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ORIGINAL ARTICLE

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"This is not life, this is just vegetation"—Lived experiences of long-term care in Europe's largest psychiatric home: An interpretative phenomenological analysis

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Abstract

Purpose: Understanding the experiences of long-term care (LTC) may help to improve care by assisting mental health professionals and allowing mental health policies to be customized more effectively.

Design and Methods: Semistructured interviews were analyzed using interpretative phenomenological analysis (IPA).

Findings: Three main themes emerged as a result: 1. *Perception of selves*, 2. *Experience and representation of the institution*, 3. *Maintenance of safe spaces*.

Practice Implications: Communication with patients, investigation of their identity processes, and relationship toward their past and present self during LTC might aid in well-being and sense of congruency in their identities. Nurses should encourage patients to keep connected with their memories and past selves through different activities.

KEYWORDS

Central and Eastern Europe, Hungary, interpretative phenomenological analysis, long-term care, mental hospitalization, psychiatry

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1 | INTRODUCTION

1.1 | The current status of psychiatry in Hungary

Hungary became a member of the European Union in 2004. However, unlike most of the other countries, which have since caught up, Hungary is still lacking an accepted appropriate mental health policy.[1] The National Program of Mental Health is existing, but the program is neither realized nor financed.[2] Meanwhile, Hungary is known for a high prevalence of mental illness[2]: neuropsychiatric disorders represent 24.7% of all medical and psychiatric diseases.[3] Mental health patients are stigmatized and rejected by the Hungarian society[4] especially the members of ethnic minorities.[5] To cope with these problems, three types of support systems have been created: long-term hospital-based psychiatric facilities, outpatient care, and community-based support. According to Turnpenny et al.,[6] Hungary has a relatively high number of beds (5456) available in hospital-based psychiatric institutions (62 units), however, many institutions have outdated infrastructure and overcrowded wards, where patient safety is quite poor.[7] Despite the wide accessibility of outpatient services[8] (120 units) and day services (98 units) throughout the country, their availability is limited due to oversubscription, shortage of mental health professionals, and high prevalence of burnout indicators among them[9]: health-care staff often works in "crises mode".[7] If we compare these figures to those of other EU countries with a similar population, they are higher than those in the Czech Republic (8583 beds in hospitals and 1137 units of outpatient services) and Sweden (1436 hospital units), while they are similar to the ones in Belgium (46 hospital units with 5339 beds and 101 outpatient services).[6] The number of mental health professionals in Hungary is low (50.3 workers per 100,000 people, WHO).[10] The total health budget for mental health (5.1% of GDP)[11] (p. 118, fig. 8.1) is also low in comparison with the European average of 8.9%[12] (cited by Kurimay[13]). For example, in Sweden, this expenditure represents 9.4% of GDP and in Belgium, the figure is 9.6%.[14] One alternative could be community psychiatry, which aims to help reintegrate people with mental health problems. However, in Hungary, such centers are still deficient[15,6] when compared with centers in other EU countries.[16]

1.2 | Large mental institutions and long-term care (LTC) in Hungary

Psychiatry was special during the communist regime in Central and Eastern Europe (Marks & Savelli, 2015). People with mental illnesses were socially excluded and hospitalized in large, outdated, long-stay[17] psychiatric asylums[15,18,19,] (p. 16). These institutions[20] avoided psychiatric deinstitutionalization[21,22,23] and have been operating with a large number of patients[24] in relatively isolated geographical areas ever since[25] with inadequate hygiene facilities and overcrowded conditions.[26] The Hospital Act of 2006 led to noneffective efforts toward deinstitutionalization.[27] These efforts left "crippled services behind"[28] (p. 308). The psychological hospitalization rates in Hungary have been increasing in recent years,[28] while the quality of professional care is decreasing due to the lack of resources, lack of deinstitualisation, lack of renovation of buildings and paternalistic institutional attitude remaining from the socialist area.[29]

1.3 | History of the Szentgotthárd Psychiatric Home

This study focuses on the Szentgotthárd Psychiatric Home (SZPH). It is one of the last remaining large psychiatric institutions in Hungary, with 734 beds currently available. SZPH was founded in 1952. The first patients came from various marginalized groups: war orphans, homeless people, and so on.[30] SZPH has operated nonstop for the last 70 years and has not undergone any significant reform to its structure at this time. Schizophrenic patients constitute the majority of those at SZPH (83%). Apart from patients with severe personality disorders (1.4%) and affective disorders (2.2%), patients with chronic substance abuse problems (7.4%) pose the greatest challenge in everyday care.[31]

1.4 | LTC in different institutional contexts

LTC is a broad concept that encompasses long-lasting psychiatric hospital care (LLP)[32] long-term care within nursing homes, dementia homes, and care homes. It operates according to formal institutional rules, and inflexible activity structures and schedules, under which people are classified into two hierarchical categories, namely, patients and nurses.[33]

In recent decades, high-quality LTC facilities have been introduced in Western Europe.[34,35] Large psychiatric hospitals have been deinstitutionalized: most effectively in North-America[36,37], but also in Western Europe.[38] Furthermore, mental illnesses, for example, schizophrenia has been de-stigmatized.[39,40,41] In contrast, mental health care is still provided in large psychiatric hospitals in Central and Eastern Europe.[42] As a result, a high proportion of people with mental illness are left without treatment.[43] This lack of deinstitutionalization may contribute to the sustained gap in life expectancy between psychiatric patients and the rest of society.[44] Reintegration is a challenge that is yet to be resolved.[45] LTC may change the resident's identity[46-48] through deprivation,[49] exposure to bureaucratic hierarchies,[50] and loss of "normality"[51] and the possibility of dementia.[52] Patients may face a series of relocations[53] and struggle with social and self-stigmatization.[54,55] Long-term hospitalization can lead to a lower quality of life.[40,56] Furthermore, patients in hospitals struggle with social deprivation and loss of involvement in community activities.[57,58] During LTC, social exclusion can be a source of stress.[59]

The harmful effects of deprivation can be intensified if patients' self-determination[60,61] is restricted. Lost competence over self-care can lead to lower self-esteem and institutional dependency.[59] They

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are at a higher risk of increased dosages of medication, which might be counterproductive in rehabilitation.[62]

1.5 | Research questions

Most of the qualitative studies which have examined conditions in LTC (not within psychiatric hospitals) have focused predominantly on staff members, nurses[63,64] older patients with dementia (e.g., Smit et al., 2016)[65] or pharmaceutical aspects of the issue.[66] Research suggests that there is a lack of person-centered care[67] and that LTC presents challenges for self-determination[61,68,69] and self-continuity. Little qualitative research has focused on the lived experience of LTC. Chamberlain et al.[57] investigated LTC homes where residents spoke of a lack of decision-making capacity, unmet care needs, aggressive impulses, and isolation. Other researchers have focused on the experiences of patients with HIV/AIDS in LTC,[70] family members' experience of having relatives in LTC[71] and nurses among older adults in LTC[72,73] focused on the challenges that residents face and their coping strategies. The aim of this study was to investigate the experiences of LTC, the various selves which exist in parallel and how these are perceived in LTC in Central and Eastern Europe. Our research questions were as follows: *1. What are the common experiences of everyday life among long-term residents for a large mental institution? 2. How do participants make sense of being in long-term care (LTC?)*

2 | METHOD

This study was conducted at SZPH from November 2017 until May 2018. The first, second, third, seventh, and eighth authors visited and investigated SZPH. The Director (sixth author) looked for volunteer patients and selected interviewees. She obtained approval from the ethics commission and the approval forms from the guardians and informed us of the patients' history of diagnosis.

The Markusovszky Academic Teaching Hospital's Regional Scientific and Research Ethics Committee approved all study protocols. All of the patients' guardians authorized their participation and signed informed consent forms.

2.1 | Sample

The authors decided that patients needed to have lived in the home for at least 20 years ($M_{\text{length of residency}}$ = 27.66; min = 21, max = 37) in order for them to be able to recount their lived experience of the changes to the institution and their own self-experience. As coherent reconstructive narration was important, dementia was an exclusion criterion. We conducted a total of 11 interviews, from which we analyzed six (three male and three female participants), as five of them did not provide the detailed information required by interpretative phenomenological analysis (IPA). Participants are referred to as patients in this study rather than clients because this is how inmates are commonly described in institutional discourse (Simmons et al., 2010). Of the six interviewees (M_{age} = 65.16; min = 42, max = 76), one patient had been diagnosed with manic depression, one with psychopathy, one with bipolar disorder, and three with schizophrenia. Characteristics of the sample are presented in Table 1.

2.2 | Data collection

Semistructured interviews were carried out (minimum: 24 min, maximum: 1 h 28 min). Questions assessed experience as patients in LTC, change in self-experience, life circumstances, and relationships. Questions included: *How does it feel to live here? What changes have occurred since you moved here?*

2.3 | Data analysis

Interviews were transcribed verbatim. The first four authors analyzed six interviews one by one using the IPA method introduced by Smith et al.[74] During the standard analysis, the left margin contained the emergent themes and the right margin contained the exploratory comments.[75]

The research team then organized the themes that emerged from the interviews. Finally, the fifth and last authors reviewed the entire analysis to ensure that an independent revision of the IPA was carried out (Fischer, 2009). Disagreements and other opinions were discussed throughout the process of finalizing the results.

TABLE 1 Characteristics of the sample including gender, age, education, length of residency, and current diagnosis

	Name	Gender	Age	Educational background	Length of residency	Diagnosis
1	György	Male	66	Primary School	37 years	Schizophrenia
2	Tamás	Male	61	Primary School	23 years	Schizophrenia
3	Lajos	Male	72	Grammar School	27 years	Psychopathy and acute psychotic disorder
4	Rita	Female	74	Grammar School	33 years	Manic depression
5	Hilda	Female	76	Grammar School	21 years	Schizophrenia
6	Eszter	Female	42	Special School	25 years	Bipolar affective disorder

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3 | RESULTS

Three master themes emerged: (1) Perception of self; (2) Experience and representation of the institution; and (3) Maintenance of safe spaces, with eight additional subthemes. The results are shown in Figure 1.

3.1 | Perception of selves

In LTC, the self-perceptions of our interviewees have changed. The first master theme comprises three subthemes.

3.1.1 | Preinstitutional self

The preinstitutional self is how patients' see the self before moving into the institution. It is a more effective agent than the current institutional self. This self has various roles in society.

> "From weeping for joy as a European champion to the madhouse." (György)

György describes himself before the institute as an overjoyed tennis champion, an extremely successful and pleased successful person. His life narrative echoes the deterioration of his successful preinstitutional self and depicts a backsliding life story.

> "I was free as a bird, however, it's a shame I clung on to my mother, we had lots of fights and arguments." (Tamás)

Tamás compares his freedom to that of a bird, however, in the second part of the sentence he describes his "shameful" co-dependent relationship with his mother. Freedom is experienced through external connections, arguments and the right to make decisions.

3.1.2 | Experience of assimilated and habituated self through dependency, uniformization, and losing independency

Residents claim that they have started to accept their status as patients and assimilate into the institutional environment. They become more and more dependent on the institution and their level of identification rises.

> "I integrated, I accommodated. I became accustomed to it, I was good." (Tamás)

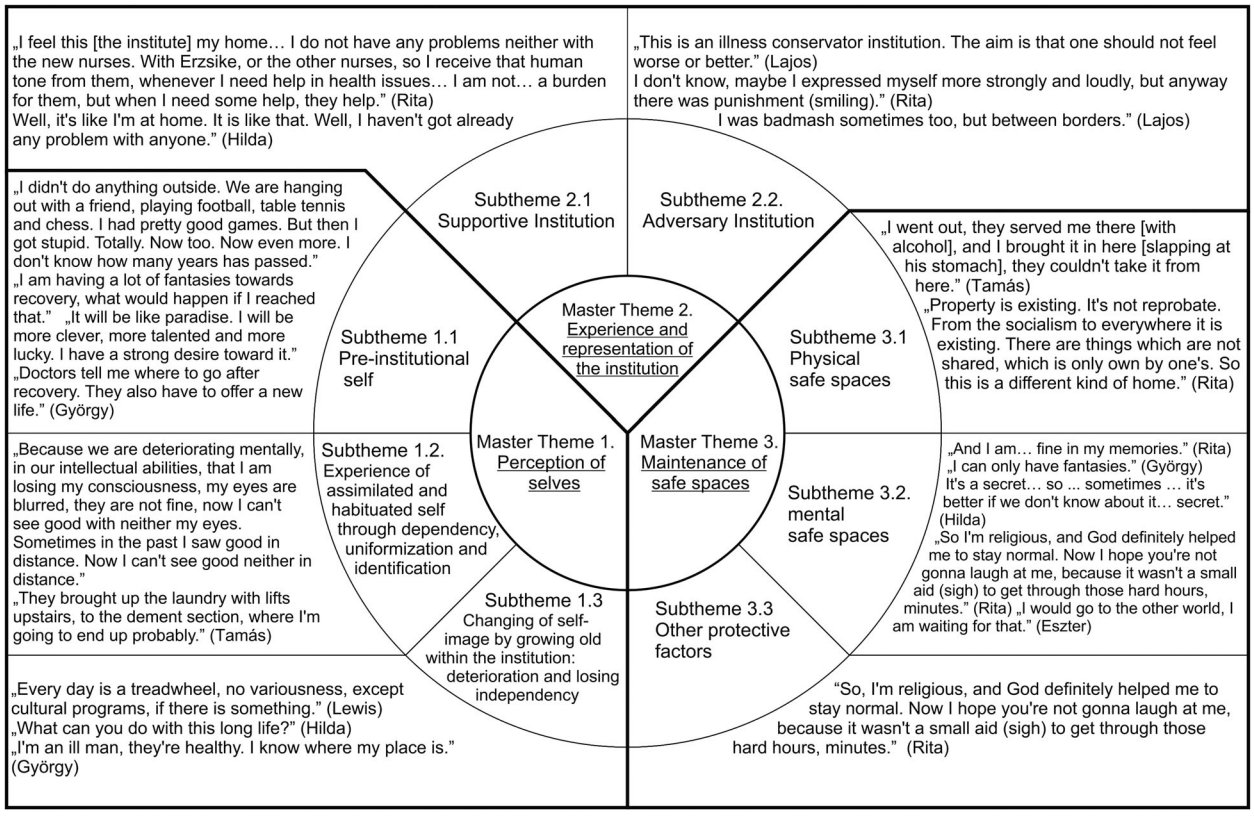

FIGURE 1 Structure of results with master themes and subthemes

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Tamás explains his experiences from the perspective of his uniformized self. He expresses the great efforts he made to become accustomed to his new circumstances. Through the integration of common rules and norms, a new self is created, which is an organic part of the institution.

> "There are people who are sent here because they stabbed someone. But there is no problem with them. The big foe (here) is alcohol." (Lajos)

There is a transition between the norms of the preinstitutional self and the resident-self. Lajos starts to speak from an outside perspective and mentions the law of society and then presents the inner rules which deem alcohol consumption as the biggest sin. This reflects a contradiction between the norms of the preinstitutional and institutional-self, which results in the dominance of the institutionalized self through the acceptance and integration of institutional norms and values.

> "They know me. If a new employee arrives, they shouldn't show him the place, they should introduce him to me instead" (Lajos.)

Lajos takes pride in being the most prototypical character in the institution. Understanding him means understanding the psychiatric home itself. He identifies himself with the institution.

3.1.3 | Changing self-imagine by growing old within the institution: Deterioration and losing independency

The change in identity through the deterioration of the preinstitutional self continues and peaks with mental and physical deterioration.

> "There was a lot of work, I could not do it anymore. I got old. Since then I haven't been able to do it." (Eszter)

In the institution, work gave Eszter the opportunity to experience herself as an active agent. By getting old, she loses her abilities, and sense of being agentive.

> "The old ones were better, but they all died. I would prefer to go to the other world." (Eszter)

Growing old within the institution has an effect on patients' social life as fellow patients pass away. The loss of company leads to a sense of loss of social stability. With the death of her generation, she also expresses her will to die.

> "Because I got those injections which made me feel like I had been reborn. But they are not offering them anymore because they are expensive, and I can't afford them." (Tamás)

Tamás wishes to regain the old self. He believes that it is possible to purchase the independent, working self again. As he does not have enough money, he does not have any independence either.

3.2 | Experience and representation of the institution

On various occasions, the experience of the institution changes. Depending on their attitudes, patients tend to describe the institution as either supportive and adversary.

3.2.1 | Supportive institution

Those who found the institution supportive tend to have fewer conflicts with the staff. They found and created a new home there (institutional self).

> "Well, it's like I'm at home. I don't have any problems with anyone." (Hilda)

Hilda describes the institution as a protective, peaceful environment, and likens it to her preinstitutional home.

3.3 | Adversary institution

> "They want my life. And I am in the place where they can gradually make you dumb slowly and carry out experiments on you." (Tamás)

Tamás describes the institution as an enemy which tries to keep him quiet and makes his mental and physical state even worse. The institution embodies the entity that is responsible for his change in circumstances, that is, it takes away freedom, connections, and preinstitutional self.

3.4 | Maintenance of safe spaces

Patients are aiming to keep the congruency and integrity of their personalities; they try to establish a balance between their preinstitutional and resident selves. Maintenance strategies are manifested in different safe spaces where the sense of autonomic preinstitutional self can be kept safe.

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3.4.1 | Physical safe spaces

When in LTC, patients' own bodies can function as a safe space.

> "I jerk off for a while, in vain, but if I were to injure my right hand, then I wouldn't be able to exist." (Tamás)

In Tamás's case, masturbation as a body-related serves as an experience of existence. Masturbation remains an important activity through which he can experience the integrity of his body. The loss of his hand would mean an end to masturbation, which in turn would threaten his existence. Masturbation is connected to strength and vitality, and therefore a safe body-image connecting him to the preinstitutional self.

Tamás operates with other body-related safe spaces as well:

> "I went out, and they served me (alcohol), and I brought it back in here (patting his stomach), they couldn't take it from here (smiling.)" (Tamás)

His body has a container function, that is, what he consumes will remain his own. His body serves as the boundary between the institution and himself. By smuggling alcohol, he experiences his strength through the autonomy of his body. This trick gives him the sense that the institution cannot cross the border of his body.

In some cases, explicit confrontation and denial of the psychiatric home's rules also serve as safe places, through the expression of physical strength.

> "I had a fight with one of the nurses. I shook the door, then she started to shake me, and screamed at me. […] Later I hit a cashier woman. Then she asked so kindly, "how much would you like Tamás, how much do you wish for?" (Tamás)

Tamás expresses his needs in an aggressive way, through his body, as verbality does not seem to be effective. Breaking the rules gives Tamás a feeling of power, a sense that he can beat the institutional system. This might give him a sense of self-control despite the fact that the institution controls his money.

In some cases, the border of the self is extended to property. Safe spaces can also be physical belongings.

> "We do have property, it's allowed. There are things that we don't share, which are only owned by one person." (Rita)

Private property is depicted as a means of keeping a distance from institutional life and other patients. It helps to maintain an image of ordinary life and keep boundaries.

3.4.2 | Mental safe spaces

Mental safe spaces function as gateways to privacy, while they also carry a sense of dissociation from the context of LTC. Safe spaces can be created by living in the comfortable past and immersing oneself in secrets, fantasies, death, religion, and other protective factors.

One strategy is to live in a comfortable past.

> "I will continue to nourish my memories because we had a beautiful life until '88." (Hilda)

Memory is a safe space for Hilda. She uses a child-related metaphor for the past, which she is "nourishing."

> "I know what I have to do." *(Lajos)*
> "What do you have to do?" *(Interviewer)*
> "Let's keep it a secret." *(Lajos)*

The decision to keep information secret and not tell anyone about it could also be considered a safe space. A part of Lajos's identity is considered something that should be kept private. He is able to establish a private core of identity which serves as a pillar for the hope of recovery.

Fantasies can be used by patients as a safe space where they can dream about what their lives will be like if or when they recover and leave the institution.

> "My first plan is to get out of here. If I succeed, the world is gonna be mine. If I have money, I will be able to accomplish a lot of things. […] If I recover, I will be able to write better, but at the moment this illness is stopping me, both physically and mentally." (György)

At the moment, his talents are stifled by illness and a lack of money. Fantasies place every goal and happiness outside the institution.

The imagination of death is also an important topic for elderly patients.

> "There are two people I used to speak to. I've lost my lust for life. I want to go to the other world." (Eszter)

This quotation indicates that the future exit from the institution, together with the loss of friends and lust for life, comprise elements of a dying self.

3.4.3 | Other protective factors

During social isolation within the institution, a relationship with God may function as a social relationship.

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> "So, I'm religious, and God has definitely helped me to stay normal." (Rita)

Belief in a higher power is experienced as a social relationship and a source of emotional support. Religion provides patients with a transcendent safe space.

Old connections with relatives and friends help keep part of the past self in the present.

4 | DISCUSSION

The aim of this study was to investigate experiences of LTC, and perceptions of selves.

Three main themes emerged as a result of the IPA. 1. *Perception of selves* reflects the transformation of patients' institutional and preinstitutional identities. Patients tend to carry on their preinstitutional identity. 2. *Experience and representation of the institution* illustrate how residents describe the institution and how the institution affects their lives. 3. *Maintenance of safe spaces* sheds light on what kind of safe spaces patients use to maintain their preinstitutional selves.

The concept of safe space originates from sociology,[76-78] and means literally spaces where one cannot be disturbed.[79,80] In qualitative research, safe space also stands for more abstract spaces, such as group memberships, or activities.[81,82] These spaces serve as a shelter from the direct control of a dominant group[83] for socially marginalized, subordinate groups, and minorities.[84] In our study, we consider safe spaces to be either physical or virtual spaces where patients are not under the influence of the institution.

The self-experiences from the Section 3 are organized and categorized in Figure 2.

Our interviewees generate meaning for their current experiences by constantly comparing the two selves. Safe spaces act as a mediator which links and provides continuity between the two selves.

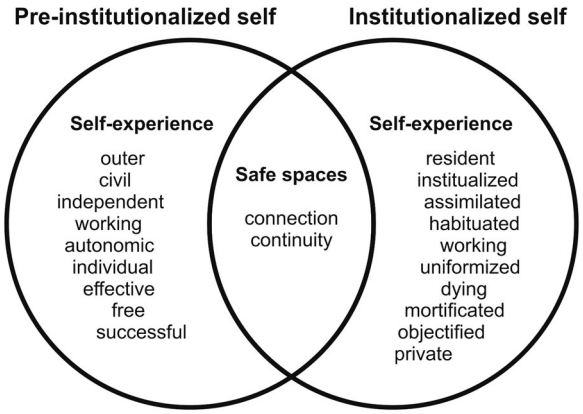

FIGURE 2 Interpretation of results

Those patients whose institutional self became stronger, and whose institutional self-experience is therefore dominant, have more motivation to create a new home in the institution. They acclimatize to institutional roles and describe the institution as supportive. Others, whose preinstitutional self remained stronger, depicted the institution as neutral or adversarial. They have more conflicts with the institution and rely on their safe spaces. These safe spaces can be nonhostile, that is, pleasant memories, religion, secrets, fantasies, or property. However, they can also be hostile, that is, breaking the rules, alcohol consumption, death.

Our results appear to support previous findings which suggest that LTC is a special context,[85] especially in Central and Eastern Europe,[86] where patients can often experience the shortcomings of LTC-care[87] and long-term care hospitals (LTCHs).[88] LTC can influence a patient's perception of reality, social interpretations, and preferences, together referred to as habitus,[89,90] which can alter and fracture during LTC. Therefore, LTC has an impact on natural changes in the self-representation of a patient through prepatient and in-patient change.[47,48,91] In LTC patients' quality of life (QoL) decreases[92] and autonomy and personal bonding[93] are weakened[60] as a result of increased deprivation.[49] This can lead to institutionalization[59] and hospitalization[40,94] of patients, both of which are a challenge to the continuity of self.[61,95] We found that under these circumstances two selves emerge. One of the selves is left behind at home, the other is established in a hospital. LTC creates a gap between the two self-experiences. This may challenge self-integrity.[33]

Self-management and self-others relationships under LTC conditions[96-99] appear to serve as protective factors. Mental and physical safe spaces are used as the basis for self-management and as the core of self-experience. We suggest extending the sociological concept of "safe spaces" to mental phenomena such as memories and self-experiences.

5 | LIMITATIONS

The limitations of this study are the same as the limitations of the IPA as a method,[100] namely, a small homogenous sample, subject specificity, inability to conclude any causal effect and ungeneralizable results.

As our interviews were carried out and analyzed in Hungarian, translation must be considered as a limitation of this study. After the coding and interpretation processes, the results were translated from Hungarian into English. Our aim was to focus on keeping the necessary information in the translation.[101]

6 | CONCLUSIONS

According to our findings, patients in LTC tend to maintain elements of their preinstitutional self and compare their institutional experiences with it. Safe spaces are important because they preserve the

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preinstitutional self and they help patients to maintain self-continuity. Through the experience of self-continuity, hospitalization is interpreted as a transition rather than as a breaking point in the patients' lives. Our results indicate that this can be an adaptive coping strategy during LTC.

7 | IMPLICATION FOR NURSING PRACTICE

Our findings suggest that the maintenance of safe spaces, that is, connections to past selves should be supported by the staff of LTC institutions, as they might function as protective factors. Communication with patients, investigation of their identity processes, and relationship toward their past and present self during LTC might aid in well-being and a sense of congruency in their identities. Nurses should encourage patients to keep connected with their memories and past selves through creative activities, communication, jobs, and so on.

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CONFLICT OF INTERESTS

In accordance with my ethical obligation as a researcher, I [the corresponding author] confirm that the sixth author of the article is the Director of the institution. This may affect the research presented in the enclosed paper. I have disclosed these interests in full and I have in place an approved plan for managing any potential conflicts arising from this. The remaining authors declare that there are no conflict of interests.

DATA AVAILABILITY STATEMENT

Transcribed interviews are available upon request from the corresponding author.

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