

Social capital of Iranian patients living with acquired immune deficiency syndrome and associated factors

S.K. Ansari,¹ S. Nedjat,² H. Jabbari,^{3,4} N. Saiepour⁵ and M.J. Heris⁶

الرصيد الاجتماعي للمرضى المصابين بفيروس العوز المناعي المكتسب والعوامل المرتبطة بذلك في جمهورية إيران الإسلامية

شيو خوشنويس أنصاري، سحرناز نجات، حسين جباري، نرجس ساعيبور، معصومة جنتي هريس

الخلاصة: لقد قامت هذه الدراسة ببحث الرصيد الاجتماعي لمرضى العوز المناعي الإيرانيين والعوامل المرتبطة بذلك. ففي دراسة مقطعية تم ملء الاستبيان الموحد للرصيد الاجتماعي من قبل عينة تتابعية ضمت 300 من مرضى العوز المناعي لدى زيارتهم لأحد مراكز الإحالة الإرشادية في طهران. فكان مجموع نقاط الرصيد الاجتماعي التي أحرزها المرضى حوالي 50% في مجالات الثقة والتلاحم الاجتماعي والعمل الجماعي والتعاون ومجالات التمكين السياسي. وأحرزوا أدنى الدرجات في مجال عضوية المجموعات والشبكات (27.1%). وفي تحليل الانحدار كان الوضع الوظيفي مرتبطاً بشكل كبير مع عضوية المجموعات والشبكات، وكان هناك ارتباط بين العمر والحالة الاجتماعية والوضع المالي من جهة، وبين العمل الجماعي والتعاون من جهة أخرى؛ وقد أثرت فترة المعرفة بالإصابة بالمرض والحالة الاجتماعية على التماسك والاندماج الاجتماعي، كما أثرت السلوكيات الخطرة على التمكين وعلى العمل السياسي. من الضروري بذل جهود لتعزيز الرصيد الاجتماعي لمرضى العوز المناعي الأصغر سناً والعاطلين عن العمل والمطلقين/الأرامل وذوي السلوكيات الخطرة وذوي المعرفة الأقصر بالإصابة بالمرض.

ABSTRACT This study investigated the social capital of Iranian patients living with acquired immune deficiency syndrome (AIDS) and the associated factors. In a cross-sectional study the Integrated Social Capital Questionnaire was filled by a sequential sample of 300 patients visiting a referral counselling centre in Tehran. The patients' social capital scores were around 50% in the trust, social cohesion, collective action and cooperation and political empowerment domains. The groups and networks membership domain scored the lowest (27.1%). In regression analysis, employment status was significantly associated with groups and networks membership; age, marital status and financial status were associated with collective action and cooperation; period of disease awareness and marital status affected social cohesion and inclusion; and having risky behaviour affected empowerment and political action. Efforts are needed to enhance the social capital of those patients living with AIDS who are younger, unemployed, divorced/widowed, with risky behaviours and shorter disease awareness.

Capital social des patients atteints du sida et facteurs associés en République islamique d'Iran

RÉSUMÉ La présente étude a analysé le capital social de patients iraniens atteints du sida et les facteurs associés. Dans une étude transversale, le questionnaire intégré permettant la mesure du capital social (*Integrated Social Capital Questionnaire*) a été rempli par 300 patients atteints du sida inclus dans un échantillon séquentiel et consultant dans un centre de conseil et de recours à Téhéran. Les scores des patients en termes de capital social se situaient autour de 50 % dans les domaines de la confiance, de la cohésion sociale, de l'action collective, de la coopération et de l'autonomisation politique. Le domaine concernant l'appartenance à des groupes et des réseaux a obtenu le score le plus faible (27,1 %). À l'analyse de régression, la situation professionnelle était nettement associée à une appartenance à des groupes et des réseaux ; l'âge, la situation matrimoniale et le statut économique étaient liés à l'action collective et à la coopération ; une période de sensibilisation à la maladie et la situation matrimoniale affectaient la cohésion sociale et l'inclusion ; et un comportement à risque influait sur l'autonomisation et l'action politique. Des actions sont nécessaires pour améliorer le capital social des patients atteints du sida qui sont jeunes, sans emploi, divorcés/veufs, qui ont des comportements à risque et ont eu une sensibilisation à la maladie plus courte.

¹South Tehran Health Centre; ²Department of Epidemiology and Biostatistics, School of Public Health, Knowledge Utilization Research Centre, Tehran University of Medical Science, Tehran, Islamic Republic of Iran (Correspondence to S. Nedjat: nejatsan@tums.ac.ir). ³Vienna General Hospital, Department of Dermatology and Department of Clinical Immunology, Allergy and Infectious Diseases, Vienna, Austria. ⁴Dermatology of Infectious Diseases, Digestive Diseases Research Institute, Tehran, Islamic Republic of Iran. ⁵School of Population Health, University of Queensland, Brisbane, Queensland, Australia. ⁶Imam Khomeini Hospital, Voluntary Counselling and Testing Centre, Tehran, Islamic Republic of Iran.

Received: 11/10/14; accepted: 19/05/15

Introduction

Combatting acquired immune deficiency syndrome (AIDS) is one of the objectives of the Millennium Development Goals, especially as AIDS can have both direct and indirect mutual effects on the other goals (1). According to a World Health Organization (WHO) report, the number of people infected with the human immunodeficiency virus (HIV) around the world was 34 million in 2011. In the Islamic Republic of Iran, statistics provided by the Diseases Management Centre of the Ministry of Health and Medical Education in September 2014 indicated that a total of 28 663 cases of HIV infection and AIDS had been identified, 88.4% of which were among males. Between 1986 and 2014, a cumulative total of 6435 such patients were identified, of whom 6016 have since died (2).

The AIDS epidemic has reached a critical point in recent years. The introduction of new treatments and also the increasing knowledge about the disease have transformed it into a controllable chronic disease rather than a deadly one. The lifespan of patients living with HIV/AIDS has increased considerably, while the side-effects and signs of the disease have lessened. Besides the side-effects of the disease itself, many patients suffer from numerous social and mental problems, such as poverty, depression, addiction and social stigma, which threaten their quality of life and social capital.

Social capital is a collection of informal capabilities and values that increases participation among members of a group, facilitates their social relations and finds a solution to their social problems in a more economical, rapid and simple manner. Unlike other forms of capital, social capital does not exist in a physical form and is the result of mutual social actions (3). Social capital influences the physical and mental health of members of society both directly and indirectly. Among the domains of social

capital, trust has shown a direct association with self-rated health (3,4). Higher levels of social capital in a society can be linked to increased life expectancy, better utilization of health interventions and a decrease in mortality related to certain causes (5,6).

Social capital plays a strategic role in the lives of people living with AIDS as a means of promoting quality of life, decreasing social stigma, increasing patients' visits for care and treatment, controlling the spread of AIDS and increasing the influence of preventive interventions (7–11). Although a number of international studies in this field exist (12,13), to the best of our knowledge, there is no research evidence about the social capital of people living with AIDS in the Islamic Republic of Iran. As social capital and social stigma are determined by the specific cultural context of a country, we designed a study to assess the social capital of Iranian patients and associated factors. It was expected that the study findings would provide useful information for necessary interventions in order to promote the social health of this group of the population.

Methods

Setting

This cross-sectional study was conducted at the behavioural diseases' counselling centre at Imam Khomeini Hospital, Tehran, during 2010–2011. This centre is an outpatient referral centre for counselling people living with AIDS/HIV and receives visitors from all over the country. The study was approved by Tehran University of Medical Sciences' ethics committee.

Sampling

On the basis of the patient registration files at this counselling centre, at the time of the study there were almost 700 patients who were known to be HIV-positive and 305 outpatients who had been diagnosed as having AIDS. Only

the patients who had been diagnosed with AIDS were included in this study. Using sequential sampling, the questionnaire was filled by all consenting patients (305 individuals) who visited the counselling centre on a regular basis to receive care and who met the study's inclusion criteria.

The inclusion criteria were patients in need of antiretroviral therapy who had entered the 3rd or 4th AIDS stage, based on the definitions and HIV/AIDS treatment guidelines of the World Health Organization in 2010. The criteria of the guidelines are: (a) a total of $CD4 \leq 350$ cells/mm³, regardless of clinical symptoms ($CD4 \leq 200$ cells/mm³ according to previous guidelines); (b) being in the 3rd AIDS clinical stage (more than 10% weight loss, history of diarrhoea and fever for more than a month, night sweats and fatigue, weakness, oral candidiasis and leukoplakia, pulmonary tuberculosis in the past year, and severe bacterial infections such as pneumonia and pyomyositis) or the 4th AIDS clinical stage (wasting syndrome, *Pneumocystis carinii* pneumonia, toxoplasmosis, extrapulmonary tuberculosis, Kaposi sarcoma, lymphoma), based on WHO definitions and regardless of CD4 count; (c) suffering from tuberculosis, regardless of CD4 count; (d) suffering from and in need of therapy for hepatitis B virus infection, regardless of CD4 count; or (e) suffering from and in need of therapy for background malignancy (especially AIDS-related malignancies). Only registered outpatients at the behavioural diseases' counselling centre were eligible for the study and only patients who give informed consent were enrolled.

The only exclusion criterion was hospitalization due to deterioration in the health of the patient. Those whose health had deteriorated or who had been hospitalized were not available for the study since patients come to this counselling centre only when they are in a better condition for consultation.

Data collection

In order to measure the social capital of patients who had been diagnosed with AIDS, a validated Iranian version of the World Bank's Social Capital Integrated Questionnaire (SC-IQ) designed for developing countries was used. A psychometric evaluation was conducted in Tehran and its validity and reliability were confirmed (14).

The questionnaire consisted of sociodemographic characteristics: sex; age (in years); employment status (employed: self-employed or employed by the state, unemployed: jobless, housekeeper, student or conscript); education level (number of years educated); and financial status (a proxy measure based on total living area of home divided by household size). A number of other characteristics were also assessed: duration of awareness of HIV infection (in years); duration of use of anti-HIV drugs (in years); and risky behaviour which might result in HIV infection (unsafe sex and intravenous drug use).

The main part of the questionnaire covered 6 domains of social capital, as follows.

- Domain 1: Groups and networks. This domain consisted of 3 questions: number of groups or associations where the patient is a member; number of friends; number of persons ready to help when the patient is in need of money or a car, etc.
- Domain 2: Trust and solidarity. This domain consisted of 28 questions: level of trust in people, local help in case of need; attempt to commit fraud in the local community; entrusting others with money (lending and borrowing); and the level of trust in 21 groups such as friends, family and different occupations. The level of trust in HIV-positive patients was also added to this questionnaire specifically for this study.
- Domain 3: Collective action and cooperation. This domain consisted of 3

questions: group work participation, where people gather around (e.g. to help an individual) to do something useful for society; working hard in order to eliminate a certain problem (e.g. clearing garbage and waste in the local community); and the probability of the local community's help when something unfortunate happens to someone (e.g. when a loved one suffers from illness or passes away).

- Domain 4: Information and communication. This domain consisted of 2 questions regarding information accessibility: how often patients follow the news and events in the country; and 3 primary sources they use to gather information.
 - Domain 5: Social cohesion and inclusion. The score for this domain was calculated using 17 questions about: level of empathy and closeness in the neighbourhood; disputes over assets, social class, ethnicity, political and religious views and whether they turned violent; socializing levels; participation in group activities; feeling of security at home and among the community at night.
 - Domain 6: Empowerment and political action. The score for this domain was calculated using 14 questions about: level of influence that change the course of one's life; level of social value and respect for an individual; level of trust in 9 government institutions; and level of cooperation and participation among people.
- Domains 5 and 6 are the outcomes of social capital (14).

The SC-IQ questionnaire was completed by 20 patients as the pilot. These individuals were then questioned about the time it took them to fill the questionnaire, its clarity and whether they felt uncomfortable with any of the questions. Based on their answers, the questionnaire was determined as clear, took nearly half an hour to fill and only 1 of the patients was uncomfortable with answering the AIDS-related questions.

Statistical analysis

In order to create equal weights for the questions, each question's score in the main part of the questionnaire was converted into a percentage and then the mean percentage score was calculated for each domain. Each social capital domain along with independent quantitative variables were described using the mean score and standard deviation (SD), while categorical variables were represented as percentages. In the bivariate analysis, the independent *t*-test and Pearson correlation coefficient were used. Variables that showed a *P*-value < 0.2 in the bivariate analysis were then entered into each domain's relevant multiple linear regression models (15). In multiple linear regression and all other tests, a *P*-value < 0.05 was considered as significant association between 2 variables.

Results

Only 5 (1.6%) of the patients who met the inclusion criteria refused to take part in the study (response rate 98.4%).

Demographic characteristics of the study population

Among the 300 patients studied 72.7% were men and 27.3% were women. Their mean duration of education was 9.1 (SD 3.6) years and their mean age was 38.5 (SD 8.4) years (range 10–60 years). Table 1 summarizes the participants' demographic characteristics.

Scores of the social capital domains

The mean scores on the domains of social capital in the SC-IQ for the participants are shown in Table 2. In most of the domains participants scored just over 50% (range 51.3–55.3%), except for the domains of groups and networks, which scored 27.1% (SD 18.8%). Only 5 domains are shown in the tables because calculation of the total score was not possible in the information and

Table 1 Descriptive results for demographic and clinical characteristics of participants (n = 300)

Variable	No. of respondents	%
Sex		
Female	82	27.3
Male	218	72.7
Level of education (years)		
Illiterate	13	4.3
Primary	58	19.4
Middle school	76	25.4
High school	131	43.8
University graduate	21	7
Marital status		
Single	144	48.6
Married	92	31.1
Divorced	32	10.8
Widowed	28	9.5
Employment status		
Government employee	16	5.7
Private sector employee	104	37.4
Jobless	85	30.7
Housekeeper	56	20.2
Retired	10	3.6
Student	6	2.0
Army conscript	1	0.4
Disease awareness period (years)		
< 5	188	63.1
5–9	78	26.2
10–14	21	7.0
15+	11	3.7
Self-stated reason of infection		
Intravenous drug use	114	38.0
Unsafe sex	39	13.0
Blood transfusion/blood products	37	12.3
Child of an HIV infected mother	3	1.0
Spouse of an individual with risky behaviour/HIV infected individual	59	19.7
Unknown	39	13.0

communication domain due to the descriptive nature of the questions.

Groups and networks domain

Among the participants, 60.3% were members of at least one group (i.e. any group/organization, network or association) while 39.6% were not in any group. Almost one-quarter of the individuals (23.5%) belonged to groups

established by members of the public. A high proportion of the patients who were group members belonged to disease support groups (148/181, 81.8%), but if disease support groups were excluded, the mean score on this domain would be 25.7% (SD 18.4%). The main advantage of group membership, as stated by 51.4% of group members

was improvement in their mental and spiritual condition. Most respondents (74.3%) stated that the common factor among group members was “the disease”, 62.4% said that decision-making in such groups was based on discussions and the agreement of all members and 75.3% said that the group leader was chosen by vote.

Trust and solidarity domain

As shown in Table 2, the domain of trust and solidarity had a mean score of 53.9% (SD 17.7%). Considering the responses on the Likert scale for each question, ranging from 1 (lowest trust) to 5 (highest trust), mean scores on social trust for each group, in descending order, were: family members 4.00 (SD 1.18), nurses and doctors 3.98 (SD 1.02), academic professors 3.73 (SD 1.19), teachers 3.38 (SD 1.25), people living with AIDS 3.14 (SD 1.34), neighbours 2.06 (SD 1.04) and strangers 1.59 (SD 0.90).

In response to questions about the neighbourhood 62.2% of the participants believed that the level of social trust among people had decreased in the past 5 years. On the other hand, 43.0% of participants agreed or totally agreed that people in their neighbourhood were willing to help when they were in need and 40.9% disagreed or somewhat disagreed that everyone in the neighbourhood was trying to cheat the others. The phrase “In our neighbourhood, people usually don’t trust each other when lending or borrowing money from each other” received a mixed response of somewhat to totally agree from 49.0% of the participants.

Collective action and cooperation domain

The mean score of the collective action and cooperation domain was 53.0% (SD 25.8%).

Information and communication domain

The responses to the questions on the information and communication domain showed that while 51.3% of

the participants followed the news on a daily basis, 11.0% never followed the news at all. The participants chose the following 3 sources as the main means of information about government activities: television (78.3%), newspapers and magazines (31.3%) and friends, relatives and neighbours (25.3%).

Social cohesion and inclusion domain

The mean score on the social cohesion domain was 55.3% (SD 14.1%). For the majority of our study patients their main social contacts were with their relatives (71.5%), and only 28.1% felt there was heterogeneity in their neighbourhood (i.e. in terms of wealth, beliefs and religion, education, ethnicity, etc.). The two main reasons why participants felt alienated were differences between a healthy and an ill person (53.5%) and differences in economic status (33.1%).

Empowerment and political action domain

The mean score for the empowerment and political action domain was 51.3% (SD 21.3%).

Table 2 Mean percentage scores on the domains of social capital in the Social Capital Integrated Questionnaire among people diagnosed with AIDS attending Imam Khomeini behavioural diseases counselling centre as outpatients (n = 300)

Social capital domain	Mean (SD) score (%)	Min.-Max. score (%)
Groups and networks	27.1 (18.8)	0.0-70.3
Trust and solidarity	53.9 (17.7)	16.1-84.8
Collective action and cooperation	53.0 (25.8)	0.0-100.0
Information and communication	43.7 (34.3)	0.0-100.0
Social cohesion and inclusion	55.3 (14.1)	23.7-89.8
Empowerment and political action	51.3 (21.3)	3.6-96.4

SD = standard deviation.

Bivariate analyses

In the bivariate analyses, respondents who were male, employed, better educated and with longer duration of disease awareness had significantly better group and network scores (Tables 3 and 4). Social cohesion and inclusion scores were significantly higher in respondents with longer disease awareness, males and single/married participants. Collective action and cooperation scores significantly improved with increasing age and were lower in the divorced/widowed than married/

single participants. The respondents with risky behaviours had significantly lower empowerment and political action scores.

Multiple regression analysis

The variables with $P < 0.2$ in the bivariate analysis were included in the primary multiple regression models (15) and then we ran the stepwise approach in which variables with $P > 0.05$ were removed from the final models (Table 5).

The multiple regression analysis of the association between social capital

Table 3 Association of patients' demographic variables with mean percentage scores on the domains of social capital in the Social Capital Integrated Questionnaire

Variable	No. of respondents	Mean score on social capital domains ^a				
		Groups and networks	Trust and solidarity	Collective action and cooperation	Social cohesion and inclusion	Empowerment and political action
Sex						
Female	82	21.1	51.3	51.1	50.4	54.3
Male	218	29.5	54.9	53.7	56.4	50.6
P-value ^b		0.001	0.166	0.483	0.048	0.512
Employment status						
Employed	130	34.0	51.5	54.6	57.2	53.1
Unemployed	164	21.6	46.0	51.5	52.5	48.6
P-value ^b		< 0.001	0.368	0.341	0.052	0.295
Marital status						
Single/married	236	27.5	50.9	55.1	56.4	52.2
Divorced/widowed	60	25.0	29.5	45.5	49.9	44.9
P-value ^b		0.368	0.243	0.017	0.010	0.253
Risky behaviour						
No	147	24.7	50.9	54.0	54.4	57.8
Yes	153	28.6	49.7	52.3	55.7	48.5
P-value ^b		0.082	0.854	0.603	0.583	0.041

^aTotal scores could not be calculated for the Information and communication domain due to the descriptive nature of the questions; ^bt-test

Table 4 Correlation of the study participants' characteristics with the domains of social capital in the Social Capital Integrated Questionnaire using Pearson test

Quantitative variables	Mean (SD) value	Min.-max. value	Groups and networks		Trust and solidarity		Collective action and cooperation		Social cohesion and inclusion		Empowerment and political action	
			r	P-value	r	P-value	r	P-value	r	P-value	r	P-value
Age (years)	38.5 (8.4)	10-60	0.02	0.737	0.25	0.120	0.19	0.002	0.11	0.188	-0.06	0.518
Level of education (years)	9.1 (3.6)	0-23	0.12	0.037	0.22	0.179	0.03	0.675	0.08	0.382	0.02	0.824
Economic status ^b	29.6 (25.7)	4-300	0.02	0.737	0.05	0.745	-0.13	0.05	0.00	0.988	-0.01	0.327
Disease awareness period (years)	4.6 (4.2)	< 1-26	0.12	0.033	-0.02	0.895	0.07	0.301	0.19	0.026	0.03	0.764

^aPearson correlation coefficients (r); ^bTotal living area of home divided by household size SD = standard deviation.

domains and the participants' demographic variables and disease specific characteristics showed a significant association between employment status and the groups and networks domain; the unemployed scored 12.9 units less in the group membership domain than the employed ($P < 0.001$).

For collective action and cooperation the score increased significantly with age ($P < 0.001$), although widowed and divorced participants scored lower than married and single respondents ($P = 0.015$) and as the financial status of participants improved, collective action and cooperation scores decreased ($P = 0.020$).

Table 5 also illustrates the significant association of the social cohesion and inclusion score with both marital status and duration of disease awareness. A longer disease awareness resulted in higher social cohesion scores ($P = 0.038$) and widowed and divorced individuals had lower scores compared with the single and married participants ($P = 0.038$). So if all other variables remained unchanged, a 1-year increase in the duration of disease awareness raised this domain's score by 0.7%. Divorced and widowed individuals scored 6.4% lower than their married and single counterparts.

A significant association existed between the risky behaviour and the political empowerment score, with a decrease of 9.3% in patients with risky behaviour.

None of the independent variables in either the bivariate or multiple linear regression analysis had a significant statistical association with the social trust domain.

Discussion

In the 1990s, the World Bank implemented a number of programmes to promote and research social development in different developing countries. One of the dimensions of

social development is social capital. The Islamic Republic of Iran has been working on this issue since 2001 and even the country's 20-year Vision Plan gave serious attention to social capital (16).

In the current study, the social capital scores in all domains of the SC-IQ were around 50%, except in the groups and networks domain, which had the lowest score (27.1%). Being younger, unemployed or divorced/widowed and having a better economic status, higher risky behaviour and shorter duration of disease awareness were the variables which decreased the scores on different domains of the questionnaire.

Social capital was also measured with the same tool in the general population of Tehran in 2008 (14). A comparison of the findings of this study with the latter could prove useful considering both were conducted with the same tool. In comparison with the Tehran study, social capital among people diagnosed with AIDS was higher in all the domains (14). The greatest difference was observed in the groups and networks domain. The mean social capital score in this domain was 27.1%, even when membership of support groups (e.g. Positive Club, the Society for the Protection of Handicapped Children and Youth *Tavanyab*, Narcotics Anonymous, Rebirth Society, Hope Foundation) was removed, the mean score of this domain was 25.7% (SD 18.4%). This score was higher than in the other study of Tehran citizens (18.9%) (14). Another study conducted in 2004 on 1759 people in Tehran also showed that the maximum score for participation in philanthropic activities was very low (around 25%) and that 53.4% of respondents had no participation at all (17). In another study done in our centre on a mix of people who were HIV-positive or living with AIDS using a different questionnaire, the lowest score was seen in the associative relation domain (18).

In 2007, an evaluation of social capital was carried out on a national

Table 5 Association of mean score on the domains of social capital in the Social Capital Integrated Questionnaire with demographic variables and patients' characteristics using stepwise multiple linear regression

Variables applied in each regression model	Groups and networks		Collective action and cooperation		Social capital domains ^a		Empowerment and political action	
	β coefficient	P-value	β coefficient	P-value	β coefficient	P-value	β coefficient	P-value
Sex	-	-	-	-	-	-	-	-
Age	-	-	0.75	< 0.001	-	-	-	-
Years of education	-	-	-	-	-	-	-	-
Employment status (unemployed/employed)	-12.86	< 0.001	-	-	-	-	-	-
Marital status (divorced or widowed vs married or single)	-	-	-10.27	0.015	-6.40	0.038	-	-
Economic status	-	-	-0.14	0.020	-	-	-	-
Risky behaviour (yes vs no)	-	-	-	-	-	-	-9.29	0.041
Years of disease awareness	-	-	-	-	0.68	0.038	-	-

^aNone of the variables had significant association with the trust and solidarity domain. Hence this domain was excluded from the table. Variables with P-value > 0.05 are shown with a dash (-).

scale in the Islamic Republic of Iran. According to the results of this evaluation, the social capital scores in the country as a whole and in Tehran were lower than the average international score. One basic factor which holds a rather weak position in Iranian society is communal relationships. These consist of a population's participation in associations and private establishments. The second factor is inter-personal trust. In the Islamic Republic of Iran social capital is of a more traditional type; it relies on familial and ethnic relationships which is termed "bonding social capital". But the social capital that results from widespread participation, national social integrity, associative relations and cooperation in establishments has not yet been fully established in the Islamic Republic of Iran (2).

Half of the patients in our survey (51.4%) believed the greatest advantage of group membership was an improvement in their spiritual and psychological state. One of the reasons the score of this domain was higher in these patients, even without including membership of support groups, is perhaps their need for spiritual uplift. This difference may also be attributed to selection bias, since in the previous Tehran study random sampling was done in the general population. In our study, however, the samples were chosen from those visiting the counselling centre. Hence our findings may not be representative of all people living with AIDS. Evidence shows that social capital can positively affect health with respect to the quality and type of social networks the person is a member of by promoting health and quality of life. On the other hand, it may also negatively affect it by increasing the risk of disease, injury and even death in special groups (19). Researchers have reported strong social associations between criminal, smuggling and sexual activity networks and groups whose level of trust is dependent on unhealthy and socially unacceptable behaviour (19). A qualitative study was performed on 52 HIV-positive Filipino homosexual men in Los Angeles between July 2004 and August 2005. Unlike other diseases such as cancer, when friends and family learned about someone's HIV-positive status, they were no longer supportive, resulting in a disruptive social capital. The result was an inclination toward participation in high-risk groups (20). Hence it seems that encouraging patients to visit behavioural counselling centres and becoming members of relevant support groups can help boost their social capital and health.

On examining the associations between the different domains and demographic variables, the social capital of patients in terms of groups and networks was significantly associated with the employment variable. When compared with employment, unemployment reduced the score of this domain by 12.9 units. The other demographic variables were not significantly associated with this domain. Male participants had significantly better group membership scores in the bivariate analysis, although this association became non-significant in the adjusted model. This finding is in accordance with the other study of social

capital among people living with HIV/AIDS in the Islamic Republic of Iran (18). A study performed on patients in China showed a direct association between reduced social support and ageing, lower levels of education and lower income. Living alone and losing one's job were identified as factors lowering social capital. On the other hand, good family relations and a successful marriage were identified as protective factors in preserving social capital (21).

Regarding economic status, in our study the only significant association with this variable was the collective action and cooperation score. However, in the other study on people living with HIV/AIDS in the Islamic Republic of Iran, economic status showed a significant association with 3 out of the 4 social capital domains evaluated (18). The reason for this discordance might be the non-linear association of the economic status and social capital, as in the above-mentioned study the social capital domain scores of respondents in the middle economic status group were significantly higher than those of both poorer and richer ones.

The mean social capital score obtained in the trust and solidarity domain was 53.9%, which is almost identical to the score of 53.7% among Tehran citizens (14). This domain was not significantly associated with any of the sociodemographic variables and patient characteristics studied. In the Iranian study on people who were HIV-positive and people living with AIDS in this centre, none of the variables showed a significant association with the score of social trust and associative relations, while the individual trust score was significantly lower in women than men respondents in this study (18).

The responses among our patients to the question "To what extent can people be trusted?" were as follows: 54.4% chose low or very low; 36.1% average and 9.5% high or very high. In contrast, 45.5% of Tehran citizens chose the low or very low options and

11.5% chose the high or very high options. Hence, when compared with the general population of Tehran, the level of trust seems to be lower among people living with AIDS (14). The level of trust in people is higher among the general population in some other countries as well. For example, in 2008 48% of Canadians agreed that "most people can be trusted", although this rate was 32% in 2009 (22). In 1998 49% of New Zealanders, 40% of Australians, 36% of Americans and 31% of British people agreed with the same statement (23). Similar to our finding, a study conducted in China on 294 people living with AIDS showed lower social trust scores than in the general population (21).

An international multi-centre, cross-sectional study was conducted on social capital in 1963 people living with AIDS in 16 centres in Canada, China, Thailand, United States, Namibia and Puerto Rico in 2009–2010. The overall mean social capital score of these patients was 2.68 out of 4.00 on the Onyx and Bullen scales, which was higher than the average total social capital score compared with previous research using the same scale (12).

In our study 62.0% of respondents believed that the level of trust among the community had decreased compared with 5 years earlier. This finding is consistent with the social capital study conducted in Tehran in which 771 out of 2484 citizens also believed the level of trust had decreased (12). Based on another Iranian national study conducted in 28 provinces in 2001, social capital had decreased overall across the country (13).

According to our findings an increase in the duration of awareness of their disease was directly related to a significant increase in the social cohesion and inclusion scores of people living with AIDS. This score was 6.4 units lower in the divorced or widowed patients than in the married ones. Other studies too have reported that the social

cohesion score is lower in single and widowed individuals (3,14).

A significant association existed between risky behaviour and the empowerment and political action domain score; risky behaviour reduced the score by 9.3 units. This means an increase in risky behaviour negatively affected the individual's value in society and subsequently his/her influence over life matters.

The potential role that social capital can play in health interventions carried out for people living with AIDS has been addressed in various studies. These interventions may be in the form of helping patients build trust in medical groups and social service organizations. These interventions should take place before therapeutic and lifestyle training interventions (24,25). However, we must remember that although patients' health is affected by their social capital, social capital itself can be affected by patients' health, and AIDS can result in a lower social capital.

Furthermore, according to the World Bank report the prevalence of HIV infection in a population negatively affected social capital, such that 1 SD increase in prevalence led to a 1% decline in trust at the country level. The report also stated that if a person travelled from a country with a low prevalence of HIV, such as Estonia, to a country with a high prevalence, such as Zimbabwe, an 8% decline in social capital would be observed (20). On the other hand, the degree of social capital seems to have a beneficial effect on HIV infection and sexually transmitted infection rates and can play a significant role in the decline in the disease trends (26–28). It is recommended that policy-makers consider involving public social groups and networks in the planning and delivery of intervention strategies for reducing HIV transmission (27).

Some limitations of the current study should be noted. The questionnaire was not filled in the same way by

all participants. It was self-administered by 66% of the participants, while the other 34% were filled by the interviewers or with their help because the patients were illiterate or did not want to fill it themselves. There is a possibility of desirability bias because of the nature of the questions in the self-administered questionnaire. This possibility is greater in the members of certain groups (Narcotics Anonymous, Positive Club), because these individuals have participated in multiple research projects and are more familiar with the questions. Although our counselling centre is a referral centre and the high response rate can enhance the generalizability of the findings to elsewhere in the country, there is a possibility of selection bias. The study was conducted on people living with AIDS visiting a counselling centre, and we had no samples from people who were not visiting such centres. The social capital status of these people may be worse than those participating in our study, and care should be taken in generalizing the data. Causality inference cannot be assumed,

due to the cross-sectional nature of the study, and only the associations should be considered.

Conclusion

Most of the social capital domains received scores of 50% or more, except for the groups and networks domain which scored 27.1% and the information and communication domain which scored 43.7%. Being younger, unemployed or divorced/widowed, and having a better economic status, greater risky behaviour and shorter disease awareness period were the variables which decreased social capital.

Studies need to be designed to develop and evaluate appropriate intervention programmes to improve the social capital status among these groups in the future. Future studies might include evaluating the effectiveness of interventions such as creating employment opportunities for patients, encouraging inter-patient marriages,

expanding the role of groups and associations, using trained individuals in these groups to clarify the goals and steer the groups, and holding counselling sessions for patients' spouses to prevent divorce. Since a large percentage of patients are audiences of mass media, transferring necessary health messages via TV, newspapers and journals could prove effective.

Acknowledgements

This study was part of the MPH thesis of Shiva Khoshnevis, supported by Tehran University of Medical Sciences (grant no: 11860-27-01-90). We would also like to extend our gratitude to the personnel of the behavioural diseases counselling centre for their efforts in collecting the data.

Funding: The study was financed by the Deputy of Research of Tehran University of Medical Sciences (project number: 90-01-27-11860).

Competing interests: None declared.

References

- Azin A. An overview on the 2008 UNAIDS Report on the Global AIDS Epidemic. *Iranian Journal of Epidemiology*. 2010;6(2):56-8.
- Center for Disease Management. The HIV-AIDS statistics in Iran. Tehran: Ministry of Health and Education; 2012 [in Persian].
- Tanhai AH, Somea M. Conceptual Qualitative analysis of social capital among citizens in TEHRAN. *J Sociol (Melb)*. 2008;4(4):49-69.
- Bolin K, Lindgren B, Lindström M, Nystedt P. Investments in social capital-implications of social interactions for the production of health. *Soc Sci Med*. 2003 Jun;56(12):2379-90. PMID:12742602
- Del Rey Calero J. Exclusion social, pobreza y salud. [Poverty, social exclusion, social capital and health]. *An R Acad Nac Med (Madr)*. 2004;121(1):57-72. PMID:15553403
- Kennelly B, O'Shea E, Garvey E. Social capital, life expectancy and mortality: a cross-national examination. *Soc Sci Med*. 2003 Jun;56(12):2367-77. PMID:12742601
- Sivaram S, Zelaya C, Srikrishnan AK, Latkin C, Go VF, Solomon S, et al. Associations between social capital and HIV stigma in Chennai, India: considerations for prevention intervention design. *AIDS Educ Prev*. 2009 Jun;21(3):233-50. PMID:19519238
- Samuels F, Pelto P, Verma R, George CK. Social capital and HIV risk behavior among female sex workers and men who have sex with men in Andhra Pradesh: insights from quantitative and qualitative data. *Horizons Research Update*. Washington (DC): Population Council; 2006 (<http://www.odi.org.uk/sites/odi.org.uk/files/odi-assets/publications-opinion-files/1792.pdf>, accessed 9 July 2015).
- Morrison SD, Howard R, Hardy C, Stinson B. Social capital, health and HIV awareness of girls in a rural Caribbean community. *Int Electron J Health Educ*. 2005;8:135-45.
- Thomas-Slayter BP, Fisher WF. Social capital and AIDS-resilient communities: strengthening the AIDS response. *Glob Public Health*. 2011;6 Suppl 3:S323-4. PMID:21943211
- Nandi A, Tracy M, Aiello A, Des Jarlais DC, Galea S. Social support and response to AIDS and severe acute respiratory syndrome. *Emerg Infect Dis*. 2008 May;14(5):825-7. PMID:18439373
- Webel A, Phillips JC, Rose CD, Holzemer WL, Chen WT, Tyer-Viola L, et al. A cross-sectional description of social capital in an international sample of persons living with HIV/AIDS (PLWH). *BMC Public Health*. 2012;12(12):188. PMID:22414342
- Tajbakhsh, K, Saghafi M, Nejad MK. Social capital and social policy. *Social Welfare Quarterly*. 2003; 10(3):155-200.
- Nedjat S, Majdzadeh R, Kheiltash A, Jamshidi E, Yazdani S. Social capital in association with socioeconomic variable in Iran. *Soc Indic Res*. 2013;113:1153-70.
- Jewell NP. *Statistics for epidemiology*. Boca Raton (FL): CRC Press; 2004.
- d'Hombres B, Rocco L, Suhrcke M, McKee M. Does social capital determine health? Evidence from eight transition countries. *Health Econ*. 2010 Jan;19(1):56-74. PMID:19301350

17. Nateghpoor M, Firuzabadi A. Social capital and its determinant in Tehran. *Iranian Sociology Journal*. 2003;4(6):59-91 [in Persian].
18. Rimaz S, Nikooseresht Z, Vesali S, Nedjat S, Asadi-Lari M. A study on factors that drive variation in the levels of social capital among people living with HIV/AIDS in Iran. *Glob J Health Sci*. 2015 May;7(3):351-7. PMID:25948461
19. Cairns RB, Cairns BD, Neckerman H, Gest SD. Social networks and aggressive behavior: peer support or peer rejection? *Dev Psychol*. 1988;24(6):815-23.
20. Antonio CD. HIV/AIDS and Social capital in a cross-section of countries. World Bank Policy Research Working Paper 4263. Washington (DC): World Bank; 2007 (<http://elibrary.worldbank.org/doi/pdf/10.1596/1813-9450-4263>, accessed 9 July 2015).
21. Zhang S, Chen Y, Chen M, Liu J, Lei K, Tan H. [Study on the social support condition and its influence factors among people living with HIV/AIDS]. *Wei Sheng Yan Jiu*. 2011 May;40(3):338-41 [in Chinese]. PMID:21695908
22. Canadians and trust. Kanata (ON): ZINC Research, The Corpen Group and Dufferin Research; 2009 (<http://www.zinc-tank.com/include/get.php?nodeid=22>, accessed 9 July 2015).
23. The social report 2004, Indicators of social wellbeing in New Zealand. Wellington: Ministry of Social Development; 2004.
24. Adam BD. Epistemic fault lines in biomedical and social approaches to HIV prevention. *J Int AIDS Soc*. 2011;14 Suppl 2:S2. PMID:21968038
25. Patton C. Rights language and HIV treatment: universal care or population control? *Rhetor Soc Q*. 2011;41(3):250-66.
26. Semaan S, Sternberg M, Zaidi A, Aral SO. Social capital and rates of gonorrhoea and syphilis in the United States: spatial regression analyses of state-level associations. *Soc Sci Med*. 2007 Jun;64(11):2324-41. PMID:17400352
27. Frumence G. The role of social capital in HIV prevention: experiences from the Kagera region of Tanzania [Dissertation]. Umeå, Sweden: Department of Public Health and Clinical Medicine Epidemiology and Global Health, University of Umeå; 2011 (<http://www.diva-portal.org/smash/get/diva2:454854/fulltext01.pdf>, accessed 6 July 2015).
28. Frumence G, Emmelin M, Eriksson M, Kwesigabo G, Killewo J, Moyo S, et al. Access to social capital and risk of HIV infection in Bukoba urban district, Kagera region, Tanzania. *Arch Public Health*. 2014;72(1):38. PMID:25671111