer for negative social comparison

has been identified as 'psychological complexity' (Linville, 1987). Psychological complexity suggests that if people make negative comparisons they will have less effect on well-being if they have a wide range of roles and constructs that are of value to them. Thus interventions that increase the roles and activities of people with intellectual disabilities may provide a framework within which cognitive interventions can be developed to reflect positive social interactions. Cognitive interventions for people with intellectual disabilities are likely to need to address fundamental self-evaluations around the issue of disability. Schema focussed work of this type has not been discussed in the intellectual disability literature; however, models for intervention exist and positive schema development would provide a clear focus for therapeutic intervention (Padesky, 1994).

In summary, the findings of the current study have implications for the application of individual psychological models and the social model. By demonstrating a theoretical link between the experience of stigma and psychological distress, these findings support a social cognitive view of the importance of the social world to people with an intellectual disability, and the psychological damage that stigmatization can cause. This provides support for interventions that integrate both social and cognitive domains.

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