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SOCIO-DEMOGRAPHIC CORRELATES OF INTERNALIZED STIGMA AND EMPOWERMENT IN A SAMPLE OF PEOPLE WITH PHYSICAL DISABILITIES

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SUMMARY

Advances in understanding internalized stigma and empowerment in people with physical disabilities as well as factors which could enhance developing stigma resistance is vital for their better quality of life and psychological well-being.

The aim of the cross-sectional study was to explore socio-demographic correlates of internalized stigma and empowerment in a sample of people with physical disabilities.

The sample consisted of 119 persons with different kind of physical disabilities, of different age (18-70), of various levels of education, employment, marital and living status. Self-stigma was assessed using Internalized Stigma of Mental Illness Scale. Subjective feelings of empowerment were assessed using the Boston University Empowerment Scale. As for socio-demographic variables, significant differences were found regarding the age, level of education, employment, residential and marital status. Stigma is more internalized by unmarried participants, younger, participants living in extended families, not living in their own apartments, with lower level of education and unemployed. Gender differences were not found. Lower level of empowerment is established in participants with lower level of education, unemployed, those who were younger, not living in their own apartment. Demographic variables appeared to have considerable importance for the processes of internalizing stigma in the population of people with physical disabilities. The results of the study suggest designing an anti-stigma campaign with respect to socio-demographic correlates, which could empower and provide better quality of life for people with disability in Serbia.

Key words**:** empowerment, internalized stigma, physical disability, socio-demographic variables

INTRODUCTION

Understanding disability as a medical problem that comes from within the person has been shifted to the models that define disability beyond simple medical explanations. For example, the Social Model of Disability understands disability as a socially defined problem and puts an emphasis on barriers that people with disabilities face in everyday life. According to this model, "disability is not a personal characteristic but is instead a gap between personal capability and environmental demand" (Verbrugge & Jette, 1994, p.1). Likewise, the Human Rights Model focuses on the dignity of human beings, where, in the context of disability, four values are of particular importance: dignity, autonomy, equality and solidarity. Recognizing the value of human dignity serves as a reminder that persons with disabilities have a place in society and are entitled to that place

with dignity (Quinn, Degener, & Bruce, 2002). Despite core concepts the Social Model of Disability and the Human Rights Model have proposed people with disabilities are still discriminated within society (Tervo & Palmer, 2004; Vilchinsky, Findler, & Werner, 2010). Similarly, Miller and Major (2000) suggested that social stigma can negatively influence the quality of life of people with physical disabilities.

Therefore, we were interested in exploring socio-demographic factors which could help us to understand individual vulnerability to the stigma, more specifically, internalized stigma. Internalized stigma is experienced when a person is aware of stereotypes that describe stigmatized group that he/she is a member of, agrees with them and finally apply it to oneself (Corrigan, Larson, & Ruesch, 2009). Furthermore, internalized stigma is defined as "...subjective process taking part in specific social-cultural context, depicted by negative feelings toward oneself, maladaptive behavior, identity transformation, stereotypes acceptance emanating from personal experience, perception or anticipation of negative social reactions based on particular health condition" (Livingston & Boyd, 2010, p.2151). Therefore, internalized stigma is associated with various psychosocial outcomes such as poor quality of life low empowerment, reduced self-efficacy and self-esteem, and hopelessness (Lysaker, Roe, & Yanos, 2007; Taft, Ballou, & Keefer, 2013).

One of the psychological constructs important for a person's well-being and life satisfaction is empowerment. Empowerment is an important factor for overcoming stigma, so it is often thought that empowerment and internalized stigma are two poles of a continuum (Watson & Larson, 2006). A number of scholars were interested in exploring this construct, which resulted in a number of different definitions (e.g., Clark & Krupa, 2002; Rappaport, 1987; Segal, Silverman, & Temkin, 1993). Empowerment can be defined as "a process, a mechanism by which people, organizations, and communities gain mastery over their affairs" (Rappaport, 1987, p.122), or as a process of gaining control over one's life and influencing organizational and societal structure in which one lives (Segal et al., 1993), or as "an individual or group process that increases personal control by way of critical thinking, action and power sharing, that ensures dignity and equity through social exchange" (Clark & Krupa, 2002, p. 342). In summary, empowerment is important for an individual to feel having their life and actions under personal control. This particularly can be questionable regarding people with physical disabilities as very often decisions have been made for them, such as from their caretakers. Thus, exploring factors which could contribute to empowerment would give us a valuable insight how to support people with physical disabilities.

Socio-demographic variables associated with internalized stigma and empowerment

Examining relationship between psychological constructs and socio-demographic variables is important as it helps us to understand which categories of people are more vulnerable in developing internalized stigma and consequently in decreasing levels of empowerment. In people with mental illness and with disabilities, findings pertinent to association between socio-demographic characteristic and internalized stigma are not consistent.

Findings related to gender are diverse. In the studies conducted with participants with intellectual disability (10% had mobility problems; Ali, King, Strydom, & Hassiotis, 2016) and bipolar disorder and depression (Brohan, Gauci, Sartorius, Thornicroft, & GAMIAN–Europe Study Group, 2011) no relationship between internalized stigma and gender was found On the other side, among participants with mental illness men had higher internalized stigma scores than women (Krajewski, Burazeri, & Brand, 2013). Due to mixed results related to associations between gender and internalized stigma we hypothesized that no difference among man and women with physical disabilities exists in expressed levels of internalized stigma.

Findings regarding associations between age of the participants and internalized stigma are also mixed. While some studies did not find correlation between these constructs (e.g., Kamaradova et al., 2016) other showed that degrees of internalized stigma increased with the age (Ali et al., 2016). Further research is needed to examine relationship between gender and age of the participants and internalized stigma.

In regard to level of education, few studies found that participants with mental illness and inflammatory bowel disease who had higher level of education reported less internalized stigma (Brohan et al., 2011; Krajewski, Burazeri, & Brand, 2013; Taft et al., 2013). These results are somewhat expected as people with higher levels of education are more likely through their university experiences to develop relationship with peers which consequently can mitigate stigma internalization. Thus, we would expect to see lower levels of internalized stigma among people with physical disabilities with university degrees in comparison to the ones with high school diploma.

Furthermore, marital status could be a protective factor of perceived discrimination (e.g., Schulz & Decker, 1985). Accordingly, people with mental illness in Czech Republic who were married or in a relationship had a lower levels of internalized stigma (Kamaradova et al., 2016), while married Serbian people with physical disabilities less perceived discrimination than unmarried participants (Milačić Vidojević, Tošković, Dragojević, & Čolić, 2017). Based on the current findings, we expect that married participants report lower degrees of internalized stigma in comparison to unmarried participants.

Employment status was significantly associated with levels of internalized stigma. Particularly, employed participants had lower scores of internalized stigma, compared to unemployed participants (Brohan et al., 2011; Krajewski, Burazeri, & Brand, 2013). Presented findings show that more educated individuals and the ones who were employed had lower scores of internalized stigma. It could be that the ones who have higher education are also the one who are employed as well.

Presented findings related to associations between different socio-demographic correlates and internalized stigma and empowerment are mainly obtained in a sample of people with mental illnesses. To the best of our knowledge, these associations were not examined in people with physical disabilities. Therefore, our study aims to fill in gaps related to relationship among socio-demographic characteristic and internalized stigma and empowerment.

The aim of the study was to examine if there were differences between scores of internalized stigma and empowerment in relation to socio-demographic characteristics (gender, age, education level, marital status, living arrangement, employment status) of participants in a sample of people with physical disabilities.

METHOD

The sample

Participants were 119 adult persons, aged between 18 to 70 years (M = 35.68; SD = 14.63), with different disorders of the musculoskeletal system (spinal cord injury, muscular dystrophy, multiple sclerosis, amputation, orthopedic cases, cerebral palsy; see Milačić Vidojević et al., 2020 for more details). Table 1 shows the socio-demographic characteristics of the sample.

Table 1. *Socio-demographic characteristics of sample (N = 119)*

		Frequency	Percent
gender	male	59	49.6
	female	60	50.4
education	primary	19	16.0
	secondary	78	65.5
	higher	22	18.5
employment	unemployed	43	36.1
	student	20	16.8
	employed	31	26.1
	retired	25	21.0
marital status	single	75	63.0
	married	35	29.4
	divorced	4	3.4
	widowed	5	4.2

Instruments

In the study two scales were administrated: revised *Internalized Stigma of Mental Illness Scale* (ISMI) and *Boston University Empowerment Scale* (BUES). With regard to aim of the present study, ISMI was adapted using term "physical disability" instead of "mental illness". Other studies also revised ISMI in accordance with their sample, such as epilepsy, leprosy, etc. (see Milačić Vidojević, Čolić, Tošković, & Dragojević, 2020). The BUES was translated in Serbian language and back translated to English, while we applied Serbian version of ISMI (Milačić Vidojević, Dragojević, Tošković, & Popović, 2014).

Internalized stigma was assessed using revised *Internalized Stigma of Mental Illness Scale* (Ritsher, Otilingam, & Grajales, 2003). ISMI consists of the following five subscales: a) *Alienation* (6 items) that measures a personal experiences of feeling as not being equal member of society b) *Stereotype Endorsement* (7 items) which examines the degree with which a person agrees and accepts stereotype about disability, c) *Perceived Discrimination* (5 items) explores perception of the individual in relation to other people discriminate persons with disabilities, d) *Social Withdrawal* (6 items) measures degree of social withdrawal, and e) *Resistance* (5 items) explores resistance to stigma

internalization . It is a 4-degree Likert-type scale, with four degrees of accepting the item, ranging from not agree at all (score 1) to agree completely (score 4). Higher score points to higher degree of stigmatization. Ritsher, Otilingam, and Grajales (2003) found strong internal consistency ($\alpha = 0.90$) and high test-retest reliability ($r = 0.92$).

Subjective feelings of empowerment were assessed using *Boston University Empowerment Scale* (Rogers, Chamberlin, Ellison, & Crean, 1997). BUES contains 28 items measured on a 4-point Likert scale ranging from "strongly agree" to "strongly disagree". The items are grouped into five subscales: *righteous anger, optimism and control over the future, self-esteem-self-efficacy, perceived power-powerlessness, and community activism and autonomy*. Higher scores represent a lower capacity of making decisions and lower levels of self-esteem/self-efficacy and power. The scale has demonstrated good consistency and internal reliability, factorial validity and known-groups validity. The scale had high internal consistency with Cronbach alpha 0.86 and 0.82, and good factorial validity (Rogers et al., 1997).

Data analysis

Pearson correlation coefficients, One-way analysis of variance (ANOVA), Scheffe post hoc test, and t- test for independent samples were applied in analyzing the data.

Procedure

The fourth semester students of the Faculty of Special Education and Rehabilitation at University of Belgrade were trained to conduct an interview and administrate the ISMI and the BUES. The organizations of people with different types of physical disabilities in Serbia were contacted and invited to participate in the study. The participants were recruited through the organizations which agreed to participate. Interviews were conducted in a private room with participant. The participants were informed that their responses would be kept confidential and they could terminate the participation in the study at any moment without negative implications for care received. The testing procedure lasted 30–45 minutes. Local requirements for ethical approval of the study were met. The participants provided oral consent for taking part in the study.

RESULTS

In the *Internalized Stigma of Mental Illness Scale* ($M = 2.06$; $SD = 0.47$), the highest mean value was observed in the *Resistance* subscale ($M = 2.83$), and the lowest in the *Endorsement* subscale ($M = 1.70$). According to the results found in participants with physical disabilities in the *Boston University Empowerment Scale*, the highest arithmetical mean was noticed in the *Power* subscale ($M = 1.70$), followed by the subscales *Self-esteem* ($M = 18.52$), *Community* ($M = 10.62$), *Anger* ($M = 9.32$) and *Optimism* ($M = 8.47$).

Socio-demographic correlates of stigma

The independent sample *t* test didn't reveal any significant difference between genders on stigma and empowerment scores.

The independent sample *t*-test showed that unmarried participants had higher scores on internalized stigma *perceived discrimination subscale* ($t = 1.995$, $df = 117$, $p < 0.05$), than married participants. Further, we established that participants who did not live in their own apartment reported higher level of *alienation* ($t = -2.696$, $df = 117$, $p < 0.01$), *perceived discrimination* ($t = -3.475$, $df = 117$, $p < 0.01$), *withdrawal* ($t = -3.205$, $df = 117$, $p < 0.01$) (Figure 1), as well as lower level of empowerment subscale *community* ($t = -3.627$, $df = 117$, $p < 0.01$) and *power* ($t = -2.656$, $df = 117$, $p < 0.01$) (Figure 2), than participants who had lived in their own apartment (Figure 1).

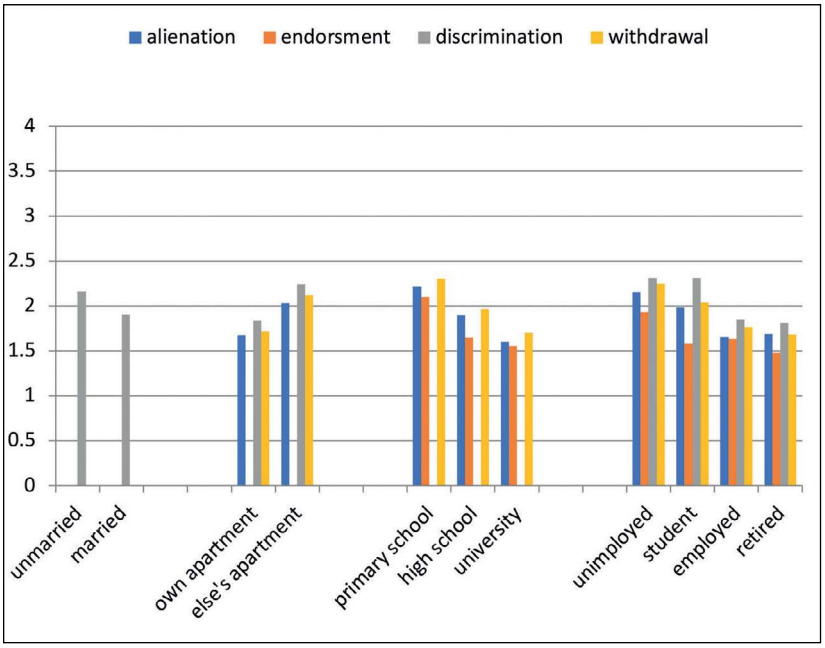

Figure 1. Internalized stigma scores in relation to socio-demographic variables

One-way analysis of variance (ANOVA) on the level of education was conducted for each of stigma subscales. Results indicated that the level of education was associated with *alienation* ($F(2,116) = 4.197$, $p < 0.05$), *endorsement* ($F(2,116) = 6.064$, $p < 0.01$) and *withdrawal* ($F(2,116) = 4.165$, $p < 0.05$) subscales of internalized stigma (Figure 1). Also, level of education was related to empowerment *self-esteem* ($F(2,116) = 5.204$, $p < 0.01$) and *optimism* subscale ($F(2,116) = 3.339$, $p < 0.05$) (Figure 2). Participants with a lower education levels showed higher degree of internalized stigma alienation, endorsement and withdrawal, as well as lower level of empowerment self- esteem and optimism.

In addition, ANOVA was conducted to examine relation of current professional level (student, unemployed, employed and retired) for stigma subscales separately for each

factor. Analyses showed that the professional level was related to *alienation* ($F(3,115) = 4.307, p < 0.01$), *endorsement* ($F(3,115) = 4.314, p < 0.01$), *discrimination* ($F(3,115) = 6.235, p < 0.01$) and *withdrawal* ($F(3,115) = 5.361, p < 0.01$) subscales of internalized stigma (Figure 1). Also, professional level was related to empowerment *self-esteem* ($F(3,115) = 3.226, p < .05$), *community* ($F(3,115) = 9.703, p < 0.01$) and *optimism* subscales ($F(3,115) = 3.768, p < 0.05$) (Figure 2). Scheffe's post-hoc tests revealed that participants who were unemployed reported a higher level of alienation than participants who were employed, and a higher level of endorsement than retired participants. Analyses also indicated that participants who were unemployed experienced more withdrawal from society and overall internalized stigma than both participants who were employed and retired participants. As for empowerment scales, results showed that unemployed participants experienced less self-esteem than students, and less belief in community than retired participants (Figure 2).

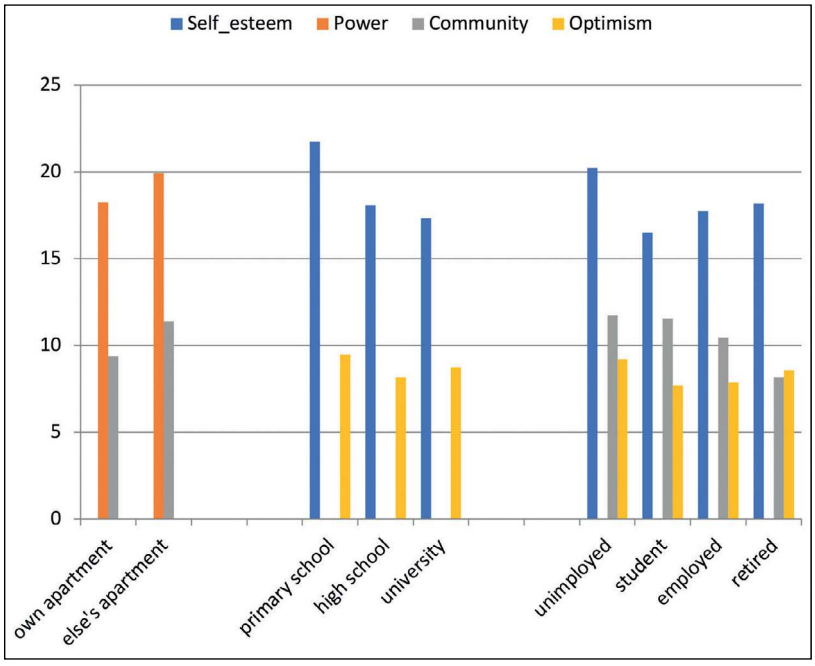

Figure 2. Empowerment scores in relation to socio-demographic variables

Pearson correlation was used to examine the relationship between the age of participants and each subscale of internalized stigma scores and empowerment scores. Results revealed a negative relationship between age and *alienation* ($r = -0.201, p < 0.05$), *endorsement* ($r = -0.193, p < 0.05$), *discrimination* ($r = -0.301, p < 0.01$), *withdrawal* ($r = -0.275, p < 0.01$) on subscales of internalized stigma and empowerment *community subscale* ($r = -0.359, p < 0.00$). Younger participants felt having more alienation, endorsement, discrimination and withdrawal and less belief in community strength.

DISCUSSION

The study aimed to explore the relationship among the components of internalized stigma and empowerment and socio-demographic characteristics of adult people with physical disabilities.

As far as socio-demographic correlates of internalized stigma and empowerment are concerned, there were no differences neither in stigma nor in empowerment due to gender of participants. Unmarried compared to married participants had higher scores on ISMI subscale perceived discrimination. Social support due to marital status is found to be connected to lower *perceived discrimination* (Schulz & Decker, 1985).

Participants not living in their own apartments had higher scores on *alienation*, *perceived discrimination* and *social withdrawal* subscales of ISMI and lower levels on *community and power* subscales of BUES compared to participants living in their own apartments. The result is in accordance with results of other studies which established that the highest anticipated discrimination intensity was found in participants who lived in extended families, then in those who lived in primary families, and the lowest intensity was in those living alone (Milačić Vidojević, Tošković, Dragojević, & Čolić, 2017). In Serbia 94% of persons with physical disability live with family members. These persons would have to 100% participate in paying the service of living with support what is not a possible option considering low employment rate of target population (Dinkić, Ljubinković, Ognjenović, Rajkov, & Milojević, 2008).

In the study, participants of lower levels of education had higher scores on *alienation, endorsing stereotypes* and *social withdrawal* subscales of ISMI and lower scores on *self-esteem* and *optimism* subscales of BUES. Perhaps they have less efficient coping strategies and are less familiar with their rights and opportunities. A study conducted in Ethiopia revealed that with increasing levels of education for people with schizophrenia internalized stigma was lower (Assefa, Shibre, Asher, & Fekadu, 2012). Similar results were found among people with mental illness in Europe (Brohan et al., 2010). Also, it was established that carrying out fulfilling activities strengthen the sense of meaning (Viemero & Krause, 1998). Herth established that more educated participants of general population obtained higher scores on Hope scale (Herth, 1992). The more educated persons more easily see the ways to achieve positive goals in the future and more easily notice the provided opportunities. In accordance is the result of the study that more educated participants expressed stronger capacity for problem solving (Langelaan, 2007).

Unemployed compared to employed participants had higher general score on ISMI scale as well as higher scores on *alienation, endorsing stereotypes, perceived discrimination and social withdrawal* subscales of ISMI. Unemployed compared to retired participants obtained higher general score on ISMI scale as well as higher scores on *endorsing stereotypes* subscale of ISMI and lower scores on *community* subscales of BUES. Also, they have lower levels of *self-esteem and optimism* subscales of BUES compared to students. Unemployment leads to feelings of alienation and marginalization (Milačić-Vidojević, Jovanović, & Brojčin, 2010), which is an additional burden for persons with disabilities. Persons with disabilities may experience discrimination in looking for a job or keeping a job. Unemployment can have serious negative effect on the lives of disabled

persons, such as financial and psychological stress, feelings of frustration and being constrained to live on state benefits. Employment status appeared to be important for social identity and feeling of self-esteem of persons suffering from schizophrenia. Unemployed participants felt isolated and marginalized (Milačić-Vidojević et al., 2010). Satisfaction with life situation in persons with physical disability is connected to the profession or meaningful activities, to social integration, to sense of life meaning (Viemero & Krause, 1998), and to increased independence (Fleming, Fairweather, & Leahy, 2013). These studies confirm that engagement in purposeful activity supports satisfaction with various life domains.

There is no systematically processed data related to the employment level of people with disabilities available in Serbia. In developed EU countries the employment level of adults with disabilities is around 50%, whereas in some other countries, i.e. Poland, it's less than half (Łukomska, 2008). Moreover, according to some studies, most employers in Poland hardly even consider the possibility of hiring persons with disabilities, primarily due to the stereotypes linking disabilities with a lack of independence, skills, potential and ambition (Kowalik, 2007).

Younger participants had higher scores on *alienation, endorsing stereotypes, perceived discrimination and social withdrawal* subscales of ISMI and lower scores on *community* subscale of BUES compared to older ones. Younger participants have higher life expectations in terms of performing developmental tasks, which is difficult to achieve due to disabilities. These results are in line with the studies which showed a negative relationship between age and internalized stigma (Livingston & Boyd, 2010) but not in accordance with the study which showed positive association (Krajewski, Burazeri, & Brand, 2013). An additional research is necessary. The experiences of discrimination are more evident at young age which leads to self-stigmatization. Young people have less experience of believing in the community, they have not yet been able to empower themselves.

Examining intensity of anticipated discrimination in persons with physical disabilities it was established that discrimination is more anticipated by unmarried participants, younger, participants living in extended families and by participants not living in their own apartments (Milačić Vidojević, Tošković, Dragojević, & Čolić, 2017), the results in accordance with findings about internalized stigma and empowerment in target population.

Most persons with disabilities are fully aware of their exposure to this stigma, which adversely affects their self-esteem and general disposition, increases sensitivity to stressful events, impairs communication, lowers aspiration levels, diminishes possibility of receiving social support, and generally lowers their quality of life (Abraham et al., 2002; Cooney et al., 2006; Jahoda et al., 2010; Paterson, McKenzie, & Lindsay, 2012), including issues in finding and keeping employment. As a consequence of a series of intertwined external and internal barriers, belonging to the "disabled" category often becomes the person's primary identity and overshadows all other identities such as religious, ethnical or gender (Beart, Hardy, & Buchan, 2005). Family members are often exposed to the stigma as well, particularly parents, which deepens the social exclusion of both the person with a disability and their family, creating further difficulties in participating in social, cultural, economic and political life and isolating them from the

community (Milačić Vidojević, Gligorović, & Dragojević, 2014; Munyi, 2012; Ouellette-Kuntz et al., 2009).

CONCLUSION

Socio-demographic variables appeared to have considerable importance for the understanding of internalized stigma and of empowerment in adult people with physical disabilities. It was revealed that higher levels of internalized stigma had unmarried, unemployed, younger, less educated participants, and participants who did not live in their own apartments.

Thus, in designing anti-stigma campaigns and programs for empowerment it is important to take into consideration specific socio-demographic characteristics of the targeted individuals. Specifically, anti-stigma and empowerment programs tailored for Serbian people with physical disabilities should be aimed at unmarried, unemployed, younger, less educated participants, and participants who do not live in their own apartments.

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