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計畫主持人：熊秉荃

計畫參與人員：熊秉荃

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Validation of the Social Impact Scale in patients with HIV infection in Taiwan

Abstract

A cross-sectional study was designed to develop social impact scale (Taiwan version) and evaluate its psychometric properties in order to advance and achieve the full potential of HIV related stigma research in Taiwan and cross-culturally. A total of 206 HIV-infected patients from the outpatient clinic of Taipei Municipal Venereal Disease Control Institute and the inpatient unit of National Taiwan University Hospital participated in this study. Results showed that the psychometric analyses on the Social Impact Scale (Taiwan version) indicate this instrument is reliable and valid generic stigma instrument in patients with HIV infection.

Keywords: social impact scale, HIV, Taiwan

Introduction

The contagious and fatal nature of HIV illness and its association with socially defined deviant and/or immoral behaviors contribute to patients' been stigmatized (Alonzo, 1995). Based on Goffman (1963), stigma is a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons (Alonzo, 1995). Individuals are discredited because they have attributes that do not meet socially accepted standards. Even these attributes may at times not apparent, the stigmatized tend to internalize the social standards and experience self-stigmatization. Therefore, actual experiences of being discriminated against and potential for stigmatization have been recurrent themes that overshadow illness experiences of patients infected with HIV (Moneyham et al., 1996). However, no instrument is available to measure perceived stigma of patients with HIV until recently. The two instruments, one is HIV specific stigma scale (Berger, 2001), the other one, Social Impact Scale, was developed to measure and compare the stigma experience of patients with cancer and with HIV infection (Fife, 2000), are currently available in the literature.

Several reasons highlight the importance of a valid instrument to measure HIV related stigma experienced by patients. First, researchers proposed that stigma is not a static phenomenon but patients experience it differently as they go through various stages of HIV disease (Alonzo, 1995). During the concealable asymptomatic period, patients might not confront with overt prejudice but experience internal fear of rejection and isolation. As the disease progress, signs and symptoms are stigma producing. Patients might experience further psychological isolation, anxiety, and stress. A valid stigma instrument can be used to punctuate how patients experience stigma differently over the illness course of HIV. Secondly, the HIV literature suggests that impacts of stigma on individuals are multiple aspects. Consequences of being stigmatized might include devaluation, isolation, rejection, depression, anxiety, loneliness, decreased self-esteem, and reduced life chances (Katz, 1979; Alonzo, 1995; Berger, 2001; Fife, 2000). Concerns of stigmatization also affect patients' decision of disclosure and interactions with health care systems (Chesney & Smith, 1999, Hsiung, 2000). A valid stigma instrument can be used to capture and verify the relationships between stigma and the abovementioned concepts. Thirdly, efforts to minimize HIV stigma include micro and macro levels' strategies. In the micro level, individuals use a variety of strategies to manage stigmatization (e.g. passing, concealment, information management, withdraw, or challenge)(Goffman, 1963; Alonzo, 1995, Berger, 2001). In the macro level, community efforts have been effective in targeting HIV stigma (Busza, 2001; Gilmore & Somerville, 1994; Taylor, 2001). A valid stigma measurement can be used to test the effectiveness of strategies of stigma management both in micro and macro level. Fourthly, the nature of the two available stigma instruments speaks for their different purposes. One is HIV specific stigma scale (Berger, 2001), the other one is a generic stigma scale (Fife, 2000). The potential of a valid generic stigma scale is that it can be used to compare stigma experiences among different diseases (e.g. HIV disease, cancer, mental disorders, etc). At last, prejudice against patients with HIV seems to occur in western societies as well as other places in the world (Busza, 2001; Hsiung, 1998; Songwathana, 2001). A valid stigma scale can be useful for cross-cultural comparison of patients' stigma experience.

In Taiwan, the available evidence of patients' stigma experience is qualitative and anecdotal evidence (Hsiung, 1998). A valid stigma instrument is needed in order to advance and achieve the full potential of HIV related stigma research in Taiwan and cross-culturally. The purposes of this study were to develop Social Impact Scale (Taiwan version) and evaluate its psychometric properties.

Methods

Development of the Social Impact Scale (Taiwan version)

The Social Impact Scale (SIS) was first translated from English to Chinese by the first author. Then, using the back-translation procedure, a bilingual scholar translated the Taiwan version back into English. Comparisons were made between the two versions. The research team discussed and clarified the minor differences in wording and finalized the Taiwan version of SIS.

Subjects

A total of 206 HIV-infected patients were recruited, and informed consent obtained, from the outpatient clinic of Taipei Municipal Venereal Disease Control Institute and the inpatient unit of National Taiwan University Hospital. These two sites provide comprehensive therapy and services for the majority of patients with HIV infection in Taiwan.

The measures

Social Impact Scale (SIS)

SIS measures patients' perceived stigma to them and to their illness. It includes 24 items and covers 4 subscales: social rejection, financial insecurity, internalized shame, and social isolation. Each item uses a 4-point Likert-type scale, with 1 indicating strongly agree, 4 indicating strongly disagree. A higher score indicates the less sense of being stigmatized.

Self esteem

Rosenberg's Self Esteem Scale (1979) was used to measure patients' self esteem. It includes 10 items using a 4-point, Likert-type scale. After reversing negative items, a higher score indicates more positive feelings of personal worth. Cronbach's alpha coefficient of reliability using these data was 0.86.

Satisfaction of health related quality of life (Sat-HRQOL)

Sat-HRQOL is a single item measure of overall satisfaction of health-related quality of life. Scores range from 0 to 100, with 0 indicating the least satisfactory and 100 the most satisfactory health-related quality of life.

Health status measures

The health status measures used in this study included: (1) the self-perceived health status and self-perceived happiness, both were a single item questions used a 5-point Likert scales. A higher score indicates a favorable state; (2) the number and intensity of HIV-related symptoms were measured using the revised Chinese version of the Sign and Symptom Check-List for Persons with HIV disease (SSC-HIV-CR). This instrument consisted of the original 28 items from the SSC-HIV-C (Tsai YF), plus two additional items, blurred vision and numbness, which were suggested by health care professionals experienced in providing HIV care. Item scoring for the SSC-HIV-CR ranges from 0 to 4, with 0 indicating not having the corresponding

symptom, 1 indicating the least symptom intensity, and 4 the most intensity of the symptom. Cronbach's alpha coefficient of reliability using these data was 0.95.

The authors hypothesized that if SIS accurately captured the perceived stigma of HIV-infected patients, then: (1) the subscale scores should positively correlate with self esteem, Sat-HRQOL, self-perceived health status, and self-perceived happiness, and (2) the subscale scores should inversely correlate with the number and intensity of symptoms.

Statistical analysis

Descriptive statistics, reliability, correlation, Student's t test, the analysis of variance (ANOVA), and factor analyses were run on the data by using SPSS for Windows Version 10.0 and by using LISREL 8.

Results

Characteristics of subjects

The majority of the patients were male (96.1%) with a high school education or more (92.8%). Patients ranged in age from 21–75 years (mean = 35 years, standard deviation = 9.14 years). Most of them (90.8%) were receiving highly active antiretroviral therapy, with current CD4 cell count > 200/mm^3. A high percentage (61.2%) of patients reported experiencing more than 10 symptoms. The characteristics of the 206 HIV-infected patients are summarized in Table 1.

Reliability

The Cronbach alpha of the entire scale was 0.93. The reliability of subscale scores was 0.89 (social rejection), 0.80 (financial insecurity), 0.76 (internalized shame), and 0.86 (social isolation), respectively. The Cronbach alphas demonstrate good internal consistency.

Validity

The range of correlations between item and its subscale was 0.62 to 0.87, and for inter-subscale was 0.37 to 0.80 (all $p<0.0001$, Table 2). It demonstrates that SIS has good content validity. Criterions used to test for criterion-related validity included self esteem, Sat-HRQOL, self-perceived health status, self-perceived happiness, and the number and intensity of HIV-related symptoms. All SIS subscales were positively correlated with self esteem (range 0.23-0.63), Sat-HRQOL (range 0.24-0.55), self-perceived health status (range 0.30-0.55), and self-perceived happiness (range 0.39-0.67) and negatively correlated with numbers of symptoms (range –0.17- –0.51) and intensity of symptoms (range –0.22- –0.52). The statistically significant correlations between subscales with all the criterions (all $p<0.0001$, Table 3) showed that SIS has good criterion validity.

Table 4 shows the SIS scale means broken down by various health indicators and compared using Student's t test and the analysis of variance (ANOVA). In general, HIV-infected patients without AIDS and with higher CD4 cell count score higher on all four SIS subscales (no significant differences). Patients with higher self esteem, better health related quality of life, with fewer symptoms and with less intensity of symptoms obtained significantly higher scores on all four SIS subscales (significant differences). This demonstrates the discriminant validity of SIS.

Regression analyses were carried out to examine the prediction validity. Self esteem and Sat-HRQOL were well predicted by the four subscale scores, with

explained variances of 41% and 30%, respectively. Social isolation score was the best predictor of both self esteem and Sat-HRQOL.

For exploratory factor analysis (EFA), principle axis factoring method with promax rotation was applied. An eigenvalue greater than one was the criterion for determining the number of factors extracted. As a result, four factors (social rejection/isolation, financial insecurity/social rejection, internalized shame, social isolation/rejection) were extracted. About 61.4% of the total variance was explained by the four factors.

To determine whether the four original factors fit the data, four first-order item-subscale structures were examined. Confirmatory factor analysis (CFA) was conducted on each of the factors with their corresponding items as the indicators. CFA was conducted on the social rejection factor with 9 indicators, the financial insecurity factor three indicators, the internalized shame factor with five indicators, and the social isolation factor with 7 indicators. The four model-fit indices (CFI=.983) suggested that each of the four factors is appropriate. Then, a second-order factor analysis was conducted. CFA was conducted on the four factors using their corresponding indicators as a whole stigma model. The model-fit indice indicated that this model is appropriate to the data. Therefore, the CFA results suggested that the original four factors of the SIS are also appropriate.

Discussion

The psychometric analyses on the Social Impact Scale, Taiwan version, indicate this instrument is a reliable and valid generic stigma instrument in patients with HIV infection. The subscale scores were well correlated with self esteem, Sat-HRQOL, self-perceived health status and self-perceived happiness, and inversely correlated with numbers and severity of symptoms. The subscale scores also discriminated between HIV-infected patients with different level of self esteem, health related qualify of life, and between HIV-infected patients with different number and intensity of symptoms.

Previous studies have consistently shown that the presence, number, and intensity of symptoms are the major determinants of quality of life in HIV-infected patients (Siegel & Krauss, 1991; Hall, 1998; Hsiung PC, Tsai YF, 2000; 熊、蔡、梁、施, 2000). Clinical stage has only a weak association with quality of life after adjusting for the number of symptoms (Siegel & Krauss, 1991). Using number and intensity of symptoms as the disease severity markers, we found that the SIS has good discriminant validity among patients with different severity of HIV disease.

The results of factor analysis in this study showed that some items were not best correlated with their related domains. This is most likely due to the overlapping of constructs between the domains, especially when perceived from the viewpoints of HIV-infected patients.

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Table 1. Characteristics of 206 patients with HIV infection

Characteristics	n =206 (%)
Age (years)	
≤ 30	70 (34.0)
31–40	100 (48.5)
> 40	36 (17.5)
Male	198 (96.1)
Education of high school or above	191 (92.7)
Presence of AIDS	49 (23.8)
Current antiretroviral therapy	
None†	19 (9.2)
PIs or NNRTIs-based regimens*	187 (90.8)
Self-perceived health status	
Very poor	9 (4.4)
Poor	43 (20.9)
Fair	86 (41.8)
Good	52 (25.2)
Excellent	14 (6.8)
Self-perceived happiness	
Very unhappy	13 (6.3)
Unhappy	42 (20.4)
Moderately happy	99 (48.1)
Happy	41 (19.9)
Very happy	11 (5.3)
Current CD4 cell count (/mm^3)	
≤ 200	24 (11.7)
201–500	89 (43.2)
> 500	93 (45.1)
Number of symptoms	
None	9 (4.3)
1–10	71 (34.5)
11–20	78 (37.9)
21–30	48 (23.3)

† including treatment-naive fresh cases and patients under structured treatment interruption

*PIs: protease inhibitors NNRTIs: non-nucleotide reverse transcriptase inhibitors

Table 2. Correlation coefficients between subscales of SIS (n=206)

NAME	SR	FI	IS	SI
Mean	2.84	2.61	1.95	2.58
SD	0.55	0.73	0.54	0.59
SR	1			
FI	0.705	1		
IS	0.427	0.365	1	
SI	0.796	0.644	0.508	1

Abbreviations: SR=social rejection FI=financial insecurity
IS=internalized shame SI=social isolation
Note: All p value < 0.0001

Table 3. Correlation coefficients between SIS and other measures (n = 206)

	SR	FI	IS	SI
Self esteem	0.563***	0.445***	0.229***	0.632***
Sat-HRQOL	0.445***	0.438***	0.244***	0.545***
Health status	0.391***	0.434***	0.295***	0.547***
Happiness	0.470***	0.516***	0.389***	0.670***
No. of symptoms	-0.451***	-0.410***	-0.167**	-0.509 ***
Intensity of symptoms	-0.444 ***	-0.409 ***	-0.221 **	-0.517***

Abbreviations: SR=social rejection FI=financial insecurity
IS=internalized shame SI=social isolation
* p value < 0.05 ; ** p value < 0.01 ; *** p value < 0.001

Table 4. Comparison of the SIS means and significance of differences

	n	SIS	SR	FI	IS	SI
Presence of AIDS						
Yes	49	2.49	2.75	2.54	1.94	2.53
No	157	2.57	2.87	2.63	1.96	2.60
p -value		0.3316	0.2052	0.4921	0.7572	0.4570
CD4 count						
≤ 200	24	2.40	2.69	2.53	1.84	2.39
201–500	89	2.53	2.81	2.55	1.99	2.54
> 500	93	2.61	2.91	2.68	1.95	2.67
p-value		0.1574	0.1607	0.4470	0.4591	0.0753
Self esteem						
High	130	2.73	3.02	2.81	2.04	2.82
Low	76	2.25	2.54	2.26	1.81	2.18
p-value		<0.0001	<0.0001	<0.0001	0.0043	<0.0001
Sat-HRQOL						
High	115	2.75	3.04	2.81	2.05	2.86
Low	91	2.30	2.59	2.35	1.83	2.23
p-value		<0.0001	<0.0001	<0.0001	0.0033	<0.0001
No. of symptoms						
More	89	2.28	2.56	2.24	1.82	2.26
Less	117	2.76	3.06	2.89	2.06	2.83
p-value		<0.0001	<0.0001	<0.0001	0.0011	<0.0001
Intensity of						
High	84	2.30	2.56	2.26	1.87	2.28
Low	122	2.73	3.03	2.85	2.01	2.79
p-value		<0.0001	<0.0001	<0.0001	0.0544	<0.0001

Abbreviations: SR=social rejection FI=financial insecurity
IS=internalized shame SI=social isolation

Note: Number and intensity of symptoms were compared with measures (14.07 and 22.21, respectively)

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