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Well-Being in Social and Ecological Context

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Differences of Subjective Well-Being in European Long-term Care Regimes

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Introduction: With the increase of life expectancy, the issue of quality of life (QoL) for the elderly is getting more focus. Beside the individual view, social and economic aspects are becoming more pronounced.

Aims: In this study, we set out to establish a new classification of long-term care (LTC) regimes by examining the relationship between care systems and subjective quality of life.

Methods: Our work was based on data from the Survey of Health, Ageing and Retirement in Europe through a secondary analysis of CASP-12 results. It was assumed that higher quality of life values could be observed in countries providing a higher standard of social care. We studied the background variables in different LTC regimes.

Results: The data shows that the development and availability of care systems have a significant indirect correlation with older people's subjective well-being. Our results raise the possibility of a new subdivision of care regimes.

Conclusions: Those countries featured earlier as family-based systems and Central-Eastern European countries were growing closer to each other in this classification. As our statistical method proved, family-based and Central-Eastern European regimes are not significantly different (Minimisers). Northern countries, where investment and quality of life are also high, remain highly positioned on the scale (Maximisers). Countries that have medium-level investments and subjective well-being parameters place in the middle of the scale (Optimisers). Global changes (climate, migration, political culture, technology) are expected to have an effect on social care regimes, especially on Minimisers, where the realization or failure of investments is a critical question.

Keywords: SHARE, CASP-12, LTC, quality of life, social care

Introduction

Ageing in Europe

According to Eurostat's latest report on the elderly's everyday life in the European Union – published in September 2019 – (Eurostat, 2019), in the EU population those aged 65 years or more are currently around 20% and by 2050 will be close to 30%. This increase is also remarkable in absolute terms, as it means a rise from 100 million to nearly 150 million. The phenomenon of population ageing bears a significant impact on the functioning of societies, both in numerical and structural terms (Jackson, 2007). In addition to increasing life expectancy, drastic reductions in infant and child mortality also contribute to numerical growth. The shift in age-group ratios, that is, structural ageing, is primarily a consequence of changes in fertility and birth rates. All this leads to an increase in the old-age dependency rate, which will have serious economic effects. Firstly, the decline of the ratio in the active-age-group compared to the elderly causes problems in maintaining the pension system. Secondly, provision for the elderly in need of care will be a problem and, as a result of the decline in the generation capable of caring, it is expected to place a greater burden on the state.

From a care provider standpoint, the projection of a 60% increase in the 75–84 age group by 2050 compared to 2018 is particularly important. In addition, the number of so-called oldest old people (aged 85 and over) will be at least doubled, and the number of centenarians (people aged 100 years or more) will be five times higher (Eurostat, 2019). All of this predicts that age-related decline in functioning and therefore, consequently, the need for care, will increase. Although some differences exist between the individual member states in terms of demographic trends, the median age will increase by almost four years in each country, by 2050. These tendencies are particularly challenging should we focus on the long-term care (LTC) sector, but huge differences exist also among the member states in terms of cost and care systems' development.

Long-Term Care (LTC) Systems

Population ageing increases the costs of long-term care services, as well. According to the further scenarios, GDP related LTC costs will increase to 153–224% till 2060 (De la Maisonneuve & Martins, 2015). The growing pressure influences the national budgets and determines the availability and quality of services. Consequently, long-term care systems can influence the quality of life, too. According to the OECD (2021), long-term care is defined as "consists of a range of medical, personal care, and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people", but it also has a strong social dimension, as it aims to reduce personal dependency and, if necessary, compensate for it with assistance.

EU member states, based on their particular characteristics, are often grouped into North (Scandinavian), Western European, Southern and Eastern European systems (Carrera et al., 2013). Classification of care systems is typically based on characteristics found in the divisions of state roles, family, and market, on how care tasks are organised, and on the development and availability of care needs and care services.

We used three care models as a basis of our analysis:

1. Kraus et al. (2011) formed four care clusters according to the extent of public and private financing, service, and/or care support. Models were evaluated using empirical research and secondary analysis of national databases. Main variables identified by cluster analysis were the popularity of informal care systems among users, organisation level of the systems, and generosity of funding for care systems. The first cluster was identified by the lower need of private contribution, and higher focus on informal care (Czech Republic, Germany, Slovak Republic, Belgium), the second was formed as a group of countries with generous and accessible services (Sweden, The Netherlands, Denmark), the main characteristic of the third cluster consisted of high private contribution, with good accessible services (Austria, England, Finland, France, Spain). The fourth cluster contained two countries (Hungary, Italy) formed by high care needs of informal care and a low level of financing.

2. Nies et al. (2013) revised Lamura's (2008) system classification, used in the analysis of need for care, extent of formal care, and informal care support. They identified four care models ("*care mix*", "*universal – Nordic*", "*family-based*", "*transitional*"). They found that although elderly care needs in Central and Eastern European countries ("*transitional system*") are lower, there remains a serious need to support informal care due to the underdevelopment of their formal-institutional care systems. Countries with a "*care mix*" system of care, in addition to the moderately advanced institutional care system, are trying to compensate for higher care

needs with the provision of personal financial support for care (cash for care). For countries in the "*universal care system*" group, the support for informal systems is complementary to a high level of formal care. Countries belonging to the "*family-based care*" system typically focus on the role of family care, assisted by low-quality family support forms. However, it should be noted that in many cases, this model is objectionable. For example, the Czech Republic started to shift to cash for care in 2006, and as a result, it provides a unique care system in Eastern European countries that resembles more the Austrian than the Slovakian system (Kubalcikivá & Havliková, 2016). In Spain, where traditionally family-based care remains common, the capacity of institutional care has increased in a few years (Valarino et al., 2018).

3. The international working group on Mobilising the Potential of Active Ageing in Europe (MoPAct) developed the typology used by Leichsenring and Schulmann (2016); during the creation of this system, emphasis was placed on the conditions found in Central and Eastern European countries. Long-term care systems have an impact on the lives and QoL of individuals, yet paradoxically, long-term care is most needed in those countries where long-term care systems remain underdeveloped or difficult to access (Srakar et al., 2015). This results in a corresponding burden of unmet needs on older people and their families. (See in Table 2.)

Several comparative studies have been carried out to explain the creation of groups and their characteristics, highlighting examples using the member state groups defined above (Geerts et al., 2012). Ogg (2005) analysed three such groups of welfare regimes (i.e., North, Mediterranean and Post Socialist) and found that systems have an impact on the risk of old-age social exclusion. Even before the turn of the millennium, a growing body of evidence showed that health deterioration and the QoL related to a longer life span (higher age) are influenced by social inequalities, the societies' health, and elderly policies, as well as their care systems (Marmot, 2010; Nussbaum & Sen, 1993; Scharf et al., 2005; Townsend, 1979; Wilkinson, 1996).

Niedzwiedz et al. (2014) examined the impact of welfare systems on QoL by using the Survey of Health, Ageing and Retirement in Europe (SHARE) database and found that countries with more generous welfare systems are characterised by a higher QoL and a smaller difference in QoL among all members of society. In the Southern and post-communist countries, the socio-economic position of their previous career more affects the QoL of the young-old. Scandinavian countries seem to be an exception, where the previous career has a minimal effect on QoL. The above-mentioned authors also point out the role of financial difficulties and its use in measuring these phenomena. They found that early old age financial difficulty / tension is related to the financial situation of the previous career. The recognition of this relationship can potentially be a focus of social policy intervention since the elimination of financial difficulties can lead to the improvement of the QoL (Niedzwiedz et al., 2015).

Measuring Well-Being

Measurements of prosperity, as well as the development of countries and societies, started in the mid-20th century. The early researchers focused their first approaches on economic aspects, which identified welfare states. Later, human/societal aspects came to the forefront. There existed a need to define aspects and factors of "the good life" on a scientific basis. In addition to material and economic aspects, they also mentioned emotional and psychological factors. After many decades of research, the OECD Better Life Initiative project launched in 2011 had garnered considerable results. In line with these, in 2013 OECD published the Guidelines on Measuring Subjective Well-being (OECD, 2013), which described and grouped a list of indicators, and the authors underlined that they based the guidelines on methodological and not political issues. However, this study was based on the work of the Commission on the Measurement of Economic Performance and Social Progress in 2009 (headed by Joseph Stiglitz, Amartya Sen, and Jean-Paul Fitoussi) (Stiglitz et al., 2009). This essay marked a milestone in terms of advocating that GDP has a strong limitation in representing the prosperity of a society. Nevertheless, GDP has an influence on individual and communal material living conditions, wealth, earnings, and other material circumstances that are only certain aspects of describing a country's progress. On the other hand, a variety of factors determine social and individual well-being, such as capabilities, perceptions, moods, emotions or satisfaction.

Influences on QoL in old age include factors such as housing conditions (Szabo et al., 2018), current or active age employment, position at work, and the income and pension resulting from it (Blane et al., 2007). In addition, physical and psychological factors together with the relations of the person, with special emphasis on the family and neighbor relations, also play a key role in maintaining the QoL (Webb et al., 2011; Jivraj et al., 2014). Social relationships have been found to have a positive impact on QoL even in vulnerable groups of elderly people

(Fekete et al., 2019). Furthermore, "ageing in place" is an important factor of the QoL in old age (Gilleard et al., 2007).

The quality of life concept stands fundamentally based on Diener's (1984) philosophical and theoretical considerations. Nevertheless, the indicators of QoL show great variety. The conceptualisations of both QoL and subjective well-being (SWB) have changed over time. Formerly, many considered happiness to be the source of well-being, as it is "the highest good and ultimate motivation for human activity" (Diener, 1984, p. 542), while later the negative aspects came into focus and "human unhappiness was explored in depth" (Diener, 1984, p. 542). Although the characteristics of SWB are more or less stable, its definition greatly depends on the context and goal of its use. Firstly, SWB is a subjective concept, so it is a measure rated by the individual without noting its connection to objective factors such as wealth and health. Secondly, SWB is prominently based on positive measures but negative experiences also carry a great role in the assessment. Thirdly, SWB is multidimensional, since the different measures can place the emphasis on different aspects, and the time frame also influences the results. Diener's collection of measures dateing from the 1960's introduces single-item and multi-item scales (Diener, 1984). The reliability and validity of single-item measures remain questionable as several aspects of SWB are not considered in such investigations. Multi-item scales can show more aspects and domains of life-satisfaction. Interestingly, many of the multi-item scales listed by Diener were tailored to older respondents since they were used in the geriatric field.

The concept of SWB remains elusive still, and it lacks a precise definition. Social scientists' application of SWB measures has vastly contributed to further shaping the original definition (Diener, 1984). Higgs and his colleagues published a new, older-population-fitted tool for identifying QoL (Higgs et al., 2003). This study set out to develop a tool for distinguishing causes and consequences – the well-being indicators and factors. They argued that, against common belief, that health status, material conditions, or existence of social connections do not determine older people's QoL.

The conceptualisation of QoL is especially interesting in terms of the early old age (Hyde, 2003). As generations change, this population is renewing, harboring different needs than previous young elderlies. Higgs and colleagues placed the focus on the needs in their QoL conception, and they identified satisfaction as a measurable factor.

The CASP-12, one of the several tools that measure QoL, contains four dimensions (control, autonomy, self-realization and pleasure). Numerous international research studies used this method, the SHARE (Börsch-Supan & Jürges, 2005) being one among them. We also base our study on this data analysis. The original 19-items and the revised 12-items versions of CASP scale measure the degree to which the older adults have their needs covered. The scale conceptualizes QoL in psychosocial terms and focuses on advantageous features of ageing (Higgs et al., 2003).

Aims

The aim of this research was to examine the impact of societies' social policies and care systems on the subjective QoL based on the SHARE database. The hypothesis was that higher CASP-12 values would occur in countries where a higher standard of care is provided, which meets multiple social care needs, and where the public sector plays a significant role in care. This complex set of underlying variables can be examined by using the concept of LTC systems. The purpose of this paper is to examine the relationship between LTC models and QoL based on the SHARE database. We do this with the help of CASP-12 data. Another goal is to present a new approach to classifying the LTC regimes, which takes into account the subjective QoL in addition to state expenditures.

Methods

This study is based on a secondary analysis involving waves of SHARE research databases. SHARE – as mentioned above – used a shortened version of the CASP-12 questionnaire. It includes each of the four dimensions with three items. Each item is answered on a four-point Likert scale (1 = never; 4 = often), and some items have a reversed score (positive and negative aspects of personal feelings). The total score for QoL ranges from 12 to 48, where higher scores indicate a better QoL. The CASP has shown a strong internal consistency for the total score (Cronbach's alpha = .83) (von dem Knesebeck et al., 2007). This study used data from the waves of W2, W4, W5, and W6 of SHARE directly.

Table 1. A CASP-12 Mean Rank by Countries, and the Overall Rank of Each Country Based on CASP-12

Country	W2		W4		W5		W6		rank mean	rank difference
	mean	rank	mean	rank	mean	rank	mean	rank		
All	36.96		37.06		37.95		37.08			
Denmark	40.6	1	40.71	3	41.5	1	41.37	1	1.50	2
Switzerland	40.5	2	40.76	1	40.93	2	40.78	2	1.75	1
Netherlands	40.37	3	40.75	2	40.81	3	–	–	2.67	1
Ireland	39.14	4	–	–	–	–	–	–	4.00	–
Austria	37.82	7	39.71	4	40.17	4	39.84	3	4.50	4
Luxemburg	–	–	–	–	39.69	6	39.75	4	5.00	2
Sweden	38,93	5	38.85	6	39.8	5	39.53	5	5.25	1
Slovenia	-	-	39.24	5	39.43	7	38.33	7	6.33	2
Germany	38.64	6	38.7	7	39.08	8	39.16	6	6.75	2
France	36.71	9	37.74	8	38.16	9	37.89	9	8.75	1
Belgium	37.32	8	36.92	9	37.81	10	38.27	8	8.75	2
Spain	35.43	11	35.67	10	35.87	11	36.06	10	10.50	1
Croatia	–	–	–	–	–	–	36.04	11	11.00	–
Poland	34.52	13	35.35	11	–	–	35.86	12	12.00	2
Israel	35.91	10	–	–	35.62	12	34.81	16	12.67	6
Hungary	–	–	34.91	13	–	–	–	–	13.00	–
Estonia	–	–	35.23	12	35.29	13	35.39	14	13.00	2
Czech Rep.	35	12	34.57	14	35.18	14	35.53	13	13.25	2
Italy	33.39	15	33.79	15	33.65	15	34.83	15	15.00	0
Greece	34.12	14	–	–	–	–	31.84	18	16.00	4
Portugal	–	–	32.17	16	–	–	33.34	17	16.50	1

The supply systems of the countries examined can be grouped according to several approaches. The three grouping systems mentioned in the introduction were used in this study: Kraus et al. (2011); Nies et al. (2013); Leichsenring and Schulman systems (2016). The Eurostat (2015) provided the LTC expenditures for 2015.

The first step of data analysis involved calculating CASP-12 data averages for each country in W2, W4, W5 and W6. The total CASP-12 average (for all countries) was then calculated for each wave. The next step consisted of determining the rank order of countries. Then it was possible to examine changes in each country's rank in successive waves. The country averages were compared according to the grouping of Leichsenring and Schulman (2016); we used the ANOVA and Kruskal-Wallis tests for this. The relationship between LTC expenditures and CASP-12 has been investigated by point diagram plotting and developing a regression model. SPSS v22 and Excel 2007, SP3 were used for statistical analyses. The error level was 0.05.

Results

CASP-12 Averages and Country Rankings

The first table shows the CASP-12 averages and the order for the different waves (Table 1). Denmark ranked first (1.50) based on cumulative averages, while Portugal was the last (16.50). The lowest CASP-12 average was recorded in the sixth wave (W6) (Greece: 31.84). Denmark (41.5) achieved the highest value in the fifth wave (W5). It is worth noting that the CASP-12 values and the order of the countries did not change significantly in the different waves. Israel showed the largest change in the ranking of each wave (6), followed by Austria (4). For other countries, the change of order was 0–2.

Table 2. SHARE Countries by LTC Models

Country	mean of order	Kraus et al. (2011)				Nies et al. (2013)				Leichsenring and Schulman (2016)			
		1th Cluster	2ndCluster	3rdCluster	4thCluster	Care mix	Universal	Family-based	Transition	Standard care mix	North universal	Family-based	Central- Eastern European
Denmark	1.50		X				X				X		
Switzerland	1.75												
Netherlands	2.67		X				X				X		
Ireland	4.00							X				X	
Austria	4.50			X		X				X			
Luxemburg	5.00												
Sweden	5.25		X				X				X		
Slovenia	6.33												
Germany	6.75	X				X				X			
France	8.75			X		X				X			
Belgium	8.75	X											
Spain	10.50			X				X				X	
Croatia	11.00												
Poland	12.00								X				X
Israel	12.67												
Hungary	13.00				X					X			X
Estonia	13.00									X			X
Czech Rep.	13.25	X								X			X
Italy	15.00				X			X				X	
Greece	16.00							X				X	
Portugal	16.50							X				X	

Care Models and CASP-12

The first step in studying the care models involves classifying countries according to the LTC based on the systems discussed (Table 2). Column 2 shows CASP-12 rankings – same as in Table 1. The results are displayed in relation to three LTC systems models (Kraus et al., 2011; Nies et al., 2013; Leichsenring & Schulman, 2016). Not all SHARE-participating countries can be found in these three models, as only countries typical of each regime were included in them.

The four classification groups of Leichsenring and Schulmann (2016), and Nies et al. (2013) were compared using the national mean of the CASP-12 (ANOVA) and the rankings of the countries (Kruskal-Wallis). Both analyses resulted in statistically significant differences between the groups (F (3, 43) = 57.9, p = .001; K-W df = 3, Chi-Square = 34.88; p = .001). A Tamhane Post-Hoc analysis found that the countries belonging to the Standard care mix and the countries of the North universal LTC regimes are significantly different from each other, while the Family-based and Central-Eastern European regimes are not significantly different.

Figure 1. Relationship of LTC Expenditures and Means of CASP-12
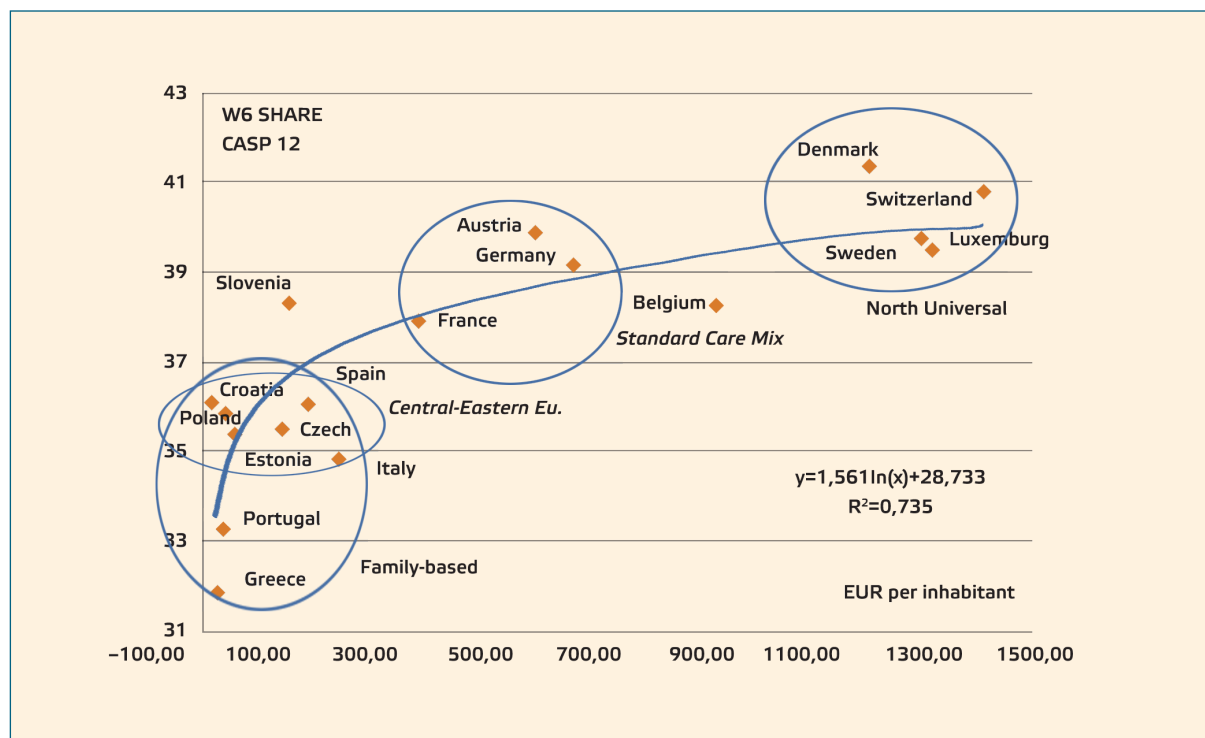
Discussion

LTC Expenditures and CASP-12

We used the statistical regression model to examine the previous prediction that family-based and Central-Eastern European regimes are not significantly different. For this purpose, we included the LTC cost per capita variable in the research study. LTC cost per capita was related to CASP-12 values. The horizontal axis of Figure 1 shows per capita spending on long-term care in 2015, while the vertical axis shows the CASP-12 values in wave 6. It can be seen that the means of CASP-12 values increase non-linearly with LTC expenditures (Figure 1). The logarithmic model fitted the regression models best.

Care systems are very difficult to compare due to the different member states' care practices. These systems are the products of multidimensional analysis of care systems and care needs, thus it may be important to recognise how much member states are able to nominally spend on care. In the cost of care context, three interpretable sets have been developed (see the three separate sections in Figure 1) that are different from the previous four care systems (see Table 2).

One of the country groups – with subsidiary systems, found in the North Universal regimes – is typically one with advanced care systems and a stable mix of organisational solutions. These countries stand clearly distinct from the other countries. The Central-Eastern European and Family-based systems, which form similar overlapping sets in terms of expenditures, lie on the other side of the graph. The lowest CASP values can be found in the context of the Eastern and Southern countries' systems and expenditures. Countries of the Standard care mix settle in the middle of the graph.

Despite the difficulty of modeling and the diversity of model-developing aspects, some similarities can be observed between the regimes described by the three models and the rankings based on the country's CASP-12 values. Based on their CASP-12 scores, nations with higher CASP-12 scores sit at the top of the list and typically belong to the Care mix and Universal regimes (Nies et al., 2013), or, similar to the Leichsenring and Schulman (2016) model, belong to the Standard care mix and North universal regimes. Countries at the bottom of the rankings with low CASP-12 scores belong to Family-based and Transition, (Nies et al., 2013) or to the Family-based and Central-Eastern European (Leichsenring & Schulman, 2016) regimes. In the model of Kraus et al. (2011), one can also see some relationship, but it is not strong.

Strength and Limitations

Each LTC regime has a relationship with the CASP-12 values measured in each country, or more precisely, with the subjective quality of life expressed by CASP-12 that exists almost independently from the theoretical models describing these regimes. Further possible explanations may obtain. First, LTC regimes might have a direct impact on the elderly's subjective well-being. In this case, one assumes that the factors fundamentally affecting the QoL of the elderly who have an increasing socio-economic importance, should be found in the range (diversity) of supply services provided by a particular regime – in the specific content and quality of services and in the availability of services (equity vs. inequity). If this is the case, then it is possible to show a difference that can be demonstrated by data in the supply services of the nations in each regime.

The other possible explanation: the effect of a variable not studied in this research may influence the relationship, specifically the rate of old-age activity. The positive correlation between old-age activity and subjective well-being has been well-documented and the items in the CASP-12 are also closely linked to the activity of the elderly. Finally, another aspect of the relationship can be placed into the broader interpretative framework of the LTC regime. If we study their societies and the social policies of the countries, including the age-specific labor market policy, one can see that in the standard care mix of the North universal regimes, there is more emphasis, more resources, and broader services provided to support active ageing compared to the family-based and Central-Eastern European regimes. In Central-Eastern European regimes, the emphasis on old age shifts to meeting the needs of those elderly who become partially incapable.

Conclusion, Implications and Future Directions

Our new results identify three different types of regimes in terms of the relationship between social care systems and quality of life, in the so-called LTC-related QoL domain. We find that European countries can be distinguished into Minimiser, Maximiser and Optimiser categories. We emphasise that the design and naming of these categories was based on our search for a relationship between expenditure on care and older people's perceptions of their own quality of life.

The data shows that the development and availability of care systems have a significant indirect correlation with the elderly's subjective well-being. However, while studying the care systems, it became clear that the less developed care systems in the Eastern European and Southern European countries resulted in lower CASP values overlapping each other. This was confirmed by the previous analysis of other QoL scales (SMT, ADL, EURO-D) available from SHARE databases (Hüse et al., 2016). Based on the data, we can distinguish three groups of countries instead of four, which are referred to as LTC-related QoL domains.

Figure 1 and its associated classification support this statement. The data shows that some European states are looking for a minimal investment and the outcome results in a low SWB. This is called *minimiser* in the LTC-related QoL domain. Family-based and Central-Eastern EU countries are included. At the other end of the spectrum lie nations that, at very high cost, achieve high SWB for the age group under study. This is the North Universal group, which is called the *maximiser* domain. Between the minimizing and maximizing domains, a group of countries exist that achieve a higher SWB compared to minimisers but less than maximisers at a moderate investment. The figure includes Standard care mix countries, which are called *optimisers*. This is a good indication of the optimum proportion of GDP as well as the reasonably high QoL that it achieves. The quality and availability of care pose a challenge to all of Europe in the future but will place a greater burden on the Southern and Eastern member states as they will only be able to achieve the appropriate quality care via a significant increase in costs.

According to projections by Eurostat, a demographic division of Europe can be expected in the future (Eurostat, 2019). The population will be increasing in the Northern and Western European countries until 2080, and moderate changes will be observed in Finland and Germany. Southern and Eastern European nations can expect a drastic decline in population. These effects, due typically to external and intra-community migration processes, will have a direct impact on the sustainability of the pension systems and the care systems ensuring the elderly's well-being. According to these projections, the research on the factors affecting the well-being of the elderly is of paramount importance. The question may be how far global changes (global warming, migration, new political culture, technical achievements) are already affecting the model outlined (minimiser, optimiser, maximiser) and how they affect the issue of future development or regression. From this point of view, minimiser countries are likely to be indicators of the process, as the benefits of an increasing investment may be most pronounced in their case.

Author contributions
Márta Fekete: conceptualization, design, methodology, investigation, project administration, writing original draft.
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Lajos Hüse: conceptualization, design, methodology, investigation, writing review and editing.
Éva Huszti: conceptualization, design, methodology, investigation, project administration, interpretation, supervision, writing original draft, writing review and editing.
Péter Takács: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, supervision, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement
The authors have no conflicts of interest to disclose.

Ethical statement
This manuscript is the authors' original work.
Human participants have been not involved in this study.
No ethical approvement, informed consent, or data handling policy was needed.

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RESEARCH ARTICLE

How Do Poles Perceive Schizophrenia? Furnham and Chan's Questionnaire in Poland

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Introduction: Individuals with psychosis spectrum disorders may be negatively affected by exclusion and rejection. It is important to answer "why"? This article presents social representations of schizophrenia in Polish society.
Aims: The study's aim was to examine the properties of the sixty-item questionnaire on attitudes, attribution and beliefs about schizophrenia in the Polish sample and to compare the results with the results obtained in the English-Chinese sample.
Methods: The study included 398 participants (aged 19–74); all were working persons. Furnham and Chan created the questionnaire, a tool containing 60 items describing general beliefs about schizophrenia, causal explanations in the etiology of schizophrenia, as well as beliefs about the role of hospitals and society in the treatment of schizophrenia. Factor analysis (PAF) was carried out separately for three parts of the tool.
Results: The structure of the questionnaire that was obtained on the Polish sample differs from that obtained on the English-Chinese sample. Some factors remain similar. Reliability analysis based on Cronbach's Alpha values reached satisfactory levels in most of the factors revealed.
Conclusions: The questionnaire is a reliable tool for examining social representations of schizophrenia. The Polish sample does not show punitive inclinations, does not attribute negative traits to schizophrenics, and does not agree to creating social distance.

Keywords: schizophrenia, Poland, mental illness, social representations, lay knowledge

Introduction

According to statistics published by the World Health Organization, in Europe 110 million people suffer from mental illness (World Health Organization Regional Office for Europe, 2018). Psychiatric patients suffer not only from mental illness, but also from stigma. The stigma of mental illness is strong and ubiquitous in society. It has a harmful effect on people with mental illness. It hinders the healing process because it places a huge burden on patients (Link et al., 2001).

People with mental illness experience stigma from a variety of sources: society, family, colleagues, healthcare professionals. Most stigmas are associated with the anxiety and misperception of others. Perception and negative images of people with mental illness can be rooted in the lack of knowledge about the nature of mental illness in society. Mass media can also contribute to promoting the wrong perception of patients as violent persons with criminal tendencies, especially so, when providing information about a committed crime, they state that the perpetrator was undergoing psychiatric treatment. This associates mental illness with crime, even though research actually indicates that mental

illness does not determine the commission of a crime (Vogel, 2014). The media omits other important motivational factors, e.g., personality. Such images lead to the greater isolation of patients and their families in society, especially in the case of schizophrenia (Reavley et al., 2016). This is an important problem, all the more so because, according to the CBOS (Centrum Badania Opinii Społecznej [Public Opinion Research Center]) survey (Wciórka & Wciórka, 2002), Poles encounter mental illness mainly through the media – television, radio, books, magazines – and rarely through personal contacts that could promote destigmatization. It has been proven that with increasing contact with mentally ill people, perception of danger and the desired social distance decreases (Alexander & Link, 2003).

The stigmatizing etiquette of mental illness provides its external effects on opportunities in areas such as wages, housing, health and life (Link & Phelan, 2001). At the same time, stigmatization has subjective internal effects, such as lowering self-esteem and social withdrawal as a way of dealing with the possibility of being rejected (Link et al., 2001).

Research indicates a mismatch of attitude components towards the mentally ill. Most of the respondents accept the participation and active presence of patients in public space, and their functioning in social and professional roles. However, in relation to their own personal space, they do not agree to cooperate with a mentally ill person in a common workplace (66.7%). The respondents reveal a strongly negative affective component of attitudes towards the mentally ill (anxiety -52%), which can be considered as a factor blocking the implementation of the presented views, and under unfavourable conditions it can lead to opposite discriminatory behaviour (Gzocha & Kurpas, 2011). Research by Bożena Mroczek, Izabela Wróblewska, Anna Kędzierska and Donata Kurpas (2014) showed that mentally ill people are perceived as dangerous (70%), aggressive (61%), unpredictable (85%) and according to respondents, they should be isolated from society (31%). The feelings that they most often evoke are: fear, compassion, and helplessness. The following terms are used in the respondents' environment: *crazy, psycho, nuts*. 96% avoid mentally ill people and 65% will not offer help to a sick person.

The CBOS study (Wciórka & Wciórka, 2002) says that 26% of Poles say they have never heard of schizophrenia, 62% admit that they know very little about it, and only 11% say they have a good deal of knowledge about this disease. Half of the respondents have an idea of schizophrenia as a mental illness, and 27% mention interpersonal, individual, and social problems of patients. However, 15% of respondents include schizophrenia in the general category of diseases, without indicating their relationship with the psyche. People with a higher social status defined schizophrenia more accurately and better assessed their knowledge about it. Lower social position was associated with poor familiarization or a complete lack of knowledge in this area. In addition, respondents from small towns showed a lower level of knowledge than people from large cities.

This study deals with lay knowledge, intuitive, abstract representations of mental illnesses, which people rely on to understand, interpret, and predict their social world. Lay knowledge can be very different from scientific knowledge, but it provides a cognitive framework for perceiving groups and also it could be related to prejudiced processes and practices (Hong et al., 2001).

The study aims to develop a Polish version of Furnham and Chan's tool and describe the views of Polish society on schizophrenia. The theory of social representations is one of the concepts falling within the sphere of lay knowledge (Borowiec & Lignowska, 2015). The article presents social representations of schizophrenia including, as Furnham and Cheng (2000) suggest, the causes of the problem (mental illness), behavioral manifestations, and optimal treatment.

Methods

Material

The study included metric variables such as age, gender, education, occupation, level of knowledge about schizophrenia (7-grade scale, where: 1 means – I do not have any knowledge, and 7 – I have a very extensive knowledge) and the psychiatric treatment history of examined individuals, their friends and family (contact with a mental illness).

Questionnaire on Views on Schizophrenia

The questionnaire on views on schizophrenia comes from a tool used by Furnham and Chan (2004) for studying views on schizophrenia. The questionnaire questions used by the authors were taken from earlier research (Furnham & Bower, 1992) on laical and academic theories of schizophrenia. However, the tool's authors have added a few questions regarding superstitious beliefs about schizophrenia. The questionnaire's items cover areas such as attitudes towards treatment, preferred social distance, or general beliefs about people with schizophrenia.

The questionnaire was divided into three sections. The first section includes 21 questions on beliefs about people with schizophrenia. The second section includes 16 questions on the causes of schizophrenia. The third section, consisting of 23 questions, deals with what people think about the role of psychiatric hospitals and society in the treatment of schizophrenia. Due to the possibility of giving a neutral response, the original 6-point scale was changed to a 7-point scale (1 – completely disagree; 7 – completely agree).

The reason for choosing the tool was an attempt to examine a wide range of views on schizophrenia, in particular the fact that the tool includes questions about spirituality, which may be significant in the Polish population, as 94% declare a religious affiliation (GUS, 2018).

Surveyed Persons

The sample included 398 people aged 19 to 74 (M = 36.14; SD = 11.10). 71.1% (n = 283) of the examined group were women and 28.9% (n = 115) were men. The respondents were employed people with a secondary (15.8%; n = 63) or higher education (84.2%; n = 335). The group was diverse in terms of their professions. The level of knowledge about schizophrenia was rated (on a 7-point scale) as 4.00 on average (SD = 1.68), so this suggests an average level of knowledge about the disease in question. 5.3% of the group (n = 21) has been or is undergoing psychiatric treatment, and 28.4% (n = 113) have in their family a person who is suffering from a mental disorder. In addition, 42.7% of respondents (n = 170) have a mentally ill person among their friends.

The Procedure of Developing the Polish Version of the Questionnaire on Views on Schizophrenia

First, we obtained the consent of Furnham, the author for using his questionnaire. A psychologist with a fluent English knowledge translated the questionnaire's original English version into Polish. The tool was subjected to the *back–translation* procedure with the participation of an independent English speaker. The final version underwent a language correction by a Polish philologist.

We posted the survey on MySurveyLab; information about the survey was posted on Facebook accounts and sent to email addresses. In this way, 251 people filled the questionnaire. Additionally, in order to reach a wider group including those who do not use Facebook, we asked students of pedagogy to distribute the questionnaire in paper form, and 147 people completed this paper version of the tool.

Statistical Analysis

Data analysis was conducted using the procedures available in the SPSS 25 Package. First, we exploratory factor analysis was conducted using the Principal Axis Factoring (PAF) method – separately for each section of questions, which means that three analyses were performed (similar to the original study by Furnham and Chan). KMO and Bartlett's sphericity test were calculated via factor analysis and descriptive statistics of questions. For identifying the number of factors included in each section of the tool, Henry Kaiser's eigenvalue criterion was used. In all three cases of factor analysis, we used *Oblimin* rotation.

After conducting the factor analyses, we carried out the contents analysis of the factors and distinguished components were named, and then initiated the reliability analysis of these scales. The reliability analysis was carried out using the Cronbach's Alpha method. Alpha statistics were calculated separately for all subscales identified in the factor analysis. The scales for which the Alpha statistics stood at least .7 were considered reliable (Badyńska & Brzezicka, 2007).

Results

Factor analysis of the questionnaire's first part

In order to examine the structure of beliefs about people with schizophrenia, we initiated a factor analysis of the questionnaire's first 21 questions. The KMO Sampling Adequacy Measurement of 0.865, and Bartlett's sphericity test, which proved to be statistically significant (χ^2 = 2415.507, df = 210, p < .001), showed that it is possible to perform factor analysis on the data obtained. Five eigenvalues have exceeded the value of 1, which means that five factors are distinguished. Components with factor loadings are shown in Table 1. A 55.03% variability of all questions can be explained by five distinguished factors.

Table 1. Model Matrix – Beliefs About People Suffering From Schizophrenia

Questions of the questionnaire	Factor				
	1	2	3	4	5
17. People who suffer from schizophrenia are mostly from the lower socioeconomic class	.705	.027	.147	–.111	.026
10. Once individuals have been diagnosed as schizophrenic, they should spend the rest of their lives in an institution or be 'locked up'	.640	–.171	.074	.061	.062
8. Many schizophrenics are the vagrants and 'drop-outs' of our society	.624	.074	–.035	.096	–.027
5. The term 'psychopath' is the best way to describe a schizophrenic	.403	–.062	.072	.291	–.154
15. Society has the right to punish or imprison people like schizophrenics, whose behavior breaks moral standards even if they do not break the law	.403	–.104	.176	.077	.266
2. It would not be wise to show any favors to a person who is schizophrenic	.353	–.044	.064	.294	–.176
12. It is possible to treat schizophrenics with surgery	.323	.056	.009	.047	–.014
9. Schizophrenics have the right to be released when their behavior is acceptable to society	–.056	.584	–.011	.145	–.057
14. Schizophrenics have the right to be treated sympathetically	–.074	.561	–.020	.039	.227
11. Schizophrenics have the right to be left alone as long as they do not break the law	.205	.473	–.007	–.125	.019
6. Schizophrenics have the right to be treated as responsible adults	–.008	.435	–.012	–.188	–.068
19. Schizophrenia may not be an illness because the patient may be controlled by evil spirits	–.053	–.031	.812	.053	–.061
20. Schizophrenia can be treated by seeking help from God or other spirits	–.056	.063	.790	.016	–.012
21. When patients report that they have delusions, what they see or hear are ghosts	.314	–.086	.615	–.119	.073
3. Schizophrenic behavior is nearly always bad and wrong	.209	–.062	–.008	.587	–.158
1. It would be impossible for schizophrenics to be employed as they cannot be trusted	.011	–.128	.118	.571	.052
4. Being schizophrenic is an 'escape' from the pressure of society	.153	.206	.182	.543	–.192
7. At any time, a schizophrenic may 'lose control'	–.058	–.038	.106	.526	.221
13. Many schizophrenics commit outrageous acts in public places (e. g. shouting in the street)	.233	–.005	–.083	.430	.181
16. Schizophrenia cannot be cured completely	–.005	.052	–.026	.009	.418
18. I will choose not to be friends with people suffering from schizophrenia	.196	–.099	.130	.249	.253

The first factor consists of the following items: 17, 10, 8, 5, 15, 2, 12. This factor can be called: *Low social status of people suffering from schizophrenia*. This factor also includes two items indicating high punitiveness towards schizophrenics. It explains 27.42% of the total variance, and its reliability measured by the Cronbach's Alpha method is .779. All items in this factor have an average below 2 (except for items 12 – M = 2.11), which indicates that respondents neither attribute a lower socio-economic status nor show punitive attitudes toward schizophrenics.

The second factor (including items: 9, 14, 11, 6) was named: *Rights of people suffering from schizophrenia*. This factor explains 8.98% of the variance and its reliability is 0.585. Average scores above 4.00 indicate that participants generally agree with the right of people suffering from schizophrenia to be released, treated as responsible adults, and with the right to compassion and the right to be left in peace until they break the law.

The third factor (items 19–21) is named: *Superstitious beliefs*. It explains 7.17% of the variance and its reliability is .806 (Cronbach's Alpha). The average results within the items included in the discussed factor (< 2.00) suggest that the study participants do not have superstitious beliefs about schizophrenia and are not inclined to claim that it can be treated by seeking help from God or ghosts.

The fourth factor contains the items: 3, 1, 4, 7, 13 and explains 6.1% of the variance. It has been named: *Negative features of people suffering from schizophrenia*. The reliability of the second factor is .743. All items within

Table 2. Model Matrix – Causes of Schizophrenia

Questions of the questionnaire	Factor		
	1	2	3
29. Traumatic experiences in early childhood can cause schizophrenia	.833	.232	.103
25. Having parents who are inconsistent in their behavior towards the child leads one to become schizophrenic	.724	–.080	.067
31. Schizophrenia is caused by patients' parents manifesting extreme emotions and giving them contradictory messages	.682	–.075	.139
24. Sexual and/or physical abuse in childhood is the cause of schizophrenia	.679	–.005	.138
30. Stressful life events such as losing one's job can lead to schizophrenic behavior	.641	.120	.036
36. Having too much social pressure on people to behave properly causes people to be schizophrenic	.619	–.245	–.109
22. Strong rejection from family or close friends at an early age causes one to become schizophrenic	.583	–.155	.048
27. The cause of schizophrenia is the 'sick' society in which we live	.527	–.392	–.183
28. Schizophrenia is caused by possessing low intelligence	–.040	–.829	.046
32. Schizophrenia is caused by having a low birth weight	–.064	–.751	.180
37. Schizophrenia is infectious	.023	–.676	–.017
26. Schizophrenia is caused by learning strange and bizarre behaviors from others	.331	–.604	–.038
34. Schizophrenia is caused by having a parent or both parents who are schizophrenic	–.007	–.019	.792
23. Schizophrenia is caused by having blood relatives who are schizophrenic	.057	–.123	.621
33. Brain damage in a serious accident can result in schizophrenia	.203	–.220	.307
35. Schizophrenia is caused by an imbalance of chemicals in the body	.034	.024	.298

this factor have an average below 4.00, indicating that the subjects are not willing to attribute negative traits to people suffering from schizophrenia.

The fifth factor includes the items 16 and 18. It explains 5.37% variance and can be named: *Incurableness and aversion.* The reliability measured by the Cronbach's Alpha coefficient is very low (.262). Within this factor, the respondents tend to agree with the view that schizophrenia cannot be cured completely (M = 5.94) and to disagree with the statement suggesting a reluctance to maintain friendship with a sick person (M = 2.40).

Factor Analysis of the Second Part of the Questionnaire

In order to examine the structure of perception regarding the causes of schizophrenia, a factor analysis of the items 22–37 was initiated. The KMO Sampling Adequacy Measurement of 0.883, and Bartlett's sphericity test, which proved to be statistically significant (χ^2 = 3018.668, df = 120, p < .001), showed that it is possible to perform a factor analysis on the data obtained. Similarly to the first part of the questionnaire, we used Kaiser's method to determine the number of factors. Three eigenvalues exceeded the value of 1, which means that three factors are distinguished. Components with factor loadings are shown in Table 2. The three identified factors can explain 60.15% of the variance.

The first factor included the following items: 29, 25, 31, 24, 30, 36, 22, 27. Named *Social factors,* this factor explains 39.88% of the total variance, and its reliability measured by the Cronbach's Alpha coefficient is .888. The average results in all items of the questionnaire listed here amount to less than 4.00, which means that the subjects are inclined to disagree with the given social causes of schizophrenia.

The second factor consists of the following items: 28, 32, 37, 26. This factor has been named *Biological and behavioral factors.* It explains 12.02% of the variance. The reliability of the second factor is .835 (Cronbach's Alpha). The average results of the items listed are less than 2.00, which means that the subjects do not agree with the causes of the disease listed here.

Within the third factor, which was named *Genetic, chemical and mechanical factors,* the items included are: 34, 23, 33, 35. This factor explains 8.25% of the variance. Its reliability is .614 (Cronbach's Alpha). The average results in all items of the questionnaire listed here amount to less than 4.00, which means that the subjects are inclined to disagree with genetic, chemical and mechanical causes.

Factor Analysis of the Questionnaire's Third Part

In order to examine the structure of views on the role of psychiatric hospitals and society in the treatment of schizophrenia, we initiated a factor analysis of the items 38–60. The KMO Sampling Adequacy Measurement of 0.851, and Bartlett's sphericity test, which proved to be statistically significant (χ^2 = 3552.684, df = 253, p < .001), showed that it is possible to perform a factor analysis on the data obtained. Kaiser's method was used to determine the number of factors. Five eigenvalues have exceeded the value of 1, which means that five factors are distinguished that together explain 59.43% of the variance. Components with factor loadings are shown in Table 3.

The first factor included the following items: 46, 47, 43, 51, 48, 45. We named this factor: *Obligations of society.* It explains 21.81% of the variance and its reliability is .834 (Cronbach's Alpha). All items obtained an average above 4.20, which means that the respondents agree with social obligations related to providing care to people suffering from schizophrenia.

The second factor consists of the following items: 42, 53, 41, 39, 50, 40. It was named: *Functions of psychiatric hospitals.* This factor explains 19.83% of the variance. The factor's reliability was .794 (Cronbach's Alpha). All items included in the discussed factor obtained an average below 3.00 (except for item 53 – M = 3.10 and item 40 – M = 3.43). Such results suggest that the subjects do not agree with the listed functions of psychiatric hospitals.

The third factor is called: *Distance and protective function of psychiatric hospitals.* It includes the following items: 59, 58, 60, 38, 49, 44. This factor explains 7.13% of the variance and its reliability is 0.746. The average values of the items listed here stand at less than 3.00, which suggests that the respondents do not agree with creating a distance between society and people suffering from schizophrenia and eliminating them from social life.

Within the fourth factor, the following items can be found: 52, 57. It was named: *Respect for freedom.* This factor explains 5.79% of the variance. The factor reliability measured by the Cronbach's alpha coefficient was .803. The average values of the items included in the fourth factor range from 4.15 to 4.23, which means that the respondents take a neutral attitude towards them.

The fifth factor consists of the following items: 54–56. It was named: *Treatment.* It explains 4.87% of the variance and its reliability is .665 (Cronbach's Alpha). The averages of the three items mentioned above assume values higher than 4.00, which suggests that the respondents tend to agree with conventional (therapy, social skills training, hospitalization) treatments for people suffering from schizophrenia.

Discussion

In no part of the questionnaire did the factor structure reflect the structures obtained by Furnham and Chan (2004). The authors in the first part list as many as seven factors: danger, superstition, abnormality, norms, rights, social status, and morality. In the Polish version, on the other hand, only five factors appeared, which we named: low social status of people suffering from schizophrenia and severity of society's punishment, rights of people suffering from schizophrenia, superstitious beliefs, negative features of people suffering from schizophrenia, incurableness and aversion. Only two factors are similar: the rights of people suffering from schizophrenia in the Polish version to those rights in the English-Chinese version, and superstitions in the English-Chinese version to superstitious beliefs in the Polish version.

In the second part, concerning the determinants of the disease, both versions of the tool reveal three factors. The first factor in the Polish version (social factors) is analogous to the first factor in the English-Chinese version (sociological explanations). The other two factors differ in content. The original version of the tool highlights biological and cognitive causes. In the Polish version, however, biological and behavioral factors constitute the second factor, while genetic, chemical, and mechanical causes constitute the third factor.

In the third part, regarding the opinion on the role of psychiatric hospitals and society in the treatment of schizophrenia, the original version of the tool included six factors: functions of hospitals, care, society's duty, respect, acceptability, treatment. Five factors appeared in the Polish version. The first, second, fourth and fifth factors (obligations of society, functions of psychiatric hospitals, respect for freedom, treatment) are analogous to the factors from the original version. The third factor, however, contains different items, such as distance and the protective function of psychiatric hospitals.

The authors of the original did not provide reliability analysis, so there is nothing to compare to the Polish version. In the Polish version, the Cronbach's Alpha coefficients display a wide range (from .262 to .888). Most scales have exceeded the value of .7, so they can be considered reliable (in terms of general views on schizophrenia:

Table 3. Model Matrix – Views on the Role of Psychiatric Hospitals and Society in the Treatment of Schizophrenia

Questions of the questionnaire	Factor				
	1	2	3	4	5
46. It is society's duty to provide people and places to treat schizophrenics	.807	.015	−.045	.212	−.078
47. The duty of society is to change and reduce the stresses and strains on schizophrenics and others	.782	−.022	.224	−.131	.029
43.Society has a duty to provide places where schizophrenics can go for help with their problems	.650	.093	−.130	.275	−.176
51. It is the right of the schizophrenic to be cared for by society	.630	−.080	−.117	−.058	.011
48. The most effective way of helping schizophrenics is to create a society which is truly fit for them to live in	.511	.078	.160	−.343	−.025
45. Society has a duty to respect the liberty of the schizophrenic	.493	−.027	−.211	−.226	−.087
42. Mental hospitals sometimes end up simply providing shelter for the poor and other unfortunates while doing little to get these people out of the hospital and back into society	.002	.854	−.001	.164	−.110
53. Mental hospitals are often used to remove troublemakers from society	−.019	.725	−.034	−.043	−.013
41. Whatever the aim of a mental hospital, it often ends up becoming a dumping ground for the poor and disadvantaged	.078	.702	−.055	.090	.003
39. Mental hospitals are used to keep schizophrenics away from society, and they have little interest in cure	−.071	.560	.128	−.153	.079
50. A mental hospital is a kind of concentration camp, where people are subdued and degraded in order to make them easier to control	−.136	.524	.120	−.185	.124
40. Producing a more comfortable and less stressful society is the best way to treat schizophrenics	.140	.206	.182	−.178	−.153
59. Psychiatric patients' rehabilitation facilities should be far from their community	−.007	.010	.707	.008	.102
58. Schizophrenic patients should best be kept in mental hospitals until they completely recover	−.036	−.067	.644	−.019	−.172
60. I prefer not to live near any psychiatric rehabilitation facilities	.038	.102	.619	.182	.116
38. Society has the right to protect its people from schizophrenics	−.057	.103	.476	.059	−.110
49. Mental hospitals are best used to remove schizophrenics from stressful homes to quieter settings	.009	.096	.410	−.171	−.210
44. The function of the hospital is to rid society of those who threaten it	−.009	.235	.355	−.232	.200
52. The best way to treat schizophrenics is to respect their right to lead their own lives	.200	.136	−.272	−.574	−.234
57. The best way to treat schizophrenics is to respect their liberty and right to lead their own life	.109	.031	−.123	−.509	−.424
55. Mental hospitals should be used to teach schizophrenics to act responsibly so they can fit in with society	.040	−.025	.149	.001	−.654
54. The main function of the mental hospital is to provide an atmosphere for care and cure	.181	−.063	−.100	.081	−.594
56. A one-to-one relationship with a skilled therapist is the best way to treat schizophrenics	−.011	.076	.071	−.109	−.574

low status of people suffering from schizophrenia and the severity of society's punishment, negative features of people suffering from schizophrenia, superstitious beliefs; in terms of the disease's causes: social factors, biological and behavioral factors; in the scope of views on the role of hospitals and society: obligations of society, functions of psychiatric hospitals, distance and protective function of psychiatric hospitals, as well as respect for freedom). Other factors possess lower reliability ratios; however, these factors often appear in research rights of people suffering from schizophrenia (.585), genetic, chemical and mechanical factors (.614) and treatment (.665). The

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factor of incurableness and resentment (.262) was unreliable, which may be caused first of all by a small number of items comprising it (two items). A small number of questions, even with the questionnaire's good consistency, goes along with smaller values of Cronbach's α statistics. Secondly, this factor is heterogeneous – one item relates to assessing the cure rate of schizophrenia, the other refers to the possibility of establishing and maintaining friendship with a sick person – which may also result in lower reliability (Tavakol & Dennick, 2011). In general, however, we find the results of the reliability analysis satisfactory.

The obtained results indicate that the respondents do not attribute a lower socio-economic status to people suffering from schizophrenia, nor do they show punitive attitudes (average < 2), are not inclined to attribute negative traits to them (average < 4) and do not have superstitious beliefs about schizophrenia (average < 2). They do not agree with the social (average < 4), biological, behavioral (average < 2), genetic, chemical or mechanical (average < 4) reasons given. In addition, they do not equate the functions of psychiatric hospitals with negative connotations (average < 3.5), and they do not agree with creating a distance between society and people suffering from schizophrenia and eliminating them from social life (average < 3).

Respondents showed a neutral attitude (average range from 4.15 to 4.23) regarding respect for the freedom of people suffering from schizophrenia, but they tend to agree with the right of schizophrenics to be released, treated as responsible adults, with the right to compassion and the right to remain in peace until they break the law (average > 4) and agree with social obligations (average > 4,5) related to providing people suffering from schizophrenia with care and recognizing the effectiveness of conventional treatment for them (average > 4.20).

Strength and Limitations

The study demonstrated positive or neutral attitudes of Polish society towards schizophrenics. One of the strengths of the study lies in the differentiation of the sample due to the occupation and in the method of conducting the survey (paper and internet), which increases the ecological validity of the study.

Besides its strengths, this study also has some limitations which should be discussed. The main limitation lies in the sample size. The sample size was too small to perform a confirmatory factor analysis. Without the CFA, we cannot talk about full validation of the tool in Poland.

The second limitation of the presented study is that it was carried out using the self-report method, which indicates the cognitive aspects of attitudes. However, attitudes may differ in natural situations in which the behavioral component of attitudes will be revealed.

Conclusions, Implications and Future Directions

Based on the results obtained, the Polish version of The Questionnaire on Views on Schizophrenia can be considered a reliable tool for studying general beliefs about this disease, its causes as well as views on the role of hospitals and society in the treatment of schizophrenia. Developing the Polish version of this tool offers an introduction to further research on attitudes towards schizophrenia in Polish society.

Prior research suggests that individuals with psychosis spectrum disorders may be negatively affected by exclusion and rejection (Lincoln et al., 2021). According to the results of the presented research, this risk is low in Polish society. The Polish sample does not show punitive inclinations, does not attribute negative traits to schizophrenics, and does not agree to creating social distance.

The article provides practitioners (psychiatrists, psychotherapists, psychologists) with the knowledge about social representations of schizophrenia in Polish society. This knowledge can be used in their work with suffering from schizophrenia, as proof of undermining concerns related to negative social beliefs against the disease.

However, the cognitive and behavioral components of attitudes towards schizophrenia may differ. Therefore, it is important to examine attitudes (behavioral component) in real situations in the future.

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Author contribution
Joanna Góźdź: conceptualization, design, investigation, project administration, data management, formal analysis, interpretation, writing the original draft, reviewing and editing.
The author gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement
The author is an employee of University of Silesia in Katowice.

Ethical statement
This manuscript is the author's original work.
The author declares that all participants in the research completed the questionnaire voluntarily and anonymously, which was their consent to participate in the study. Data are stored in coded materials and databases without personal data, and she has policies in place to manage and keep data secure.

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RESEARCH ARTICLE

The Role of Informal Leaders in Restraint and Confining People with Mental Health Issues in Manggarai, Indonesia

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Introduction: A person experiencing mental health issues may be physically confined at the suggestion of an informal leader who sees that individual's violent behavior as a threat to the community.

Aims: The aim of the study is to explore the perceptions of the *tu'a golo*, a man who serves as informal village leader, regarding his role in confining a person with mental health issues in Manggarai, on the island of Flores, in Indonesia.

Methods: The study uses an ethno-semantic approach. Data collection and analysis were carried out using Spradley's Developmental Research Sequence; the researchers interviewed one *tu'a golo* from each of fifteen villages in Manggarai. They then analyzed the data via using domain, taxonomy, componential, and cultural themes.

Results: The researchers found that the *tu'a golo* has three important roles in confining a person with mental health issues: (1) before physical restraint and confinement, as an *adviser* to the family and to the person exhibiting mental health issues; (2) before physical restraint and confinement, as a *mediator* between the family of the individual with mental health issues and the community; (3) during physical restraint and confinement, as a *protector* of the person with mental health issues, the family, and the community.

Conclusions: In areas with limited mental health services, informal leaders take on important roles in the physical restraint and confinement of the mentally ill. Therefore, healthcare professionals must include informal leaders in programs to improve mental health services and reduce the use of physical restraint and confinement.

Keywords: physical restraint and confinement, culture issue in mental illness, community mental health, informal leader, pasung

Introduction

Informal leaders play a significant mental health care role in developing countries. The World Health Organization (WHO) suggests that primary care in mental health needs to be supported by self-care and informal community care to achieve an optimal mix of services (World Health Organization, 2007). Mental health care can be achieved in the community if all key stakeholders, including informal leaders, support the unwell and their families. However, not all informal leaders, particularly those in developing countries, possess a sufficient understanding of mental health. Studies show that in developing countries, community stigma towards those with mental health issues still remains high (Buanasari et al., 2018; Crowe et al., 2016; Eaton et al., 2018; Endale et al., 2020; Hartini et al., 2018; Ignatova et al., 2019; Minas & Diatri, 2008; Musyimi et al., 2017; Thornicroft et al., 2016; Umucu, 2019; McDaid & Park, 2011).

Some stakeholders, including informal leaders such as those in Ethiopia and China, see the behavior of people with mental health issues as abnormal and socially unacceptable (Asher et al., 2017; Guan et al., 2015; Wong et al., 2018). In addition, ineffective treatments may be tried which might worsen the condition of a person with mental health issues.

The poor treatment of a person exhibiting mental health issues results from limited mental health services (Asher et al., 2017; Daulima, 2018; Laila et al., 2019; Minas & Diatri, 2008; Suryani et al., 2011; Tay et al., 2017). Given this, families and communities are forced to find non-medical treatment (Laila et al., 2019; Lund et al., 2012; Maramis et al., 2011). Instead of curing these mental health issues, however, this type of treatment may increase the violent behavior of the person experiencing issues (Suryani et al., 2011). Therefore, a family may eventually choose to confine a person as a way of controlling that behavior and protecting the community. Physical restraint and confinement, known as *pasung* in Indonesian, is defined as physical restraint whereby a person showing mental health issues is isolated in a room and their legs are tied and secured inside stocks and/or wooden blocks (Daulima, 2018; Laila et al., 2018, 2019). In Indonesia, physical restraint and confinement has been banned since 1968 because it violates the human rights of the confined. However, some still practice it (Minas, 2009). In 2018, the Indonesian Ministry of Health stated that nineteen thousand people with mental health issues; that is, 14.4 percent of the total number of people afflicted with schizophrenia or other psychotic illnesses in Indonesia, are confined (Ministry of Health Republic Indonesia, 2018).

Predicting factors of physical restraint and confinement in Indonesia include violent behavior, a high level of burden carried by the family, and stigma the community exhibits (Daulima, 2018; Hartini et al., 2018; Hidayat et al., 2020; Laila et al., 2018; Minas & Diatri, 2008; Ottewell, 2016; Rafiyah et al., 2011; Yulis et al., 2021). Another study also found that stakeholders, including informal leaders in Indonesia, see physical restraint and confinement as a solution to overcome the violent behavior of people possessing mental health issues (Laila et al., 2019). Informal leaders may be directly or indirectly involved in managing people with mental health issues and their families. Studies in Ethiopia highlighted that families ask for help from the tribal leader in handling family members with mental health issues (Ginneken et al., 2017; Musyimi et al., 2017). Two studies in Indonesia also found similar situations (Puteh et al., 2011; Tay et al., 2017). However, research exploring the duties of informal leaders in such issues, especially in dealing with physical restraint and confinement, still remains limited.

Indonesia is an archipelagic nation. In the archipelago's eastern region, the island of Flores serves as home to tribes including the Manggarai (who provide the name to the district in which this study took place), and the Bejawa, Ende, Maumere, and Flores Timur, all of which have both formal and informal leaders in their villages. In the Manggarai tribe's language, the informal village leader, called a *tu'a golo, serves as* a village chief (*tu'a* means chief, *golo* means village), a role passed down from father to son (Iswando et al., 2015). The *tu'a golo* does not fall under the authority of the formal village head, who deals with village administration. The *tu'a golo* informally handles social problems and wields more influence than the formal village head (Iswando et al., 2015). Physical restraint and confinement continues to be used in villages in Manggarai as a method of managing people with mental health issues who become aggressive. People usually view it as a social issue and a threat to the community and, therefore, a *tu'a golo* steps in to manage it. In 2021, the total number of people suffering from mental illness in Manggarai numbers approximately 503 people, and 67 of them are confined (Manggarai Government, 2021). Previous research suggested that informal leaders face difficulties in stopping physical restraint and confinement and need support from both formal and informal parties to do so (Daulima, 2018; Laila et al., 2018). Research exploring the role of informal leaders in physical restraint and confinement, however, still remains limited despite their significant influence on the practice.

This study of Manggarai, Indonesia, is of relevance globally as it describes the treatment of people suffering mental health issues in areas possessing limited mental health services and resources, and where people often ignore the basic human rights of those with mental health issues. Its applicability is limited, however, as physical restraint and confinement does not occur everywhere. This study also advances understanding of the factors that contribute to this widespread human rights abuse, which persons with severe mental health issues experience and where governments have failed in their responsibility to provide effective, accessible, affordable, and culturally appropriate psychiatric treatment and care.

Methods

Participants

One *tu'a golo* from each of 15 villages participated in this study. They range in age from 41 to 68 and all have the experience of observing or carrying out physical restraint and confinement. As noted, a *tu'a golo* is an informal chief found in every village in Manggarai, Flores. The position is hereditary and passed from father to oldest son. Preliminary interviews were carried out first to find out whether a *tu'a golo* was willing and able to be interviewed

Table 1. Characteristics of tu'a golo Participants

Participant code	Age	Gender	Educational background	Occupation	Tenure as tu'a golo (years)	Physical restraint and confinements conducted
P1	51	Male	Senior high school	Entrepreneur	10	2
P2	68	Male	Elementary school	Farmer	23	10
P3	41	Male	Senior high school	Entrepreneur	3	1
P4	58	Male	Undergraduate degree	Civil servant	12	2
P5	43	Male	Undergraduate degree	Civil servant	6	7
P6	65	Male	Elementary school	Farmer	30	11
P7	45	Male	Senior high school	Entrepreneur	5	4
P8	52	Male	Junior high school	Farmer	10	2
P9	56	Male	Undergraduate degree	Civil servant	17	3
P10	54	Male	Junior high school	Farmer	11	2
P11	49	Male	Junior high school	Farmer	9	1
P12	38	Male	Senior high school	Farmer	2	2
P13	51	Male	Senior high school	Farmer	12	2
P14	56	Male	Senior high school	Farmer	10	4
P15	58	Male	Undergraduate degree	Farmer	13	1

in more depth. Among the 15 *tu'a golos, three* have confined more than seven people, while the remaining 12 have confined at least one person. The majority have completed senior high school and all are male. The characteristics of the *tu'a golos*, the study participants, can be seen in Table 1.

Research Design

This study used a qualitative approach and semantic ethnography. Semantic ethnography is a methodology that aims to uncover how a community understands its culture and to explore principles behind behaviors – in this case, behind the decision to confine – via analyzing the meaning of components (Parfitt, 1996; Spradley, 1976). To understand the culture, researchers analyzed the data using James Spradley's Developmental Research Sequence, a method developed in 1979. The focus centers on searching for meaning in language in order to build a structured taxonomy of meanings (Spradley, 1976; Parfitt, 1996). This method was chosen because it is considered to be more structured than other methods available for categorizing a cultural phenomenon. The Developmental Research Sequence method is also used as an analysis method due to its systematic, clear, sequential and comprehensive approach (Garrido, 2017).

Data Collection

Researchers conducted this study in fifteen villages in Manggarai, Indonesia, with fifteen *tu'a golos*, or informal village leaders, participating. These *tu'a golos* were chosen for their experience in confining mentally ill people in their village. *Tu'a golos* generally were chosen as informants because they are well acquainted with the culture of Manggarai, including beliefs regarding mental illness. The researchers employed semi-structured interview questions, consisting of descriptive, structural, and contrast questions in each stage of the data collection process. They conducted descriptive interviews with twelve *tu'a golos,* after which they obtained no new data. Structural interviews were conducted with seven *tu'a golos*, five of whom also participated in descriptive interviews. Two *tu'a golos* were recruited for data validation purposes. Contrast interviews were conducted with eight *tu'a golos,* seven of whom participated in descriptive interviews. Researchers interviewed one *tu'a golo* to validate the data. The questions were based on Spradley's interview questions in ethnographic studies (Spradley, 1976). Expressing interest,

expressing ignorance, avoiding repetition, and taking turns were strategies adopted during the interviews (Parfitt, 1996). Data were collected using in-depth interviews with descriptive questions. The interview started with questions around the *tu'a golo's* activities and tasks, and followed with grand tour questions regarding physical restraint and confinement in the village. Based on the answers given, researchers posed further interview questions.

Data Analysis

Data analysis was carried out using Spradley's (1979) structural semantic analysis. The researchers aimed to explore the perspectives of a *tu'a golo* as an informal leader, which required an emic or insider perspective. Spradley's four-step analysis guided the process of gaining an emic perspective. First, the researchers aim to gain an overview of the study's object through domain analysis. Second, with taxonomy analysis, the researchers aim to further explain the emerging domains in order to understand the domain's internal structure. Third, the researchers conducted a componential analysis to find the specific characteristics of each domain by contrasting the elements. Lastly, the researchers used cultural thematic analysis to explore the relationship between the domains that fall within the theme of the research.

Results

Domain Analysis

Domains are categories of cultural meaning and include semantically related subcategories (Spradley, 1987), they are identified based on the knowledge of cultural terms involving lower-ranking related concepts. In other words, the domain contains terms that have been included due to semantic relationships. The first step in domain analysis involved finding semantic relationships across participants' statements. Researchers needed to find the relationships, including semantic relationships, of nouns, including terms or folk terms, and closed terms. After establishing the relationship, researchers prepared a worksheet of domain analysis (Table 2).

Taxonomy Analysis

The researchers then conducted structural interviews to explore in depth those domains uncovered in the domain analysis. In those structural interviews carried out with five *tu'a golos*; the researchers asked in detail about the tu'a

Table 2. Domain Analysis

1.	Semantic relationship:	strict inclusion
2.	Form:	X is a type of Y
3.	Example:	Giving suggestions regarding physical restraint and confinement is a type of role that *tu'a golos* take on regarding physical restraint and confinement

Include terms	Semantic relationship	Closed term
• Giving suggestions to a family regarding physical restraint and confinement • Discussing • Performing physical restraint and confinement • Helping families to cure a family member who is experiencing mental health issues • Maintaining the well-being of people with mental health issues who have been confined	*Strict inclusion*	The role of *tu'a golo* in physical restraint and confinement

Structural question: What are the types of role a *tu'a golo* takes on in physical restraint and confinement?

Figure 1. Taxonomy Analysis
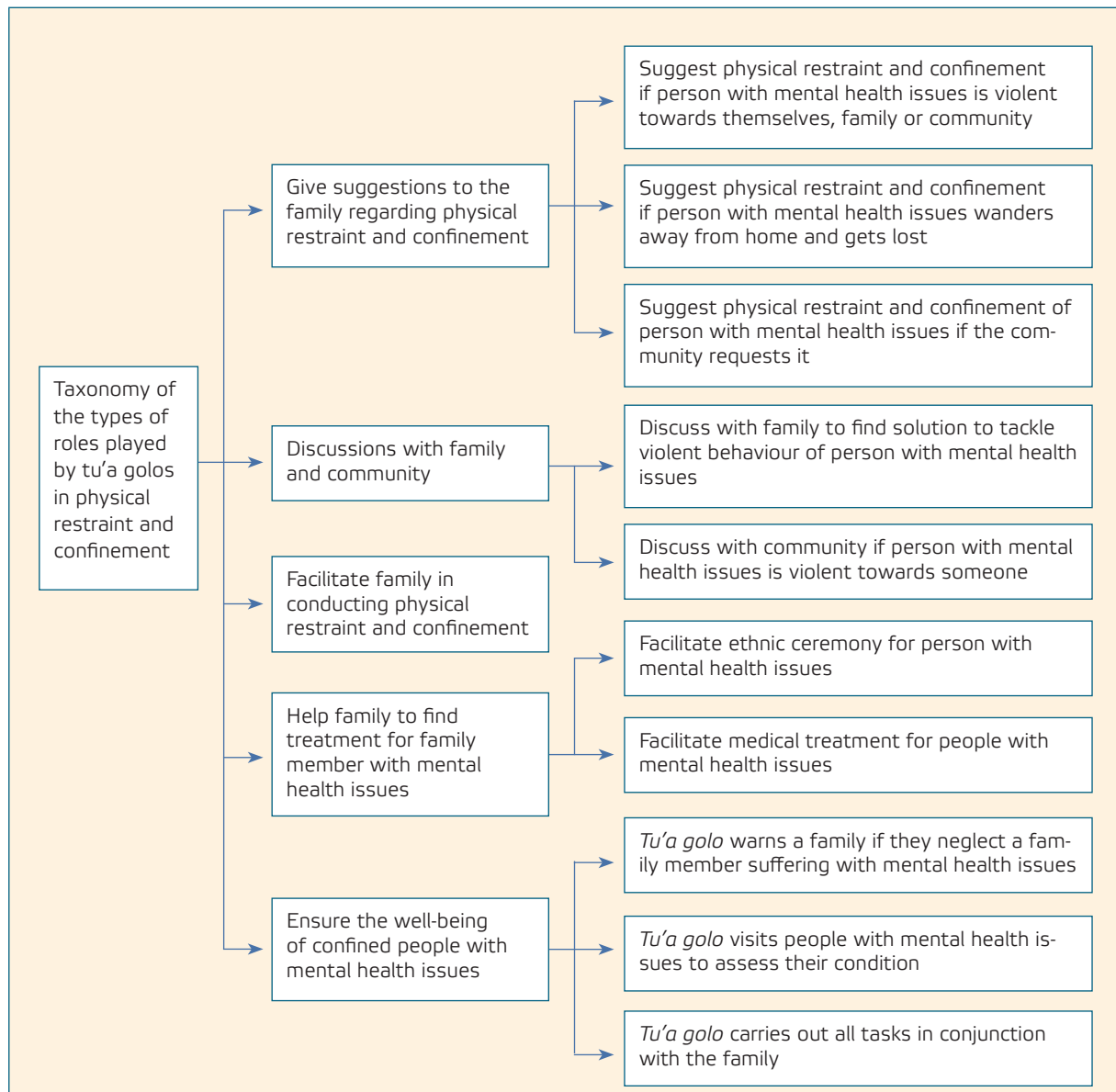
golo's role in physical restraint and confinement. Researchers began the taxonomy analysis by choosing a domain to be analyzed. They then provided the domain with additional information, including descriptions, which were taken from the domain analysis (Figure 1).

Componential Analysis

After contrast interviews, researchers carried out a componential analysis for the contrast meaning analysis stage of the Developmental Research Sequence. Contrast meaning can be found by searching for differences between folk terms. This study used triadic contrast questions. Researchers gave three folk terms in each domain and asked for differences and similarities. They also asked about differences in the tu'a golo's role types and found differences in function, time period and goal. The results of the componential analysis can be seen in Table 3.

Thematic Analysis

Cultural thematic analysis was carried out through exploring relationships among the domains that form the culture. This research found three cultural themes around the duties of *tu'a golos*: (1) *tu'a golo* as mediator, (2) *tu'a golo* as adviser, and (3) *tu'a golo* as protector. The next sections provide quotes from *tu'a golo's* related to these three roles.

Table 3. Componental Analysis

Contrast set	Domain of contrast		
	Function of *tu'a golo*	Time	Goal
Giving suggestions regarding physical restraint and confinement to the family	Adviser	Before physical restraint and confinement	Maintain well-being of family and community
Discussing	Mediator	Before physical restraint and confinement	Ensure well-being of those with mental health issues
Facilitating family in conducting physical restraint and confinement	Mediator	During physical restraint and confinement	Ensure well-being of family and family member with mental health issues
Helping family to cure family member with mental health issues	Protector	During physical restraint and confinement	Ensure well-being of those with mental health issues
Ensuring well-being of those confined due to mental health issues	Protector	During physical restraint and confinement	Ensure well-being of those with mental health issues

Tu'a golo as Mediator

As a mediator, the *tu'a golo* connects the community and the family of a person with mental health issues. This study revealed that an individual exhibiting mental illness can only be confined if they show violent behavior towards their family or community. A person suffering mental health issues who does not become violent will not be confined. In the case of violence, however, other villagers will not approach the family directly. Instead, they will go to a *tu'a golo* and ask him to pass on their concerns.

> *Tu'a golos* have many roles. The villagers and families can come to a *tu'a golo* to complain and share their problems. People with mental health issues are part of the community too. Therefore, they are the responsibility of the *tu'a golo*. The *tu'a golo* bear responsibility for maintaining peace and security in the village. Should people having mental illness create problems, then the *tu'a golo* will find a solution so that no conflict exists in the village. A *tu'a golo* will give suggestions to the mentally ill person's family. The *tu'a golo* is responsible for maintaining the peace of the village. The tu'a golo can advise the family. (P5)

> When a mentally ill person damages property or hits a villager, the villagers will not protest directly to the family. Instead, they will come to the *tu'a golo* to explain the problem. The *tu'a golo* will pass the information on to the family and ask them to find a solution. (P2)

Tu'a golo as Adviser

This study revealed that a *tu'a golo* functions as an adviser to the family, guiding them in physical restraint and confinement. The community will become concerned if a person with mental health issues is violent. Villagers seek help from the *tu'a golo*, who acts as a village leader and protector. The *tu'a golo* passes concerns on to the family of the person with mental health issues and suggests the family seek traditional treatment (*tu'a golos* generally have no knowledge of medical treatment). Physical restraint and confinement remains the last resort when traditional treatment fails.

> We, as the *tu'a golo*, have no specific authority to solve the problems of people with mental health issues. However, we can advise their family when they start to damage property or threaten the community. The *tu'a golo* can advise the families of what might happen. For example, should their family member with mental health issues not be confined, then more people may be injured. (P3)

> Physical restraint and confinement is the last step if the person with mental health issues is not cured after being given traditional treatment. During the treatment, the *tu'a golo* also gives suggestions. For example, should the person create a commotion, then the *tu'a golo* will suggest inviting in a shaman. If a shaman cannot cure them, then the *tu'a golo* will suggest physical restraint and confinement. Who will be responsible for the safety of the villagers and families if the mentally ill person throws a stone or threatens villagers with a knife? (P12)

A family will usually agree to a tu'a golo's suggestion to confine a family member who exhibits mental health issues. As a village leader, the *tu'a golo bear* the responsibility for protecting the village. A family that stands against physical restraint and confinement needs to make sure their unwell family member will not cause a problem again.

> If the families do not obey the *tu'a golos'* suggestions, then they must make a statement or special agreement, which states that should anything happen inside or outside the village, then the family will take full responsibility. (P9)

Tu'a golos recommend physical restraint and confinement because they believe that mental health issues cannot be cured by medical treatment or healthcare services.

> As *tu'a golo*, I advise a family to perform physical restraint and confinement because until now mental health issues have no cure. Taking a person with mental illness to a hospital will not cure that person. Their physical condition is good, but their mind is ill. How can this ill mind be cured? (P7)

Tu'a golo as Protector

A *tu'a golo*'s main role in the village is protector, and this includes protecting those in physical restraint and confinement due to mental health issues and ensuring their well-being. The *tu'a golo* must remind the family to take care of their unwell family member.

> The tu'a golo has several roles regarding physical restraint and confinement. The *tu'a golo's* main duty as leader is to protect each person in the village. He must protect the village and prevent conflicts. I think the *tu'a golo's* responsibility as a protector is a must because he needs to protect the village. However, he also needs to protect people with mental health issues. Therefore, the *tu'a golo* needs to check their condition in physical restraint and confinement. If their families neglect them, then he needs to warn the families. The idea of physical restraint and confinement sometimes comes from a *tu'a golo* but he is not obliged to suggest it, and whether or not it proceeds also depends on the family. (P11)

> The *tu'a golo* role is to maintain the safety of the villagers and of people suffering from mental health issues as well as their families. Although we are aware that physical restraint and confinement may be a torture for those with mental health issues, we do not have other options. It is better to sacrifice one person than the whole village. However, the *tu'a golo* must protect all villagers, including those with mental health issues. Therefore, the *tu'a golo* needs to ensure the well-being of those who are confined due to mental health issues. (P15)

The role of the *tu'a golo* in physical restraint and confinement is illustrated in Figure 2.

Discussion

Before physical restraint and confinement, the function of the *tu'a golo* is that of a mediator. Interviewees stated that their mediation duty requires them to communicate villagers' concerns about the violent behavior of a person with mental health issues to the family. Villagers also expect the *tu'a golo* to find a solution involving

Figure 2. Roles of a tu'a golo in Physical restraint and confinement
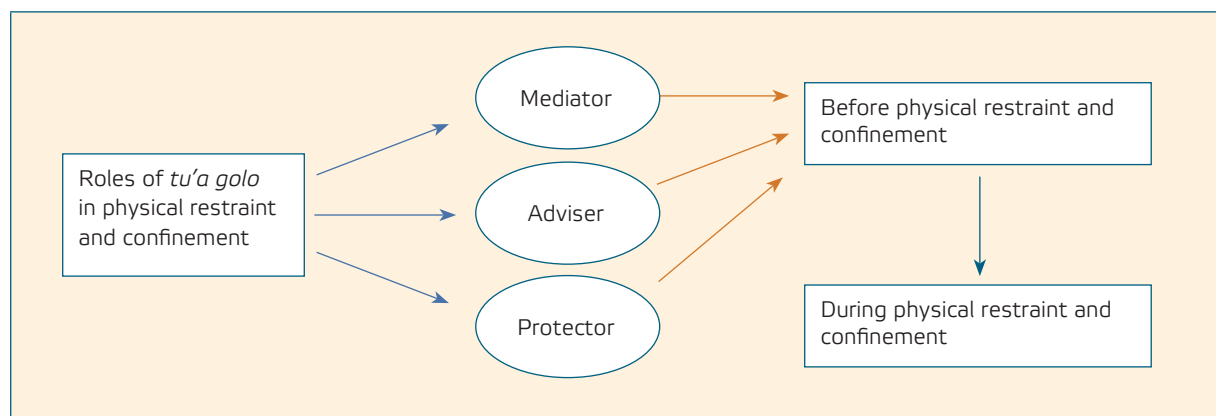
the family to bring the behavior under control. A study in Ethiopia highlighted similar findings; villagers who were afraid of the violent behavior of people with mental illness asked their community leader to find a solution (Asher et al., 2017). Similar findings were also registered elsewhere in Indonesia; the community asked for help from a community leader such as a district head or community elder when a person with mental health issues was violent (Laila et al., 2018). Violent behavior of those afflicted by mental health issues creates problems in the community, and communities view such people as threats to their village (Opitz-Welke & Konrad, 2019; Suryani et al., 2011). Stigma remains a frequent occurrence in developing countries where limited knowledge of mental health issues exists and that have limited access to healthcare services (Lund et al., 2012; Michaels et al., 2015; Smith et al., 2011).

Stigma leads to the discrimination and marginalization of people with mental illness (Hartini et al., 2018). It also increases the burden on the families of the mentally unwell and leads to poor treatment. The study found that the *tu'a golo* takes on the role of mediator in physical restraint and confinement, which occurs when an unwell person acts violently towards other villagers. The villagers do not directly complain to the family, but instead express their concerns to the *tu'a golo* and ask him to relate these concerns to the family. The *tu'a golo* carefully delivers the concerns to the family and works with them to find the best solution. The *tu'a golo* does not judge the family, but supports them. Good social support helps the family to cope (Rafiyah et al., 2011). However, knowledge of mental illness remains limited, as does access to mental health services, so the *tu'a golo* relies on physical restraint and confinement. It is, therefore, important to educate *tu'a golos* and other influential informal and formal community leaders in mental health.

The *tu'a golo* serves a secondary role as physical restraint and confinement adviser to the family. Participants stated that physical restraint and confinement remains the option of last resort should an individual having mental health issues persistently shows violent behavior which the community cannot help. Physical restraint and confinement in Indonesia is often carried out at the suggestion of the community through their formal or informal leaders (Daulima, 2018). Laila et al. (2018) found that informal leaders such as religious leaders influence family decisions in physical restraint and confinement. Formal leaders also influence physical restraint and confinement (Laila et al., 2018). Participants in the current study stated that the unwell are confined because mental health issues cannot be cured and can only be controlled with physical restraint and confinement. Lack of knowledge and understanding among the family and community regarding mental health is one of the reasons physical restraint and confinement occurs (Daulima, 2018; Minas & Diatri, 2008; Puteh et al., 2011; Tay et al., 2017). The community views mental illness as something that cannot be treated, perhaps because limited mental health services exist in the community (Suryani et al., 2011; Wong et al., 2018). Knowledge regarding mental illness, therefore, and care involving community leaders that healthcare professionals or the family can provide for the community following training, needs to be improved.

The *tu'a golo's third role* in physical restraint and confinement is protector. Participants stated that a *tu'a golo* must protect the confined by ensuring the instruments of physical restraint and confinement – the stocks and rope, among others – do not cause physical problems. The *tu'a golo* must ensure the family meets the needs of their confined family member, particularly as regards food and water. Mental health is influenced by the culture where a person resides. The customs of the community and family influence physical restraint and confinement (Hidayat et al., 2020). In Manggarai culture, people view a person with mental health issues as a blessing and the family bears an obligation to care for them. The interviewees in this study believe that treating a person with mental illness badly will invite bad karma, known as "nangki" in the Manggarai language. Therefore, the well-being of a confined person must be maintained to prevent negative repercussions for the family or the *tu'a golo*. Such beliefs are not only found in Indonesia. A study in India found that doing good to a person with mental health issues is obligatory, and bad luck may result from mistreating the mentally ill (Avasthi et al., 2013; Burley, 2014). This finding can be used to educate families and communities to improve the health of the mentally unwell; families and communities can be taught that culture forbids them from harming people with mental health issues, and that medical intervention serves as the best solution as it will not cause harm.

This study highlights the strong influence of informal leaders regarding physical restraint and confinement. Previous studies have stated that community leaders have important duties in the physical restraint and confinement of people with mental illness (Daulima, 2018; Laila et al., 2019). However, this study is the first to research how informal leaders influence physical restraint and confinement and we therefore expect it to become a reference for future research into the role of informal leaders in other areas of Indonesia. Community leaders could play a key function in rehabilitation and could effectively influence the community about treatment for

the mentally ill. Community-based social rehabilitation for people with mental health issues is one programme that puts community leaders in a key role (Stratford et al., 2014). Community leaders can take on an active role in educating the community about mental health and inviting community members to contribute to the social rehabilitation of those suffering from mental health issues (Stratford et al., 2014). The community mental health nursing model presents a similar approach, whereby community intervention serves to assist people with mental health issues to develop life skills and avoid physical restraint and confinement (Keliat et al., 2020). This study suggests that involving informal leaders such as *tu'a golos* in community-based mental healthcare will bring positive changes in preventing physical restraint and confinement.

Strength and Limitations

This study is the first to research how informal leaders influence physical restraint and confinement and we, therefore, expect it to become a reference for future research into the role of informal leaders in other areas of Indonesia. Community leaders could play a key function in rehabilitation and could effectively influence the community about the treatment of the mentally ill. The limitation of this study is the limited time and number of participants, which leads to a limited generalization of this study. Despite this limitation, the strength of this study is that it is the first exploration of how physical restraint and confinement is mediated through cultural stage and ritual. The sample was also purposively selected with maximum diversity to enrich the data.

Conclusion, Implications and Future Direction

This study aimed to explore the role of the *tu'a golo*, an informal village leader, in the physical restraint and confinement of a person experiencing mental health issues. The *tu'a golo* has three main roles regarding physical restraint and confinement: as a mediator and as an adviser before physical restraint and confinement, and as a protector during physical restraint and confinement. This study identifies that *Tuá golo* as the informal leader holds a significant influence and role in conducting physical restraint and confinement.

This study provides insight to healthcare providers, especially mental health providers, to help them collaborate with informal community leaders in reducing physical restraint and confinement's use. Health providers must work with informal leaders on educating mentally ill people, families, and the community on the effect of physical restraint and confinement.

Further studies must be carried out to explore the tasks of formal leaders in confining a person experiencing mental health issues. Further studies are needed to identify the cultural effects of physical restraint and confinement in different cultural and traditional regions of Indonesia in order to take a cultural approach to overcome physical restraint and confinement, and achieve Free Pasung Indonesia.

Author contributions
Angelina Roida Eka: conceptualization, design, methodology, funding acquisition, investigation, project administration, data management, formal analysis, interpretation, supervision, writing original draft, writing review and editing.
Novy Helena Catharina Daulima: conceptualization, design, methodology, funding acquisition, investigation, project administration, data management, formal analysis, interpretation, supervision, writing review and editing.
Herni Susanti: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, supervision, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement

The authors have no conflicts of interest to disclose.

Ethical statement

This manuscript is the authors' original work.

The study were reviewed and approved by the Faculty of Nursing Universitas Indonesia, Depok, Indonesia, license number: No.50/UN2.F12.D/HKP.02.04/2019.

All participants participated in the research voluntarily and anonymously, and provided their written informed consent to participate in this study.

Data are stored in coded materials and databases without personal data, and the authors have policies in place to manage and keep data secure.

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Appendix

INTERVIEW GUIDE

Descriptive Interview

1. Grand tour question
   - How long have you been a *tu'a golo?*
   - What is your duty as *tu'a golo?*
   - During your time as *tu'a golo,* have you ever known a person with mental illness and confined in your village?
   - How did you contribute to the physical restraint and confinement process?
   - Could you tell me how the process of before to after the physical restraint and confinement?
2. Mini tour question
   - How do you explain your feelings when you notice a person with mental illness being confined?
   - How do you as *tua golo* perform in the physical restraint and confinement process?
3. Example question
   - Could you explain the physical restraint and confinement process on mentally ill person?
4. Experience question.
   - Could you tell your experience on confined mentally ill person?
5. Native-language question
   - What is the term used to define a person with mental illness?
   - What is the term used to describe the physical restraint and confinement of a person with mental illness?

Structural interviews

Through the previous interviews, we have already identified five important roles of *tua golo* on physical restraint and confinement namely: (1) Giving suggestions regarding physical restraint and confinement to the family (2) Discussing (3) Performing physical restraint and confinement (4) Helping the family to cure their family member with mental illness (5) Maintaining the well-being of mental illness people in physical restraint and confinement. In this interview, I would like to ask about each of the components within the roles.
1) Giving suggestions regarding physical restraint and confinement to the family
   - What is the suggestion given by *tua golo* to the family regarding physical restraint and confinement?
(2) Discussing
   - What is included in the discussion between family and *tua* in the physical restraint and confinement process?
(3) Performing physical restraint and confinement

RESEARCH ARTICLE

The Influence of Health Education and Group Therapy on Adolescent Online Gamers' Self-Concepts

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Introduction: The rapid development of online games is currently marked by the increasing number of adolescent game players. This was particularly true during the COVID-19 pandemic that forced all activities to be done at home. Adolescents who play online games excessively, however, can risk their self-concept. Adolescents' ability to control the increasing habit of playing online games can help them reduce the risk of self-concept problems by enhancing their adaptive behavior at their crucial psychosocial development stage. Health education and group therapy can be employed to attain this goal.

Aims: The authors of this study aim to determine the effectiveness of health education and group therapy regarding the self-concept of adolescents who play online games excessively.

Methods: As the research design, this study applied a quasi-experimental pre-posttest with a control group. The research respondents were selected using the stratified, proportional, and simple random sampling techniques. Seventy-six adolescents comprised the respondents of this study, divided into two groups. The respondents' inclusion criteria were adolescents aged 15–16 years old who had played online games for at least the last 12 months.

Results: The self-concept of adolescents in the intervention group has increased after implementing health education and group therapy ($p < .05$). In contrast to this, the self-concept of adolescents in the control group has not changed after implementing health education and group therapy ($p > .05$).

Conclusions: Health education and group therapy effectively improve the self-concept of adolescent gamers.

Keywords: self-concept, adolescence, health education, group therapy, online games addictions

Introduction

Online game development has rapidly increased among adolescents, especially during the COVID-19 pandemic, public health responses to which forced all activities to be done at home in order to avoid the transmission of the COVID-19 virus. Online games can be a major medium to entertain adolescents when they lack social activities at home. Indonesian adolescents playing online games ranked the highest in ASEAN in 2017 (Osborn, 2016). Unfortunately, excessively playing online games can endanger adolescents' developmental age and their self-concept.

Psychosocially, the developmental stage of adolescence refers to the phase of forming a self-identity that needs to be achieved based on the goals, roles, and characteristics that exist in adolescents. Adolescents who are able to adapt to changes during their psychosocial developmental stage will have a more positive, better self-concept. Self-concept constitutes an adolescent's intact, structured, and dynamic thinking based on learning, behavior, and other people's opinions about him (Berman et al., 2016). Moreover, self-concept refers to perception and a way of thinking that shapes individual beliefs and ideas about oneself (Ducasse et al., 2019). The formation of self-concept in adolescent boys and girls is not significantly different. One study has shown that adolescent girls possess a better self-concept than do adolescent boys (Nurliana, 2015). Adolescent boys tend to be attracted to challenges, such as online games; thus, they are more likely to suffer from mental health problems. Conversely, another study describes how adolescent boys possess a better self-concept than adolescent girls because girls focus more on physical development and body image (Widiarti, 2017). Although these two studies show different perspectives, it is believed that a positive self-concept in adolescents stands always in line with healthy physical and mental conditions (Berman et al., 2016).

Excessive online gaming behavior can lead to self-concept problems and a corresponding behavior. Some studies have revealed that engaging in online games tends to increase adolescents' maladaptive self-concept (Beard & Wickham, 2016). Furthermore, excessive online gaming activities can negatively influence the formation of self-concept and real social interaction (Ayu & Saragih, 2016). Isolating behavior in adolescents increases online gaming activities (Chen et al., 2018). Individuals who experience low self-esteem tend to experience internet addiction (Sariyska et al., 2014). Low self-esteem makes them withdraw from their environment; consequently, they play online games to escape from reality and to reduce perceived stressors (Kaptsis et al., 2016). Low or negative self-concept drives adolescents out of control when playing online games; such a condition can cause mental health problems including addiction, clinical distress, bullying, all of which adversely affect adolescents mental health status, creating psychosocial problems, including decreased life satisfaction levels, anxiety, and depression. (Altintas et al., 2019; American Psychiatric Association, 2013; Bargeron & Hormes, 2017; Choi, 2014; Weinstein, 2010).

Health education and group therapy can help establish a good self-concept by optimizing the stage of adolescent psychosocial development. Establishing self-identity is one of the stages of adolescent psychological development. Adolescents are supposed to be able to understand themselves in their entirety, including their distinctions from others, recognize gender, be able to view all elements of themselves as a whole, judge themselves based on society's judgment, actualize themselves in previous, present, and future relationships, as well as set future values and goals consciously (Yusuf et al., 2015).

Health education is a method of guiding adolescents in making decisions that would lead to the development of a positive self-concept. Adolescents' understanding of how to maintain a positive self-concept could be improved by health education (Junike et al., 2015). Health education is conducted by providing information and behavioral methods. Providing information can be performed using various media, such as mass media, electronic media, and social media, and providing health service systems, whereas the behavioral method tries to encourage adolescents to behave healthily based on instructions or forms of training (Sarafino & Graham, 2006).

Adolescent group therapy constitutes a nursing intervention that is carried out in adolescent groups to stimulate the formation of self-concept through optimizing the stages of development. Group therapy is used because teenageers are interested in working in groups. (Purwati & Sulastri, 2019). They will feel secure in the group and that they are in the right place to express emotions (Sarfika et al., 2018). Group therapy can improve adolescents' adaptive behavior toward change and experience during adolescent development. Adolescents' response abilities to psychosocial, cognitive, spiritual, and creative development can be increased through group therapy (Fernandes, 2014). Providing therapy in the form of a group can offer support to group members, in this case adolescents, when an individual enters a period of chaos, has temporary decompensation, undergoes recovery, strengthens defense, and begins to include his or her classmate, who is also experiencing disorders, into the group (Sadock, 2010).

The description above denotes that the behavior of playing excessive online games can cause self-concept problems in adolescents due to a failure at the stage of adolescent psychosocial development. Several previous studies have revealed that health education and group therapy for adolescents can optimize the stage of their psychosocial development. However, these studies did not specifically or directly assess adolescents' self-concept, especially regarding adolescents who play online games. Therefore, this study aims to assess the effectiveness of health education and group therapy concerning the self-concept of adolescents who played online games excessively during the COVID-19 pandemic.

Methods

The quantitative quasi-experimental pre-posttest with control group method was employed in the study. The sample of this study consisted of 76 students made up of 71 males and five females from two state senior high schools in Indonesia's Morowali Regency, Sulawesi. The samples were selected using the stratified sampling, proportional sampling, and simple random sampling methods. The stratified sampling was implemented because the sample comprised only grade two students of senior high schools. Meanwhile, proportional sampling was employed because several subclasses existed in the 2nd grade of senior high schools. Finally, simple random sampling was selected to determine samples in each class based on the number according to the inclusion and exclusion criteria. The inclusion criteria were adolescents aged 15–16 years who had played online games for the last 12 months using a smartphone, but who had not been addicted to the games. The online gaming addiction in adolescents was assessed using the internet gaming disorder scale, containing questions about playing online games, problems caused by playing online games, symptoms of withdrawal in playing online games, and impacts on social activities when playing online games (Pontes & Griffiths, 2015). If some teenagers in the screening process had been diagnosed as addicted, further treatment would be performed to overcome the online game addiction. Before participating in the study, all the adolescents involved had submitted informed consents from themselves and their parents.

The therapy used in this study is health education and group therapy in adolescence. This investigation began with determining the research sample based on inclusion criteria and it continued with screening using an internet gaming disorder questionnaire instrument to assess addiction levels among adolescent online gamers. Adolescents who were addicted to online games were not included in this research; they were referred to medical treatment. The therapy was performed for three weeks by means of conducting a pre-test, health education, post-test 1, group therapy, and post-test 2. Health education was provided to both groups and continued with implementing group therapy in the intervention group. Meanwhile, the control group was left with free ordinary activities.

Health education consisted of two meetings in each group. The material was provided on health education regarding adolescent development, assertive communication, and online game addiction. Health education was conducted by means of lectures and discussions. Group therapy consisted of six meeting sessions: stimulating adaptation to changes in biological and psychosexual aspects at the first meeting, stimulating adaptation to changes in cognitive and language aspects at the second meeting, stimulating adaptation to changes in moral and spiritual aspects at the third meeting, stimulating emotional and psychosocial development at the fourth meeting, stimulating the development of talents and creativity at the fifth meeting and the sixth meeting, and finally, monitoring and evaluating experiences and the benefits of the training. Each group therapy session included lectures, roleplay, and independent exercises during the next session's meeting. Each therapy session lasted for 60 minutes with a two-day gap between meetings.

This study employed the self-concept clarity scale to assess self-concept (Campbell et al., 1996) that were translated into Indonesian and tested using the validity and reliability test with the item-total correlation value $\geq .3610$ ($r = .363 - .771$). The self-concept clarity scale questionnaire refers to the structural aspects of self-concepts and the extent to which adolescents can define their self-confidence externally and internally (Campbell et al., 1996).

The characteristics (age and gender) of adolescent respondents in the control and intervention groups and their self-concepts were analyzed using descriptive statistics and different statistical tests. The normality test was conducted using a Kolmogorov-Smirnov method to examine the self-concept of both groups before and after the therapy. In the bivariate analysis, the homogeneity test was conducted using Levene's test to examine the adolescents' self-concept in both groups before and after the therapy. Changes in self-concept before and after the therapy's implementation were analyzed using a parametric dependent t-test in the control group. This test was employed because the data demonstrated that the self-concept of adolescent respondents in the control group was normally distributed before and after the implementation of health education and therapy of the group. Meanwhile, changes in the self-concept of adolescent respondents in the intervention group before and after the implementation of therapy were analyzed using the Wilcoxon non-parametric test. This test was employed because the data on self-concept descriptions of adolescent respondents in the intervention group were not normally distributed before and after the implementation of health education and group therapy.

Results

All of the respondents in the intervention group were male. Meanwhile, the control group consisted of 86.8% male respondents and 13.2% female respondents. The average age of respondents in both groups came to 16 years, with the youngest respondents' age being 15 years and 17 being the oldest age.

Table 1. Characteristics of Respondents' Age

Groups	n	Mean	Min-Max	SD	SE	95% CI	p
Intervention	38	16.11	15–17	0.727	0.118	15.87-16.34	.876
Control	38	16.05	15–17	0.733	0.119	15.81-16.29	

Table 2. Characteristics of Respondents' Gender (n = 76)

Groups	Male		Female		Total	
	n	%	n	%	n	%
Intervention	38	100	0	0.0	38	100

Table 3. Description of Changes in Respondents' Self-Concept before and after the Implementation of Health Education

Self-Concept	n	Mean	SD	SE	95% CI	p
Intervention Group						
Before	38	29.47	4.164	0.675	–0.332–0.121	.346
After		29.58	4.071	0.653		
Control Group						
Before	38	27.08	4.675	0.758	–0.359–0.464	.797
After		27.03	4.103	0.666		

Table 4. Changes in Respondents' Self-Concept before and after the Implementation of Health Education and Group Therapy

Self-Concept	n	Mean	SD	SE	95% CI	p
Intervention Group						
Before	38	29.47	4.164	0.675	–1.628-(-0.635)	.0001
After		30.61	4.071	0.660		
Control Group						
Before	38	27.08	4.675	0.758	–0.725-0.725	1.000
After		27.08	3.872	0.628		

Table 3 shows that the intervention group had no significant changes in the average self-concept value before therapy implementation and after the implementation of health education, with a p of .346 ($p > .05$). This result is derived from the Wilcoxon statistical test. The same condition is also found in the control group that does not have changes in the average value of self-concept before the implementation of therapy and after the implementation of health education with a p of .797 ($p > .05$). This result is derived from the dependent t-test statistical test.

Table 4 shows that the intervention group has a significant change in the mean value of self-concept after the implementation of health education and group therapy with a p of .0001 ($p < .05$). This result is derived from the Wilcoxon statistical test. However, the dependent t-test and statistical test have revealed that the control group does not show a significant change in the mean value of self-concept after the implementation of health education and group therapy with a p of 1.000 ($p > .05$).

Discussion

Health education and group therapy provided the improvement of adolescent self-concept in the intervention group. Although there was a significant change in self-concept in the intervention group, the increase in self-concept scores was not huge. On the other hand, the adolescents in the control group who simply received health information, did not improve their self-concept at all. Health education is a process of shaping and changing lifestyles to assist individuals

or communities with making decisions related to health maintenance and improvement (Aziz & Soewondo, 2008). Health education in adolescents has not effectively improved their self-concept because health education only effectively targets their knowledge (Setiowati, 2014), especially when it utilizes leaflets (Sari, 2019) to change their beliefs, understanding, and attitudes towards health (Aziz & Soewondo, 2008). Health education effectively optimizes stages of adolescence development, but it has not been able to improve the ability of adolescents to control their emotions (Dinarwiyata, 2014). Self-concept formation must begin with the development of youth knowledge and skills.

Further exercises on the topic of health education materials are necessarily conducted using group therapy so that this therapy can be internalized, moving towards the formation of self-concept. Group therapy for adolescents constitutes a part of group therapy of which the main focus is to prevent disorders through teaching and effectively deal with emotional stress in a situation or developmental crisis (Townsend & Morgan, 2018). Group therapy targets adolescents' self-concept because it is implemented by means of discussing changes experienced during adolescent development and training. As a result, the adolescents can be creative in adapting themselves to the change they have experienced. Adolescents can apply their knowledge, acquired during health education, in the form of independent practical exercises to improve development psychomotoric and perceive the effects and benefits of the therapy (Rukmini, 2008). Group therapy was offered in several stages from Session 1 to Session 6 in order to stimulate adaptive behavior and change biological, psychosexual, cognitive, linguistic, moral, spiritual, emotional, psychosocial, talent-related, and creative aspects.

The group therapy implemented in the groups is effective because the respondents feel secure (Stuart, 2016). The group therapy could effectively increase the adaptive behavior of adolescents at the development stage. This finding lines up with other studies, which have revealed that group therapy can stimulate all development aspects and tasks of adolescents (Hasanah, 2015), improve adolescents' self-identity (Bahari, 2010), and enhance aspects of adolescent development abilities (Maryatun, 2014).

Stimulus and increased adaptation to biological aspects in the implementation of group therapy aims to assist adolescents in increasing their adaptive behavior regarding their biological changes, and their efforts to maximize their biological development. The increasing changes in adolescents' biological aspects of adolescents can be noted from the secondary sex development, such as breast growth in women, testes growth in men, and growth of armpit hair and pubis (Wulandari, 2014). Other changes include an increasing penis size, voice changes, thicker hair, changing face size, ejaculation, and an increased production of glands that trigger acne (Sarwono, 2016). Adolescents' biological aspects of development indirectly affect psychosexual aspects because changes in the biological aspects due to puberty can lead to sexual attraction to the opposite sex (Stuart, 2016). Through group therapy, adolescents can improve their understanding and optimally adapt to biological and psychosexual development.

Group therapy also provides adaptation stimuli to develop cognitive and language aspects. The cognitive enhancement adolescents experience can be assessed by explaining or proving a theory or fact as well as interpreting the objectives (Putro, 2017). According to Piaget, adolescents' cognitive development is a formal operational evolution characterized by abstract, inductive, deductive, and logical thinking and probability (Fontaine & Fletcher, 2003). The stimulus given to adolescents is intended to enrich insight and vocabulary knowledge when interacting with their environment so that the stimulus impacts adolescents' ability to develop abstract thinking. Rahayu et al. (2019) have proved that the implementation of group therapy could improve children's cognitive abilities.

Furthermore, the adaptation of stimuli to the moral and spiritual aspects of group therapy can make adolescents understand the moral rightness, wrongness, or badness of actions they do. Teens must be able to recognize such values and rules that apply in their environment. Every adolescent's behavior and actions must follow the prevailing values and norms (Putro, 2017). Adolescents also need spiritual values to shape their identity to avoid deviant behavior (Innayati, 2012). Group therapy can develop their attitudes or views as a basis for restructuring the achievement of positive self-concepts, especially the formation of self-identity based on values, rules, and environmental views (Zsakai et al., 2017).

The emotional and psychosocial development adaptations that the group therapy provides aids adolescents in recognizing their emotional condition and positively interacting with their environment. Meanwhile, adolescents' good relationships enable them to develop greater health (Yoo, 2019). Teens are expected to be able to recognize and control their emotions when interacting with others. Group therapy can improve adolescents' emotional intelligence (Dinarwiyata, 2014). Moreover, group therapy stimulates aspects of development and adaptive behavior to improve adolescents' talents and creativity since they are beginning to prepare for future goals based on their talents (Putro, 2017).

The increase in self-concept in adolescents after undergoing group therapy can be seen from changes in the ability of adolescents to assess their self-image. After therapy, adolescents are able to see their positive self-image

including aspects of shape, size, function, meaning, limitations they have, as well as other objects attached to their bodies. A positive self-image in adolescents can be built through a healthy lifestyle, such as doing regular physical activities, having a positive relationship with others, avoiding negative self-assessments, and developing an adaptive self-image (Koulanova et al., 2021).

Group therapy also enhances adolescents' self-perception as an intact or ideal personality who behaves via following certain standards, aspirations, goals, and values. Adolescents obtain the opportunity to determine or improve the standards, aspirations, goals, and values which they have owned or believed throughout their lives. Self-ideals are sometimes realistic; conversely, an individual's position or role will not be much different from what has already been believed (Berman et al., 2016). Adolescents' self-ideal depends on their perception of behaving according to their standards (Agustin et al., 2018). The better and more positive standards of values there are for them, the more positive and increasingly ideal their self-concept is.

The role in self-concept bears a positive impact on adolescents after administering group therapy. A role consists of a series of patterns in behavior, attitudes, values, and goals that the environment desires for people based on an individual's position or achievements in society and social groups (Yusuf et al., 2015). Group therapy, therefore helps adolescents find their identity and understand their role as students; moreover, they should play their roles by means of learning to achieve something as children. Finally, they should perform their roles in helping their parents do the chores.

Self-identity is an individual's awareness, based on the observations and judgments of himself and others. Group therapy assists the adolescents in understanding that they are entirely different from others. Moreover, the therapy allows adolescents to express emotions to strengthen their self-identity (Gu et al., 2020). An individual's ability to recognize his ideal role and self-image can increase his self-esteem. Increased self-esteem may also occur in individuals with high self-concepts because they are able to adapt to interpersonal relationships. (Yang et al., 2021).

Improving the respondents' self-concept can prevent the addictive behavior of playing online games. Increasing self-concepts raises coping teenagers' ability to avoid addiction to online games. Adolescents can still play online games but only to entertain themselves and spend their free time. They should not be addicted because they have priorities and goals to achieve. Good self-concept can reduce problematic behavior (Ducasse et al., 2019). Adolescents are able to focus on aspects of improving themselves and their social environment and should reject excessively playing online games. Physical activities, extracurricular programs at school, habitual book reading and playing music can become protective factors against the risk of online gaming addiction (Hong et al., 2019). Adolescents who partake in constructive outdoor activities, such as sports and recreation, can reduce the intensity of playing online games (Kapoh, 2015). Moreover, adolescents with high levels of physical activity tend to have good academic grades (Haapala et al., 2020). Good self-concept also enables adolescents to control their emotions and prevents psychosocial problems that are risk factors for addiction (Laconi et al., 2017; Wartberg et al., 2019; Yu et al., 2018). Strengthening self-identity in adolescents can protect them against privacy violations in online social media, such as online games (Elsayed, 2021).

Good self-concept in adolescents imparts an effect on good physical and mental health that facilitates them to perceive, think, and form positive beliefs and ideas about themselves (Ducasse et al., 2019). Adolescents' knowledge enables them to recognize themselves consciously and thoroughly, realizing that they are distinct from others, recognizing and accepting their gender, viewing all self-aspects in harmony, accepting and recognizing themselves as a whole without environmental influence or assessment (Yusuf et al., 2015). Adolescents' good self-confidence and attitude may demonstrate a strong stability in their self-concept (Krol et al., 2020). They can adjust and perform their duties and roles as children, students, and as members of their environment. Their ability to perform these roles will prevent them from frustration that could decrease their self-esteem (Yusuf et al., 2015).

Strength and Limitations

The strength of this study is that it provides problem solutions in the field of adolescent self-concept, a self-concept that can be disrupted due to excessive online gaming behavior during the COVID-19 pandemic, resulting in online game addiction. The solution lies in the form of implementing health education and group therapy for adolescents.

This study carries several limitations. First, the interventions, namely health education, and group therapy, were implemented at school during the school hours and in the course of the COVID-19 pandemic in Indonesia because the school did not allow the researchers to involve students outside of school hours. This policy affected the adolescents' focus on the research and their learning process in classrooms. Moreover, their focus on learning and exercising

their developmental tasks based on group therapy was also hampered because they had to complete school assignments. Second, respondents' demographic characteristics were not evenly distributed between the intervention and control groups. The control group had five females while the intervention group did not have any. This was due to the sampling technique carried out randomly on all students who met the study's inclusion and exclusion criteria. So, the researchers could not equally divide the respondents between the intervention and control groups based on gender.

Conclusion, Implications, and Future Directions

Health education and group therapy are effective in improving the self-concept of adolescent online gamers. A good self-concept aligns with optimal physical and mental health so adolescents can focus more on constructive activities that are beneficial for themselves and the environment, and it also enables them to abstain from excessively playing online games to avoid health problems.

This article is expected to have an impact on efforts to prevent online game addiction in those adolescents who play online games. The authors hope further research will be suitable for assessing how much influence online game addiction has on changes in the self-concept of adolescents who excessively play online games.

Author contributions
Boby Nurmagandi: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, supervision, writing original draft, writing review and editing.
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All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement
The authors have no conflicts of interest to disclose.

Ethical statement
This manuscript is the authors' original work.
The authors confirm that their research was approved by Prof. Dra. Setyowati, S.Kp., M.App.Sc, Ph.D and by the Ethics Committee of the Faculty of Nursing, University of Indonesia, Depok City, Indonesia, license number: SK-68/UN2.F12.D1.2.I/ETIK.
The authors declare that all participants participated in the research voluntarily and anonymously. The participants provided their written informed consent to participate in this study. Their data are stored in coded materials and databases without personal data, and they have policies in place to manage and keep data secure.

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RESEARCH PAPER

Parental Burnout in Hungary: Development and Psychometric Evaluation of the Hungarian Parental Burnout Assessment (PBA-HUN)

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Introduction: Parental burnout might take place when excessive demands overwhelm the parents' resources.

Aims: To develop and validate the Hungarian version of the Parental Burnout Assessment (PBA-HUN), an instrument designed to measure parental burnout; and to determine the prevalence of parental burnout in Hungary.

Methods: Data were collected via an online survey from parents with at least one child living in the household (N = 1215; 82.6% mothers; M_{age} = 38.68 years; SD_{age} = 6.27 years). Confirmatory factor analysis was used to investigate the factor structure of the PBA-HUN.

Results: The four-factor structure of the original PBA was replicated, confirming the following factors: exhaustion in one's parental role, contrast with one's parental role, feelings of being fed up, and emotional distancing from one's children. A second-order model with a higher-order factor representing overall parental burnout also fit the data well. The internal consistency of both the subscale and total scores was excellent ($\alpha \geq 0.84$). Parental burnout had a moderately strong negative correlation with life satisfaction, and weak or moderate positive correlations with perceived stress, depression, vital exhaustion, and COVID-specific perceived stress supporting the construct validity of the PBA-HUN. The prevalence of parental burnout stood at 5.8% in this sample. The weak relationship between PBA-HUN scores and sociodemographic factors was also similar to those found in prior studies. Parental burnout correlated negatively with the number of hours spent sleeping and engaging in spare time activity, respectively.

Conclusions: The PBA-HUN is a reliable and valid tool to assess parental burnout in Hungary.

Keywords: parental burnout, psychometric properties, reliability, validity, COVID-19

Introduction

One's experience of parenthood results from the costs and benefits of parenting across one's lifetime. While in an optimal case, parenthood is rewarding and contributes to parents' well-being (Nomaguchi & Milkie, 2003; Umberson et al., 2010), this sensitive balance of costs and benefits depends on many factors, including – among others – parents' psychological characteristics, stress-management abilities, child-rearing practices, the support from the co-parent and family, etc. (Mikolajczak et al., 2021). In line with these assumptions, parental burnout emerges when stress-enhancing factors overweigh the parents' resources. Demands and risk factors like perfectionism, overwhelming parental duties, low emotional intelligence, and lack of external or family support, will elevate parental stress. On the other side of the balance, resources and protective factors, such as good child care routines, positive co-parenting, and spare time activities decrease parental stress (Mikolajczak & Roskam, 2018). Accordingly, parental burnout is a possible consequence of excessive parental demands or lack of resources, an experience of overwhelming exhaustion regarding their parental role, emotional detachment from their children, and feelings of doubt regarding the ability to be a good parent. (Mikolajczak et al., 2019).

Pelsma et al. (1989) made one of the first efforts in the conceptualisation and measurement of parental burnout. These authors assessed burnout among non-working mothers of young children by the Maslach Burnout Inventory (MBI, Maslach & Johnson, 1981), which is the most widely used instrument to measure burnout on three dimensions: emotional exhaustion, depersonalisation, and decrease in personal accomplishment. Concluding that parental burnout shares similarities with job burnout regarding the emotional exhaustion and personal accomplishment dimension, Pelsma et al. (1989) also determined that depersonalisation was not confirmed in the sample of mothers. While a few studies had been conducted with parents having children and suffering from chronic diseases (e.g., Norberg, 2007; Lindström et al., 2011; Beheshtipour et al., 2016), two decades passed before the concept of parental burnout attracted broad and significant research interest. Roskam et al. (2017) were the first to develop a measure to examine parental burnout as a distinct construct. The resulting Parental Burnout Inventory (PBI) is based on the items of the MBI modified to reflect the specific context of parenting. Depersonalisation, in this measurement approach, was replaced by the theoretically more plausible emotional distancing dimension. Results supported the validity of the tri-dimensional scale.

Later, parental burnout conceptualisation and measurement proceeded with the development of the Parental Burnout Assessment (PBA), which was based on the testimonies of burnt-out parents. Through factor analysis, the authors reduced the number of items to 23 and revealed four dimensions: exhaustion in one's parental role, feelings of being fed up, emotional distancing from one's child, and a fourth, inherent dimension that contrasts with one's previous parental self. Good validity and reliability of the PBA (Roskam et al., 2018) as well as its measurement invariance across gender and languages were confirmed (Roskam et al., 2021).

Although the PBA and the PBI proved to be congruent instruments, the first remains preferable for several reasons. First, the "contrast to parental self" is a unique and important dimension not covered by the PBI. Second, all PBA items directly address different aspects of parental burnout, while the dimension "loss of accomplishment" from the PBI is addressed indirectly by means of reversed items. Based on parents' testimonies, non-reversed items are preferable to measure parental burnout. Third, according to the parental burn-out reports, loss of fulfillment in the parental role seemed to be more important than the "loss of accomplishment" captured by the PBI. Finally, PBA is a freely available instrument for measuring parental burnout, while the PBI is copyrighted (Roskam et al., 2018).

In relation to the rapidly growing interest in parental burnout, an increasing number of studies have emerged in the field aiming to identify antecedents and risk factors such as perfectionism (Sorkkila & Aunola, 2020) or outcomes like escape ideation, parental neglect and parental violence (Mikolajczak et al., 2019), as well as possible interventions to help parents cope (Brianda et al., 2020). Furthermore, the International Investigation of Parental Burnout (IIPB) Consortium, with more than 40 members, facilitates and coordinates cross-border investigations in the field. The major aim of the IIPB is to study the "conceptual validity, prevalence, and intercultural variation of parental burnout" (https://www.burnoutparental.com/international-consortium). Recently, Hungary also became a member of the consortium, making it possible for the country to take part in this multinational scientific cooperation. Our paper presents the first steps towards this goal; that is, confirming the conceptualization of parental burnout and providing preliminary data on its prevalence in Hungary.

The current study

The current study's major aim was to investigate the psychometric properties of the Hungarian version of the PBA (PBA-HUN) by testing its reliability as well as its factor structure and validity. Previously, several studies

(Aunola et al., 2020; Arikan et al., 2020; Gannagé et al., 2020; Matias et al., 2020; Mousavi et al., 2020; Sodi et al., 2020; Stănculescu et al., 2020) confirmed either a four-factor, first-order model of the PBA or a second-order model, wherein global parental burnout emerged as a second-order latent factor in addition to the four domain-specific factors. We hypothesized that one of these two factor structures would be replicated in the Hungarian data. We also aimed to provide a preliminary prevalence rate of parental burnout in the Hungarian population.

Regarding construct validity, several hypotheses have been developed. We chose variables to test construct validity mainly based on previous studies. Below, we present these constructs together with the connected hypotheses. First, life satisfaction is a cognitive and global evaluation of one's quality of life as a whole, a comprehensive assessment of subjective well-being (Pavot & Diener, 2008). It was presumed that parental burnout would be negatively related to life satisfaction as has been shown in previous studies (Aktan et al., 2020; Stănculescu et al., 2020; Matias et al., 2020; Szczygieł et al., 2020). Second, perceived stress results as a consequence of an appraisal process, when situations in one's life are evaluated as stressful (Cohen et al., 1983). It was hypothesized that PBA scores would indicate a positive relationship with perceived stress based on previous findings (Lebert-Charron et al., 2018; Roskam et al., 2017). Third, vital exhaustion, originally identified as a psychological risk factor of coronary heart disease, was considered as a potential correlate of parental burnout. The construct consists of feelings involving excessive fatigue, increasing irritability, and feelings of demoralization (Frestad & Prescott, 2017). We presumed a positive relation between parental burnout and vital exhaustion because exhaustion in one's parental role is the predominant factor in PBA. Furthermore, vital exhaustion and burnout proved to be positively correlated previously (Bellingrath et al., 2008). Fourth, considering the findings of previous studies (e.g., Roskam et al., 2017; Kawamoto et al., 2018; Aunola et al., 2020), we assumed a positive relation between parental burnout and depression.

Investigating parental burnout stands especially relevant during the COVID-19 pandemic. The pandemic triggers several social disruptions in the family system, such as job loss, financial insecurity, social distancing, and confinement. These factors negatively affect caregivers' well-being by elevating distress, parenting stress, and mental health symptoms that have the potential to damage the child-parent relationship (Prime et al., 2020). We supposed that increased parental burnout also numbered among the COVID-19 pandemic's negative affective outcomes. As Mikolajczak and Roskam (2020) noted, parental burnout has received significantly increased attention since the pandemic's outbreak, which forced parents and children into confinement. Based on the assumptions above, we investigated the relation of perceived stress to parental burnout, assuming a positive correlation would exist between parental burnout and pandemic-related perceived stress. So far, very few studies have explored the relationship between the COVID-19 pandemic-induced negative affective reactions and parental burnout, but those did indicate that concerns about COVID-19 moderately-strongly predicted parental burnout (e.g., Prikhidko et al., 2020). Furthermore, Le Vigouroux et al. (2021) compared parental burnout before and during the lockdown, and found that parents reported slightly elevated saturation levels (feelings of being fed up) during the lockdown compared to those who were included into the study prior to the lockdown. This finding also supported our hypothesis regarding the positive association between parental burnout and pandemic-related stress.

An international investigation on parental burnout, involving 42 countries, has already addressed the worldwide comparison of parental burnout prevalence (Roskam et al., 2021). Since Hungary was not part of the consortium then, the present study also aimed to determine the Hungarian prevalence of parental burnout. Based on Roskam et al. (2017), we expected that this prevalence rate would fall between 2% and 12%. We also presumed that the prevalence rate would be relatively high, since individualistic cultures (like Hungary) displayed higher burnout prevalence rate in the international investigation (Roskam et al., 2021).

Finally, based on the extant literature (e.g., Arikan et al., 2020; Stănculescu et al., 2020), only a weak association was anticipated between parental burnout and sociodemographic variables. Mainly following the protocol of IIPB (Roskam et al., 2021), we examined the relationship between parental burnout and the following sociodemographic variables: gender; age; educational attainment; socioeconomic status; marital status; employment status; number of child(ren) in the household; total number of child(ren); age of the youngest child; age of the oldest child; number of the women in the same household caring for the child(ren); number of the men in the same household caring for the child(ren); having children with disabilities or learning/emotional/behavioral problems. As far as we know, we were the first who investigated important segments of daily activity besides the hours spent with child(ren): number of hours spent sleeping a day, and the number of hours spent with spare time activity.

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Methods

Sample

Altogether, 1,215 parents (82.6% mothers) took part in the survey; their ages ranged from 18 to 69 years *(M* = 38.68 years, *SD* = 6.27 years). According to the inclusion criteria, participants had at least one child living in the same household. The most important sociodemographic characteristics of the sample are described in Table 1 and Table 2.

Procedure

The United Ethical Review Committee for Research in Psychology (Hungary) approved the protocol of the current study under #2021.02.

The Hungarian version of the PBA was developed through blind back-translation based on the French version. After a professional translation agency made an initial translation from French into Hungarian, an expert skilled in social sciences accomplished the back-translation (from Hungarian to French). The authors sent the back-translation for review to Professor Isabelle Roskam, one of the original PBA developers. During a consensus meeting, the first author and the expert who took part in the back-translation developed the final version of the Hungarian adaptation (see its text in the Appendix) also taking into account Dr. Roskam's feedback.

After the translation procedure, we developed a test battery containing questions on sociodemographic variables and the measures that will be introduced below. Data collection was conducted online using Google Forms through convenience sampling and the snowball method (respondents were asked to share the link of the survey with their acquaintances). The link to the survey was shared with the permission of the administrators in various social media groups that targeted parents. In the absence of formal grant support to allow the recruitment of a representative sample, the above-described sampling method provided the most economical strategy to reach a large enough sample to allow the validation process.

Both social media posts and the introduction part of the online questionnaire informed participants that the study addressed challenges in parents' life including parental burnout. Before starting to complete the survey, participants expressed their informed consent with a click confirming their awareness that the survey remained voluntary and anonymous, that they could withdraw at any time without justifying their decision, and that their individual data would be kept confidential.

Measures

Sociodemographic questions

Participants were asked about their gender, age, educational attainment, marital status, socioeconomic status, current employment status (later recoded as doing paid work outside of the home versus not doing so), total number of children, number of children in the same household, child(ren) with disabilities (yes/no), child(ren)

Table 1. Descriptive Statistics of the Categorical Variables

Variable	%	n
Gender		
Fathers	17.4	212
Mothers	82.6	1,003
Educational attainment		
Primary school	0.9	11
Vocational school	4.7	57
Secondary grammar school	17.7	215
Higher vocational school	7	85
College	29.3	356
University	37.6	457
PhD	2.8	34
Socioeconomic status		
Lowest	1.2	15
Lower-middle	21.7	264
Middle	61.5	747
Upper-middle	14.9	181
Upper class	0.7	8
Marital Status		
Married	76	924
Common-law marriage	14.9	181
Divorced	6.6	80
Single	2.1	26
Widowed	0.3	4
Employment status		
Having paid work	60.7	737
Maternity leave	31	383
Unemployed	3.1	38
Do not work for other reasons	4.7	57
Having child(ren) with disabilities		
Yes	12.3	150
No	87.7	1,065
Having child(ren) with learning/emotional/behavioral problems		
Yes	23.5	286
No	76.5	929

with learning/emotional/behavioral problems (yes/no), number of men and women living in the same household and taking care of the children on a daily basis. Finally, we also measured the time parents spent with certain activities: the number of hours on a typical day spent with children, spare time activities, and sleep.

Parental burnout

The authors measured parental burnout with the Hungarian version of the PBA (Roskam et al., 2018). The PBA consists of 23 items and contains four subscales: exhaustion in one's parental roles (nine items, e.g., "I have zero energy for looking after my child(ren)", contrast in parental self (six items, e.g., "I tell myself that I'm no longer the parent I used to be"), feelings of being fed up (five items, e.g., "I can't take being a parent any more"), and emotional distancing (three items, e.g., "I'm no longer able to show my child(ren) how much I love them"). All items were answered on a 7-point Likert scale (0 = Never, 6 = Daily).

Table 2. Descriptive Statistics of Continuous Variables

Variable	Mean	Standard deviation
Age (year)	38.68	6.27
Number of child(ren) in the household	2.05	0.97
Total number of child(ren)	2.17	1.14
Age of the youngest child in the household or in general? (year)	5.25	4.87
Age of the oldest child in the household or in general? (year)	9.22	6.39
Number of women in the same household caring for the child(ren)	0.94	0.40
Number of men in the same household caring for the child(ren)	0.90	3.60

Life satisfaction

Subjective well-being was measured via the Satisfaction with Life Scale (Diener et al., 1985; Hungarian version: Martos et al., 2014). The five items (e.g., "I am satisfied with my life") were rated on a 7-point Likert scale (1 = Strongly disagree, 7 = Strongly agree). Internal consistency was excellent in the present sample (Cronbach's alpha = .88).

Perceived stress

We used the Perceived Stress Scale (Cohen et al., 1983; Hungarian version: Stauder & Konkolÿ Thege, 2006) to assess the perceived level of stress in the previous month. The four-item version used in the present study showed a very strong relationship with scores to the full, 14-item version ($r = .93$, $p < .001$; Stauder & Konkolÿ Thege, 2006). Items (e.g., "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?") were rated on a 5-point Likert scale (0 = Never, 4 = Very Often). Internal consistency was excellent in the present sample (Cronbach's alpha = .83).

Vital exhaustion

Fatigue was measured with a shortened version of the Maastricht Vital Exhaustion Questionnaire (Appels & Mulder, 1988; Hungarian version: Kopp et al., 1998). This scale contains five items (e.g. "Do you sometimes feel your body is like a battery running out?"), which can be answered on a 3-point scale (No = 0 point, Not sure = 1 point, Yes = 2 points). Internal consistency was excellent in the present sample (Cronbach's alpha = .83).

Depression

A shortened version of the Beck Depression Inventory (Beck et al., 1961; Hungarian version: Kopp et al., 1995; Rózsa et al., 2001) was used to measure symptoms of depression, such as pessimism, lack of satisfaction, guilty feelings, social withdrawal, indecisiveness, work inhibition, sleep disturbance, fatigability and somatic preoccupation. This scale consists of nine items (e.g., "I feel guilty all of the time"), which can be answered on a 4-point scale (1 = Completely disagree, 4 = Completely agree). Internal consistency was excellent in the present sample (Cronbach's alpha = .84).

COVID-19 pandemic-related perceived stress

On the basis of Pedrozo-Pupo et al. (2020), a modified version of the 10-item Perceived Stress Scale was developed, adding terms referring to the "pandemic" to the original items (e.g., "In the last month, how often have you

felt that you were unable to control the important things in your life *due to the pandemic*?") (Hamvai et al., 2021). The scale aims to measure perceived stress associated with the COVID-19 pandemic. Questions were answered on a 5-point Likert scale (0 = Never, 4 = Very often). The internal consistency was excellent in the present sample (Cronbach's alpha = .88).

Statistical analysis

Confirmatory factor analysis (CFA) was used to test which theoretical model fits the data best regarding the factor structure of the PBA-HUN. First, we examined a unidimensional model wherein all 23 items were loaded on a single factor (M1). Second, a first-order model was tested (M2) that included four correlated latent factors (Roskam et al., 2018): emotional exhaustion in one's parental role (nine items), contrast in one's parental self (six items), feelings of being fed up (five items) and emotional distancing from one's children (three items). Based on previous psychometric studies on the PBA (Aunola et al., 2020; Arikan et al., 2020; Gannagé et al., 2020; Matias et al., 2020; Mousavi et al., 2020; Sodi et al., 2020; Stănculescu et al., 2020), we also tested an alternative, second-order model (M3), which included a global parental burnout dimension beyond the four first-order factors.

The confirmatory factor analyses were carried out with the lavaan package (Rosseel, 2012) of the R statistical software. We used the diagonally weighted least squares estimator as this is the recommended method in the case of ordinal, Likert-type indicators (Forero et al., 2009; Mîndrilă, 2010; Li, 2016). The model-fit was assessed by the Tucker-Lewis Index (TLI), the comparative fit index (CFI), the root mean square error of approximation (RMSEA) and the standardized root mean square residual (SRMR). The following cut-off criteria of an acceptable model fit were used: CFI and TLI 0.90 or above, RMSEA 0.6 or below and SRMR 0.8 or below. These values were recommended by Hu and Bentler (1999), who developed these cut-off values by calculating rejection rates of structural equation modeling for different kinds of true-population and misspecified models.

To examine reliability, Cronbach's alpha was calculated for the PBA-HUN and its subscales. Spearman correlations were conducted to test relationships between the PBA-HUN total score, its subscales and continuous/ordinal variables (educational attainment, socioeconomic status, number of children, age of youngest/oldest child, number of adults taking care of the children in the household, number of hours spent with children/spare time activity/sleep, life satisfaction, depression, perceived stress, vital exhaustion, and COVID-19 pandemic-related perceived stress). We used the Mann-Whitney test and Kurskal-Wallis test to examine possible mean rank differences of PBA-HUN scores across categorical variables (gender, marital status, employment status, child(ren) with disabilities, and child(ren) with learning/emotional/behavioral problems). These analyses were carried out using the IBM SPSS Statistics, Version 25.

Results

Factorial validity of PBA-HUN

Confirmatory factor analysis replicated the one factor-, first-order- and second-order model of parental burnout. For M1, Satorra-Bentler χ^2 (230) = 446.58 was significant at $p < .001$, which might indicate a discrepancy between the hypothesized model and the data, though a significant χ^2 test is not uncommon for large sample sizes like the present one. Further fit indices (TLI = 0.995, CFI = 0.996, RMSEA = 0.028, SRMR = 0.056) showed a good model fit for the single factor model of the PBA.

For M2, the confirmatory factor analysis revealed statistically significant and strong (all above 0.61) factor loadings for each item ($p < .001$, Table 3). The Satorra-Bentler χ^2 (224) = 307.24 was significant at $p < .001$, and the other fit measures (TLI = 0.998, CFI = 0.998, RMSEA = 0.017, SRMR = 0.046) indicated a good model fit.

The results regarding M3 also showed significant factor loadings ($p < .001$), all above 0.63. With the exception of the Satorra-Bentler χ^2 [(226) = 330.394, $p < .001$], all fit indices (TLI = 0.998, CFI = 0.998, RMSEA = 0.02, SRMR = 0.047) indicated that the theorized second-order factor model fitted well with the data. Correlations for all of the four latent variables were significant (Table 3).

Reliability

The Cronbach's alpha coefficients indicated excellent internal consistency for all subscales and the total score;

Table 3. Standardized Factor Loadings From the Four-Factor CFA Model M3 and Reliability Coefficients as Well as Intercorrelations of the Four PBA Subscales

		EX	CO	FU	ED
EX1	I feel completely run down by my role as a parent.	0.63			
EX2	I have the sense that I'm really worn out as a parent.	0.83			
EX3	I'm so tired out by my role as a parent that sleeping doesn't seem like enough.	0.77			
EX4	When I get up in the morning and have to face another day with my child(ren), I feel exhausted before I've even started.	0.77			
EX5	I find it exhausting just thinking of everything I have to do for my child(ren).	0.86			
EX6	I have zero energy for looking after my child(ren).	0.84			
EX7	My role as a parent uses up all my resources.	0.77			
EX8	I have the impression that I'm looking after my child(ren) on autopilot.	0.82			
EX9	I'm in survival mode in my role as a parent.	0.82			
CO1	I don't think I'm the good father/mother that I used to be to my child(ren).		0.68		
CO2	I tell myself that I'm no longer the parent I used to be.		0.81		
CO3	I'm ashamed of the parent that I've become.		0.81		
CO4	I'm no longer proud of myself as a parent.		0.85		
CO5	I have the impression that I'm not myself any more when I'm interacting with my child(ren).		0.83		
CO6	I feel as though I've lost my direction as a dad/mum.		0.87		
FU1	I can't stand my role as father/mother any more.			0.87	
FU2	I can't take being a parent any more.			0.88	
FU3	I feel like I can't take any more as a parent.			0.80	
FU4	I feel like I can't cope as a parent.			0.88	
FU5	I don't enjoy being with my child(ren).			0.79	
ED1	I do what I'm supposed to do for my child(ren), but nothing more.				0.75
ED2	Outside the usual routines (lifts in the car, bedtime, meals), I'm no longer able to make an effort for my child(ren).				0.80
ED3	I'm no longer able to show my child(ren) how much I love them.				0.83
Cronbach's α		0.93	0.92	0.92	0.84
Higher order factor of parental burnout		0.96	0.91	0.99	0.85
EX			0.87	0.97	0.80
CO				0.89	0.84
FU					0.82

Notes: All reported correlations are statistically significant at .001 level, EX, Exhaustion in parental role; CO, Contrast in parental self; FU, Feelings of being fed up; ED, Emotional Distancing.

more specifically, exhaustion in one's parental role: α = .93, contrast in personal self: α = .92, feelings of being fed up: α = .92, emotional distancing: α = .84, and for the total score: α = .97.

Construct validity

Table 4 presents the correlation coefficients between the PBA scores and the other study variables. The four subscales and the PBA total score showed significantly weak or moderately strong negative correlations with life satisfaction, significantly moderate to strong positive correlations with perceived stress, significantly moderate to strong positive correlations with depression, moderate to strong positive correlations with vital exhaustion, significant and weak to moderately strong positive correlations with COVID-19 related perceived stress.

Table 4. Spearman's Rho Coefficients Between the PBA Scores and the Ordinal/Continuous Study Variables

	EX	CO	FU	ED	Parental Burnout
Age	−0.17**	−0.04	−0.10**	0,06*	−0.12**
Number of children at the same household	0.06*	0.11**	0.06*	0.10**	0.07**
Total number of children	0.01	0.09**	0.02	0.08**	0.03
Age of youngest child	−0.19**	−0.04	−0.12**	0.04	−0.13**
Age of oldest child	−0.18**	−0.04	−0.12**	0.05	−0.12**
Number of women taking care of children	−0.01	0.01	−0.03	0.01	−0.01
Number of men taking care of children	−0.06	−0.07*	−0.04	−0.04	−0.06*
Number of hours spent with child(ren) a day	0.23**	0.13**	0.17**	−0.05	0.18**
Number of hours spent with spare time activity a day	−0.28**	−0.19**	−0.20**	−0.11**	−0.24**
Number of hours spent sleeping a day	−0.15**	−0.11**	−0.06*	0.03	−0.11**
Educational attainment	0.15**	0.10**	0.14**	0.18**	0.15**
Socioeconomic status	−0.03	−0.07*	−0.01	0.02	−0.03
Life satisfaction	−0.36**	−0.42**	−0.33**	−0.27**	−0.39**
Perceived stress	0.59**	0.60**	0.54**	0.41**	0.62**
Depression	0.63**	0.64**	0.56**	0.50**	0.67**
Vital exhaustion	0.64**	0.57**	0.54**	0.35**	0.64**
COVID-19 pandemic related perceived stress	0.36**	0.37**	0.30**	0.22**	0.37**

Notes: *p < .05 **p < .01 EX, Exhaustion in parental role; CO, Contrast in parental self; FU, Feelings of being fed up;
ED, Emotional Distancing.

Relationships with the sociodemographic variables

Overall, we observed weak to moderately strong associations between parental burnout and most of the ordinal-level sociodemographic variables, the strongest one appearing with number of hours with spare time activity, and the weakest with the number of children in the same household. No significant association was observed between indicators of parental burnout and the number of women taking care of the children in the household (Table 4).

Table 5 presents the findings concerning the relationship of parental burnout with the categorical sociodemographic variables. Mothers showed significantly higher levels of global parental burnout. Parents who were not working outside the home, as well as parents who had children with disabilities or learning/emotional/behavioral problems, reported significantly higher levels of global parental burnout. Marital status had a significant relationship with emotional distancing and according to the post-hoc tests, divorced parents experienced significantly higher emotional distancing than those who lived in civil partnerships (test statistics = -163.41; p < .05); all effect sizes were trivial, though.

Prevalence of parental burnout in Hungary

Respondents were considered as a high risk for parental burnout if they scored 92 or higher on the PBA, which is the mean score of a parent who experiences every symptom at least once a week (Szczygieł et al., 2020; Sarrionandia & Aliri, 2021). Using this cut-off, the prevalence rate of burnout stood at 5.8% in the total sample; 2.4% for fathers and 6.6% for mothers.

Discussion

The the current study aimed to 1) present the development and investigate the psychometric properties of the Hungarian version of the PBA (PBA-HUN), 2) investigate the relation of parental burnout and COVID-19 related perceived stress 3) determine the prevalence of parental burnout on the Hungarian sample and 4) examine the relationship between PBA-HUN and sociodemographic variables.

Table 5. Mean Ranks of PBA Scores Across Categorical Sociodemographic Variables

	Gender		Working at the moment?		Children with disabilities		Children with learning/		Parental Burnout				
	Fathers N=212	Mothers N=1003	Yes N=737	No N=478	Yes N=150	No N=1065	Yes N=286	No N=929	Married N=924	Common law N=181	Divorced N=80	Single N=26	Widow(er) N=4
EX	472.20	636.70	559.79	682.33	731.95	590.54	741.44	566.92	609.76	581.32	650.43	603.12	592.63
Statistics	$U=77529^{***}$ $\eta^2=0.03$		$U=140614.5^{***}$ $\eta^2=0.03$		$U=61282.5^{**}$ $\eta^2=0.01$		$U=94682^{***}$ $\eta^2=0.05$		$\chi^2(4)=2.25$ $\eta^2=0.001$				
CO	463.28	638.59	575.30	658.42	698.73	595.22	737.15	568.24	602.17	601.11	687.58	636.67	488.25
Statistics	$U=75637.5^{***}$ $\eta^2=0.03$		$U=152044.5^{***}$ $\eta^2=0.01$		$U=66266^{**}$ $\eta^2=0.01$		$U=95909.5^{***}$ $\eta^2=0.04$		$\chi^2(4)=5.11$ $\eta^2=0.001$				
FU	502.20	630.36	575.80	657.65	693.59	595.95	737.90	568.01	611.00	584.99	662.45	522.42	424.13
Statistics	$U=83888.5^{***}$ $\eta^2=0.01$		$U=152409^{***}$ $\eta^2=0.01$		$U=67037^{**}$ $\eta^2=0.01$		$U=95695.5^{***}$ $\eta^2=0.04$		$\chi^2(4)=5.48$ $\eta^2=0.001$				
ED	612.23	607.11	620.77	588.32	689.23	596.56	714.01	575.36	613.10	550.17	713.58	514.79	540.50
Statistics	$U=105421$ $\eta^2=0.00$		$U=166735$ $\eta^2=0.002$		$U=67691^{**}$ $\eta^2=0.01$		$U=102527^{***}$ $\eta^2=0.03$		$\chi^2(4)=15.04^{**}$ $\eta^2=0.01$				
Parental burnout	480.48	634.95	570.27	666.18	725.66	591.43	750.62	564.09	608.41	580.40	674.61	593.90	521.75
Statistics	$U=79283.5^{***}$ $\eta^2=0.03$		$U=148333^{***}$ $\eta^2=0.02$		$U=62225,5^{**}$ $\eta^2=0.02$		$U=92058^{***}$ $\eta^2=0.05$		$\chi^2(4)=4.29$ $\eta^2<0.01$				

Notes: $^*p < .05$ $^{**}p < .01$ EX, Exhaustion in parental role; CO, Contrast in parental self; FU, Feelings of being fed up; ED, Emotional Distancing.

Our results replicated both the first- and second-order structure of the instrument originally described by Roskam et al. (2018) and confirmed by other studies (Furutani et al., 2020; Aunola et al., 2020; Arikan et al., 2020; Gannagé et al., 2020; Matias et al., 2020; Mousavi et al., 2020; Sodi et al., 2020; Stănculescu et al., 2020). Accordingly, it can be concluded that the PBA-HUN consists of the same four dimensions as the original version of the scale: exhaustion in one's parental role, contrast with one's previous parental self, feelings of being fed up with one's parental role and emotional distancing from one's children. We can also conclude that, as a global parental burnout factor emerged in the second-order model as well, these data support the interpretation of the total score in addition to the subscale scores. These findings support the basic theoretical ideas: that is, parental burnout can be considered as a multifaceted, yet global construct. The data also indicate that the PBA-HUN had excellent internal consistency both in terms of the subscale and total scores. The correlations with other variables in the hypothesized directions also provided support for the convergent validity of the PBA-HUN: scores correlated negatively with life satisfaction and positively with perceived stress, depression, and vital exhaustion.

The present study stands among the very few that explicitly investigated the relationship between a COVID-19-related psychological factor and parental burnout. In line with our hypothesis, a positive association existed between parental burnout and COVID-19-related perceived stress. This is consistent with another study in which COVID-19-related anxiety was found to be a moderately strong predictor of parental burnout in Iran (Prikhidko et al., 2020). Interestingly though, the present findings are in contradiction with those of Mousavi (2020), who found that home quarantine did not have a significant effect on parental burnout. The author explained these findings by pointing out the buffer effect of the generally strong and extended support system available within families in Iran, which might be missing in Western cultures with more atomised family structures.

The current study also made an attempt to provide a preliminary prevalence rate of parental burnout in the Hungarian population. These data showed that the prevalence of parental burnout was 5.8% in the total sample, while it came to 2.4% among fathers and 6.6% among mothers. These results fit into the landscape of estimates proposed by Roskam et al. (2017), according to which the proportion of burnt-out parents ranges between 2% and 12% depending on the country and subpopulation. Taking into consideration that Hungary scored highly (with a rating of 80) on Hofstede's individualism dimension (Falkáné Bánó, 2014), and individualism proved to be an important factor within the cultural background of parental burnout (Roskam et al., 2021), it is not surprising that the prevalence rate stands relatively high. It is valuable to compare our findings to the prevalence rate of two other countries in the Central-Eastern-European region: Poland and Romania. While Poland (with a rating of 60 on individualism) displayed a 7.7% prevalence rate, Romania (with a rating of 30 on individualism) demonstrated just 3.8% (Roskam et al., 2021).

Regarding sociodemographic characteristics – in line with previous findings (e.g., Arikan et al., 2020; Stănculescu et al., 2020) – weak associations were observed with trivial effect sizes. Further, parental burnout has a positive correlation with the number of children in the same household and the total number of children; both being factors that can increase the demands of parenting. This continues in line with previous findings (Roskam et al., 2018; Gannagé et al., 2020; Sodi et al., 2020; Szczygieł et al., 2020; Stănculescu et al., 2020; Mousavi et al., 2020). On the other hand, parental burnout was negatively correlated with the parent's age and the age of the youngest and oldest child. Similar corollaries were found in Romania (Stănculescu et al., 2020) and Poland (Szczygieł et al., 2020).

To our best knowledge, we were the first who examined other segments of parents' daily schedules besides hours spent by caring for children, that is: hours spent with spare time activity and sleep. The fact that parental burnout positively correlates with the number of hours spent with children (see also Szczygieł et al., 2020; Stănculescu et al., 2020; Gannagé et al., 2020) and negatively correlates with the number of hours spent on spare time activities and the number of hours spent sleeping, highlighted the importance of "me time". Future studies should address factors that hinder parents finding their "me time" and methods that help them find some time they devote to themselves. The negative correlation between sleeping and parental burnout also fits indirectly into a previous finding; that is, sleep disruption negatively correlates with parental burnout (Aunola et al., 2020).

Overall, mothers showed a significantly higher parental burnout than fathers, which is in line with previous results (Stănculescu et al., 2020; Szczygieł et al., 2020; Gannagé et al., 2020; Furutani et al., 2020; Sarrionandia & Aliri, 2021). Hungary remains a typical post-socialist society wherein household chores were delegated to women before the democratic transition (Dupcsik & Tóth, 2014). During the post-socialist era, this deep-rooted notion has not changed significantly: household activities, including child rearing and parenthood, are

still perceived as mainly a mother's responsibility, even though recently, the notion of "intimate fatherhood" and "nurturing masculinity" has been more and more articulated (Takács, 2020). A future direction of research could involve investigating whether gender inequalities in household chores and child rearing are reflected in women's higher parental burnout.

Parents with paid work reported lower levels of burnout. This finding replicates data from many previous studies (Stănculescu et al., 2020; Szczygieł et al., 2020; Mousavi et al., 2020; Arikan et al. 2020). As Mousavi et al. (2020) concluded, working outside the household provides some "breath of relief", a kind of release from the ties of parenthood. On the other hand, financial security stemming from a job also might result in reduced parental burnout.

Parents who rear children with special needs bear extra burdens in parenthood. Thus, it is not surprising that Hungarian parents who had such extra responsibilities showed higher levels of parental burnout, which stands consistent with the findings of a related Polish study (Szczygieł et al., 2020).

Regarding marital status, parental burnout was only significantly different across common-law and divorced parents, with divorced parents showing the highest parental burnout. The additional challenges that a breakup/separation often causes in parents' lives might explain this effect. We can also assume that many divorced mothers might remain alone in child rearing.

Strenghts and Limitations

Developing a Hungarian version of the PBA is beneficial from numerous perspectives. First, Hungary can now take part in an emerging field of scientific investigation with a focus on a current and highly relevant subject: parental burnout. In addition, PBA can also be recommended as a diagnostic tool for various practitioners including education counseling services, family support services, and health visitors.

The current study includes some limitations. It is based on a non-representative sample; for instance, mothers, parents with university degrees and those from the middle class were over-represented. Being an online survey, our study might also have filtered out potential respondents who were not regular internet and social media users or did not have internet access. Furthermore, in order to avoid missing values, we required a response on each scale item. This might have forced some respondents to give incorrect answers when they were unable to skip the question. Regarding the examination of construct validity, we mainly used variables that represented risk factors for parental burnout; protective factors were less robustly represented in the present study. Finally, mentioning parental burnout in the introduction of the online survey might have biased the sample towards those who are more concerned with this topic. Consequently, the measured prevalence rate might be higher than the actual one.

Conclusions, Implications and Future Directions

Overall, our results support the notion that the Hungarian version of the PBA serves as an appropriate instrument to measure parental burnout and correctly represents the dimensions of the original scale. Therefore, we encourage researchers to use it in future studies aiming to better understand and manage parental burnout. We also demonstrated that the prevalence of parental burnout varies dramatically not only worldwide, but within European regions as well. Besides the Polish and Romanian findings, our results also gave a better insight about parental burnout in the Eastern and Central European region. While the prevalence rate is different in the three countries, we replicated most of the previous findings on the relationship of parental burnout and sociodemographic variables.

We also would like to make some recommendations for future studies here. First, we did not investigate criterion validity of the PBA-HUN; and so future investigations could aim to explore its relationship with possible outcomes like parents' negligent or violent behavior towards their children. Second, Hungarian validation of further instruments measuring parental burnout [e.g., Brief Parental Burnout Scale (Aunola et al., 2021) and Balance between Risks and Resources Instrument (Mikolajczak & Roskam, 2018)] would be beneficial. Third, future studies could focus on the segments of society that were underrepresented in our sample such asparents with lower educational attainment or fathers. Regarding the latter group, investigation of parental burnout among "weekend fathers" as well as fathers who raise their children alone would be especially important.

Author contributions
Csaba Hamvai: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, writing original draft, writing review and editing.
István Hidegkuti: formal analysis, writing review and editing.
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Barna Konkolÿ Thege: design, methodology, interpretation, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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The authors have no conflicts of interest to disclose.

Ethical statement
This manuscript is the authors' original work.
The study was reviewed and approved by The United Ethical Review Committee for Research in Psychology, Hungary, license number: #2021.02.
All participants participated in the research voluntarily and anonymously, and provided their written informed consent to participate in this study.
Data are stored in coded materials and databases without personal data, and the authors have policies in place to manage and keep data secure.

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Appendix

Full text of the Hungarian Parental Burnout Assessment (PBA-HUN)

A gyermekek a beteljesedés és az öröm fontos forrásai szüleik számára. Ugyanakkor néhány szülőnek a kimerültség forrásai is lehetnek. (Ez nem ellentmondásos: az önmegvalósítás és a kimerültség megférhet egymás mellett, ugyanis lehetséges, hogy Ön imádja a gyermekeit, mégis kimerültnek érzi magát a szülői szerepben). Az alábbi kérdőív a szülőként tapasztalt kimerültséggel foglalkozik. Válassza az Ön személyes érzéseit legjobban tükröző választ! Nincsen jó vagy rossz válasz. Ha sosem érezte magát így, válassza a „Soha" válaszlehetőséget! Ha volt már ilyen érzése, jelölje, milyen gyakran érzi így magát a „Néhányszor egy évben" válaszlehetőségtől a „Minden nap" válaszlehetőségig, attól függően, melyik írja le legjobban az érzés előfordulásának gyakoriságát.

    0=soha 1=Néhányszor egy évben 2=Egyszer egy hónapban, vagy kevesebbszer 3=Néhányszor egy hónapban 4=Egyszer egy héten 5=néhányszor egy héten 6=Minden nap

1. Olyannyira kifáraszt a szülői szerep, hogy már nem is tudom alvással kipihenni.
2. Úgy érzem, hogy nem tudok többé anyaként/apaként tekinteni magamra.
3. Úgy érzem, hogy, szülőként minden erőm elfogyott.
4. Semmi energiám sincs arra, hogy a gyereke(i)mmel törődjek.
5. Azt hiszem, már nem vagyok olyan jó anyja / apja a gyereke(i)mnek, mint voltam.
6. Szülőként már nem bírom tovább.
7. Szülőként úgy érzem, hogy ez nekem túl sok, „telítődtem".
8. Az a benyomásom, hogy automata üzemmódban foglalkozom a gyereke(i)mmel.
9. Úgy érzem, hogy nem bírom tovább szülőként.
10. Amikor reggel felkelek, és azzal szembesülök, hogy egy újabb napot kell eltöltenem a gyereke(i)mmel, már előre kimerültnek érzem magam.
11. Nem jelent örömet együtt lenni a gyerekeimmel.
12. Úgy érzem, hogy telítődtem a szülő szereppel.
13. Azt mondom magamnak, hogy már nem vagyok az a szülő, aki régen voltam.
14. Éppen csak annyit csinálok meg a gyerek(ek)ért, amennyit muszáj, de semmi többet.
15. A szülői szerepem minden energiámat felemészti.
16. Nem vagyok képes elviselni tovább az apai/anyai szerepet.
17. Szégyellem, hogy milyen szülő lett belőlem.
18. Szülőként már nem vagyok büszke magamra.
19. Az a benyomásom, már nem vagyok önmagam, amikor a gyereke(i)mmel vagyok együtt.
20. Már nem vagyok képes kimutatni a gyereke(i)mnek, mennyire szeretem őket.
21. Már az kimerít, ha csak arra gondolok, hogy milyen sok teendőm van a gyereke(i)mmel.
22. Az a benyomásom, hogy a rutint leszámítva (utazás, fektetés, etetés) más módon már nem tudok törődni a gyermeke(i)mmel.
23. A túlélésre játszom, mint szülő.

Szülői szerepben való kimerülés (exhaustion in one's parental role) tételei: 1; 3; 4; 8; 9; 10; 15; 21; 23
Szülői szereppel való meghasonulás (contrast with one's parental role) tételei: 2; 5; 13; 17; 18; 19;
Telítődés (feelings of being fed up) tételei: 6; 7; 11; 12; 16
Gyerek(ek)től való érzelmi eltávolodás (emotional distancing from one's children): 14; 20; 22

RESEARCH PAPER

Dementia in Czechia: Prevalence Estimations Until 2050

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Introduction: The Czechia is facing population aging. The number of people with dementia is increasing. Conflicting conclusions of European studies confirm the difficulties of quantifying the disease.

Aims: We aim to estimate the number of people with dementia in Czechia until 2050: a) projecting dementia prevalence using prevalence rates from EURODEM and EuroCoDe studies, b) projecting dementia based on mortality tables of individuals living with dementia. Comparing both approaches to dementia estimation.

Methods: We conducted a literature review. The projection is based on socio-demographic and health variables; construction of life tables for people with dementia.

Results: According to the results a) projecting the prevalence of dementia; over 300,000 seniors aged 60+ will suffer from dementia by 2050; b) estimating the number of individuals living with dementia: The number of men and women with dementia aged 65+ was estimated at over 120 thousand.

Conclusions: Czech society is not prepared for this intense increase in the number of individuals living with dementia. We argue early diagnosis as well as appropriate health and social care are urgent.

Keywords: Czechia, aging, dementia, prevalence of dementia, projection of dementia

Introduction

Population aging and the changes in the age structure belong to this century's most discussed topics. In developed European countries, including Czechia, the proportion of people aged 65+ is increasing (see Appendix). Changes in the age structure will result in increasing senior needs and a targeted approach to improve policy efficiency and public spending, health promotion, disease prevention and healthcare. A rapid increase in the number of a post-productive population above 65 years of age will be reflected in the increased need for social services and healthcare. Population aging and the significant share of seniors aged 65+ evoked a need to address this issue, since age constitutes the major risk factor for dementia. The future numerical growth of people with mental disorders invokes serious economic and health challenges for the country. In Czechia, the problem

of an aging population is primarily linked to the maintenance of the pension system. International studies, however, call attention to the seriousness of the dementia issue as a result of aging populations. Research on dementia is becoming increasingly important as this disease has far-reaching economic and health implications. It is currently known that dementia's economic costs soar higher than in the case of heart disease and cancer altogether (Alzheimer's Disease International [ADI], 2015). In the past, the overwhelming majority of people did not live up to the high age typical for dementia onset, and it was therefore considered as a natural consequence of aging. Dementia looms as a modern epidemic of the 21st century, however, with a doubling of patients over the next 20 years. According to estimates, 46.8 million people with dementia existed worldwide in 2015. By 2050 this could be 131.5 million people. By 2030, the number of patients with Alzheimer's disease in Czechia will exceed 200 thousand (CALS, 2015). Dementia and Alzheimer's disease belong to the leading causes of death. The aim of this present article is to create projection scenarios for the future development in the number of Czech individuals living with dementia by 2050. We, the authors, will base this projection on a unique dataset concerning the number of deaths by Alzheimer's disease and other mental illnesses, and the number of people hospitalized for the diagnosis of Alzheimer's disease, and other mental illnesses. All data are age-specific and sex-specific. We will calculate unique mortality tables in order to extrapolate the future development of dementia in the population. Available projections on dementia's prevalence are exclusively based on EURODEM and EuroCoDe prevalence studies. No epidemiological data exist on the prevalence of dementia in Czechia based on sufficiently large data sets, as is typical for large epidemiological studies in other European countries. Results available in this paper constitute a recommendation to the professional public and to the Czech Alzheimer's Society, which regularly draws attention to the absence of research studies on dementia issues.

Two main research questions were formulated:

Research question 1: How many men and women will suffer from dementia in 2050?

Research question 2: How do the projection results differ when a) using prevalence rates from the EURODEM and EuroCoDe studies and b) based on mortality tables of people living with dementia?

Literature Review

Worldwide, the number of people with dementia in 2009 was estimated at 34.4 million people (Wimo et al., 2010). In the following decades, due to an aging population, a significant number of people reach the age at which the incidence of dementia is highest. People aged 60+ are the fastest growing population. In 2000, around 600 million people in the world had reached the age of 60, representing 10% of the world's population. By 2050, this figure is expected to increase to almost 2 billion seniors, representing in relative terms 22% of the world population (UN, 2007). The aging of the population undoubtedly leads to an increased number of people living with dementia. The age structure in Europe is regressive and the proportion of people suffering from dementia stands higher. In the world's other regions, especially in Asia, the age composition of the population remains younger than in Europe; in the coming decades, however, the aging process will accelerate at a much faster pace. For this reason, the number of people with dementia will increase (Ziegler, 2010). Most of the existing projections do not provide reliable results that would be interpretable regarding the current trend in life expectancy. The available studies of the 20th century underestimated the rapid increase in the average life span that took place in the 21st century and thus predicted a lower dementia number than exists in reality (Häfner & Löffler, 1991, as cited in Ziegler, 2010). At the same time, research often stems from the same prevalence rates of dementia that apply to different populations. Wimo et al. (2003), in researching *The magnitude of dementia occurrence in the world*, used the same prevalence rates derived from the Fratiglioni and Rocca study (2001) and applied them to different populations. They thereby estimated the number of dementia afflicted people to rise to 63 million in 2030 and 114 million in 2050 (Wimo et al., 2003, as cited in Ziegler, 2010). Findings in the study *The effect of different diagnostic criteria on the prevalence of dementia* support the need for validating the criteria used to diagnose dementia. For example, differences in validity exist when using DSM, CAMDEX and ICD-9 or ICD-10 criteria. The proportion of subjects with dementia varied from 3.1% using ICD-10 to 29.1% using DSM-III criteria. Universal standards and the same classification criteria are needed for diagnosis (Erkinjuntti et al., 1997). The obtained prevalence rate of dementia came to 13.7% when using the DSM-IV criteria and 38.2% according to CAMDEX criteria. A wide heterogeneity in the reported prevalence rates of dementia was observed across studies (Bacigalupo et al., 2018). Table 1 illustrates the selected projections of dementia in the world and in Europe.

Table 1. Projection of the Number of People with Dementia Worldwide (in Millions)

Author, publication year	Region of projection	Beginning of the projection (year) and the projected number of people with dementia	2020	2030	2040	2050
Wancata et al., 2003	Europe	7.1 (2000)				16,2
Wimo et al., 2003	World	25.5 (2000)		63		114
Ferri et al., 2005	World	24.3 (2001)	42		81,1	
Brookmeyer et al., 2007	World	26.6 (2006)				106,8
Bickel et al., 2008	Germany	0.94 (2000)	1,55	1,82	2,20	2,62
Ziegler, 2010	Germany	0.96 (2002)				2,38

Source: Ziegler, 2010.

Within the comparison of the results from several studies, Table 2 shows the population size in different regions of the world in 2015, the prevalence of dementia, and the number of people with dementia in 2015, 2030 and 2050. The results were published in the *World Alzheimer Report* (ADI, 2015). On the population projection prepared by the United Nations (UN, 2015), organizations applied the age-specific prevalence rates. This produced an estimated worldwide number of persons living with dementia in 2015 of 46.78 million people. This figure almost doubles by 2030 (74.69 million), and in the year 2050 it is estimated to stand at 131.45 million people suffering from dementia.

According to the project results in 2015, the proportion of people having dementia stands the highest in East Asia (9.77 million) and Western Europe (Germany, Italy) (7.45 million). The results of the dementia projections predicted in 2015 match the results of the 2009 projection – developed regions were based on a high level of expected dementia, and therefore there will be only relatively modest growth in these areas (compared to developing countries) (ADI, 2015).

Currently, we possess extensive knowledge regarding dementia issues, but there remains a lack of important data on the prevalence of dementia-related illnesses for service planning. Missing data often gets replaced by qualified estimates, not only in Czechia, but also in other countries. Table 3 shows the rapid increase in the number of dementia cases in Czechia according to the Alzheimer Europe and ADI 2050, published by the Ministry of Health and the Ministry of Labour and Social Affairs (Ministry of Health, MoLSA [Ministry of Labour and SocialAffairs], 2012). According to estimates prepared by international organizations, approximately 180,000 people will acquire dementia in 2030, and by 2050, they will number approximately 227-thousand in Czechia.

Methods

a) Projection of the prevalence of dementia in Czechia until 2050 for men and women was calculated. For the projection, we used the medium variant of the population projection published by the Czech Statistical Office (CZSO, 2013b) and age-specific prevalence rates of dementia from EuroCoDe and EURODEM studies (see Table 4). Dementia prevalence rates from the EuroCoDe study were employed to calculate dementia prevalence in the age category 60–95 and older. Dementia prevalence rates from the EURODEM study were used to calculate dementia prevalence in the age group 30–59. In the calculations, Constant dementia prevalence rates developed in EuroCoDe 2009 and EURODEM 1991 were employed (Czech Alzheimer's Society, 2009). The projection was constructed for five-year age intervals until the age 95+. Dementia prevalence rates (see Table 4) were applied to the population projection results of the Czech Statistical Office (2013b), indicating the impact and character of the Czech population' age structure. Considering the unchanged rates of dementia prevalence, the number of people with dementia is affected only by the expected number of old people.

Dementia prevalence rates studies (EURODEM and EuroCoDe) vary in method and sampling. Hofman et al. (1991) pooled data from 12 European studies conducted between 1980 and 1990, which included the institutionalized population, and used DSM-III or equivalent criteria. Twenty research groups working on the epidemiology of dementia and participating in the European Community Concerted Action on the Epidemiology and Prevention of Dementia Group (EURODEM) provided 23 data sets. Age specific and gender specific prevalence rates were compared within and across studies, and the overall prevalence was computed. Prevalence

Table 2. Number of People with Dementia and Prevalence of Dementia Worldwide (2015-2050)

Regions of the world	Population aged 60+ (2015)	Estimated prevalence (%)	The number of persons with dementia			Increase (in %)	
			2015	2030	2050	2015-2030	2015-2050
Asia	485,83	4.7	22.85	38.53	67,18	69	194
Australasia	5.80	6.7	0.39	0.62	1.02	59	163
Asia and the Pacific	52,21	7.0	3.64	5.68	7.81	56	115
Oceania	0.64	3.5	0.02	0.04	0.09	83	289
Asia, middle	7.43	4.2	0.31	0.44	0.88	43	184
Asia, east	218,18	4.5	9.77	16.60	28.64	70	193
Asia, south	139.85	3.7	5.13	8.61	16.65	68	225
Asia, southeast	61.72	5.8	3.60	6.55	12.09	82	236
Europe	176.61	5.9	10.46	13.42	18.66	28	78
Europe, west	107.89	6.9	7.45	9.99	14.32	34	92
Europe, middle	26.92	4.0	1.07	1.39	1.90	30	78
Europe, East	41.80	4.6	1.94	2.03	2.44	4	26
America	147,51	6.4	9.44	15.75	29.86	67	216
North America	74,88	6.4	4.78	7.28	11.74	52	145
The Caribbean	5.78	6.5	0.38	0.60	1.07	60	183
Latin America, Cent	26.64	5.8	1.54	2.97	6.88	93	348
Latin America, South	9.88	7.6	0.75	1.15	2.05	52	172
Tropical South America	24.82	6.7	1.66	3.11	6.70	88	305
Africa	87.19	4.6	4.03	6.99	15.76	74	291
North Africa / Middle East	38.93	6.0	2.34	4.35	10.04	86	329
Sub-Saharan Africa, Cent	4.78	3.3	0.16	0.26	0.54	60	238
Sub-Saharan Africa, East	19.86	3.5	0.69	1.19	2.77	72	300
Sub-Saharan Africa, south	6.06	3.9	0.24	0.35	0.58	46	145
Sub-Saharan Africa, west	17.56	3.1	0.54	0.85	1.84	58	241
World	897.14	5.2	46.78	74.69	131.45	60	181

Source: ADI, 2015.

estimates differed across studies; the general age distribution and gender distribution was similar for all studies. In subjects under 75 years, the prevalence of dementia stood slightly higher in men than in women (Hofman et al., 1991).

In the EuroCoDe prevalence study (2009), raw data was obtained from 17 studies and utilized in the collaborative analysis of dementia prevalence rates in Europe. Total age specific prevalence rates were calculated by pooling data on prevalence case numbers and the underlying population for males and females in each 5-year age category (for the age range 60–64, the total prevalence rate was 0.6%; for the age 95+, the total prevalence came to 46.3%).

b) When constructing age and gender specific population projections, the component method is employed very often (see Fiala, 2002), supplemented by certain assumptions about the development of mortality, fertility, or expected migration. The component method remains an important tool, which is based on the assumptions we possess for the analyzed population. We have fairly accurate conjectures about the development of the expected mortality rate, which are supported by literature (Lee, 2000). A convincing scenario can be established for the development of the expected total fertility (see Fiala & Langhamrová, 2009). Migration was not included in the projection of dementia. In the present study, projecting the number of persons with dementia in Czechia will be carried out in three variants (high, middle, low) demonstrating an approach to take into account the expected development if there is a limited amount of available information and input data.

Table 3. Estimated Number of People with Dementia in Czechia, 2000–2050 (in Thousands)

Year	2000	2005	2010	2015	2020	2025	2030	2035	2040	2045	2050
Number of people with dementia	88	95	111	124	138	157	180	202	213	218	227

Source: Ministry of Health, MoLSA, 2012.

Table 4. Prevalence of Dementia According to EuroCoDe and EURODEM

Age	Males		Females	
	EuroCoDe 2009	EURODEM 1991	EuroCoDe 2009	EURODEM 1991
30–59		0.16		0.09
60–64	0.2	1.58	0.9	0.47
65–69	1.8	2.17	1.4	1.10
70–74	3.2	4.61	3.8	3.86
75–79	7.0	5.04	7.6	6.67
80–84	14.5	12,12	16.4	13.5
85–89	20.9	18.45	28.5	22.76
90–94	29.2	32.10	44.4	32.25
95+	32.4	31,58	48.8	36.00

Source: Czech Alzheimer's Society, 2009.

The projection will be performed from 1.1.2010 and its horizon will be 40 years. The remaining assumptions and subsequent construction of the projection represent the methodology.

To estimate the number of people living with dementia, shortened mortality tables of men and women living with dementia were calculated (see Appendix). Age groups are 0–4, 5–9, 10–14, 15–19, …, 85+ completed years. The number of survivors is calculated from the formula:

$$l_{t,0} = l_{t+5,0} = l_{t+10,0} = \ldots = 100\,000,$$
(1)

Using the coefficients of the probability of death q_x we can calculate the number of survivors for each year of t:

$$l_{t,x} = l_{t,x-h} \times \left(1 - k \times \frac{l_{t-5,x-h} - l_{t-5,x}}{l_{t-5,x-h}}\right),$$
(2)

where k is the coefficient of decrease in the probability of death q_x and h is the width of the age period (5 years). The death probabilities q_x for every age x, are also known as the (age-specific) risk of death. It is the probability that a person's exact age x will die within one year. Coefficient q_x is derived as the number of deaths between exact ages x and $x+1$ (referred to as d_x), divided by the number of persons surviving to the exact age x (referred to as l_x).

The coefficient of decline in the probability of death was calculated based on the findings of the Czech Statistical Office expert estimate. After calculating the l_x in the accelerated mortality tables it is possible to calculate the number of surviving people in the middle of the time intervals. The calculation is carried out by linear interpolation:

$$l_{t,x} = \frac{4 \times l_{t-1,x} + l_{t+4,x}}{5}.$$
(3)

Linear interpolation exists due to the fact that for some future estimates, a certain constant has been chosen to increase the proportion of people in the population and a certain constant in the increase in life expectancy – a population with no mental illness and a mental illness population. The reason why this constant to medium-life growth was also chosen for people with dementia is that it looks likely that the person will survive the next lifetime as healthy and then the mental illness will manifest. According to the Czech Statistical Office (CZSO), the projection for the whole prediction is also the middle version of the projection, which is also based on the linear interpolation of scenarios, and further on the shifting of age and sex-specific demographic components. It is important to note that the proportion of mean life expectancy in non-dementia is the same as the proportion of mean life expectancy.

With the use of table counts for surviving individuals, it is possible to calculate the mean life expectancy at birth, one of the options being to use the relationship mentioned by Keyfitz (1964):

$$e_0^0 = \frac{\sum_{x=0}^{85+} l_x - \alpha \times l_0 + (\alpha - 0{,}5) \times l_1}{l_0} \quad , \tag{4}$$

where α is the share of the lower elementary set of deaths (The Czech Statistical Office recommends setting 0.85).

Due to the considered shortened mortality tables, it is possible to use a simpler relationship, which is adapted to the needs of the analysis in the form of:

$$e_{0,t}^0 = h \times \frac{\sum_{x=1-4}^{85+} l_{t,x} - \dfrac{l_{t,1-4}}{2}}{l_{t,1-4}} \quad , \tag{5}$$

where h is the width of the age period (5 years).

Using the aforementioned assumptions and formulas, we constructed mortality tables of persons with dementia. Demographic projections regarding the population number of people with dementia in 2050 were calculated. Demographic projections therefore consider a decrease in the likelihood of death q_x (resp. increased life expectancy e_x^0).

Some publications state that people with dementia have higher rates of mortality than those without dementia (Bickel, 2005; Jagger et al., 2000; Wimo et al., 2003; Ziegler, 2010). However, the mortality rate of dementia sufferers and non-demographic persons is significantly influenced by the nature of the data and the size of the sample being examined. Czechia exhibits significant variability. Specific mortality rates for dementia were calculated as the proportion of dead males (or females) according to the causes of death and the number of patients hospitalized by age group.

Results

a) Projection of the prevalence of dementia in Czechia until 2050 for men and women was calculated. The middle variant of the Czech population projection was used (Czech Statistical Office, 2013b) together with age specific prevalence rates of dementia (see EuroCoDe and EURODEM prevalence rates in Table 4). The projection was constructed for 5-year age categories until the age 95+. Projection of dementia (EURODEM) also includes the age group 30–59 years. Dementia prevalence rates were applied to the results of the population projection, which pointed to the impact and character of the Czech population's age structure. When considering dementia's constant prevalence, the change in the number of people with dementia is only affected by the expected number of elderly people.

Number of people with dementia aged 60+ increased from 139,000 in 2013 to 357,000 persons with dementia in 2050 solely due to the changing age structure (prevalence rates of dementia are fixed for the entire period; see Figure 1 and 3). The number of people with dementia aged 30+ will increase the value of 130,000 in 2013 to 314,000 persons with dementia in 2050 (see Figure 2 and 4). Differences in results for age categories 30+ and 60+ is due to dissimilar prevalence rates that were used (EuroCoDe and EURODEM). Another fact is the high proportion of elderly people in the Czech population. By comparing the results for women shown in Figures 1 and 2, in the year 2050, there will be 230,000 women living with dementia (according to EuroCoDe, 2009) and 185,000 women living with dementia (according to EURODEM, 1991). Differences in female outcome are due to different prevalence rates from the EuroCoDe and EURODEM study (see Table 4). For men, the difference between prevalence rates from EuroCoDe 2009 and EURODEM 1991 is not so significant, thus the results are more similar. Results of the projection in Figures 3 and 4 point to 127,000 men living with dementia (according to EuroCoDe, 2009), respectively 128,000 men living with dementia (according to EURODEM, 1991) by 2050.

The application of prevalence rates of dementia based on European studies on the results of the population projection of the Czech Republic is necessary due to the fact that the Czech Republic does not have specific prevalence rates. Differences in outcomes are due to a deviation in method and different prevalence rates obtained from EuroCoDe and EURODEM studies.

To explain the differences in results regarding the number of people with dementia using EuroCode and EURODEM prevalence rates, we can further rely on conclusions made by Alzheimer Europe (2019). A cumulative

difference exists on the prevalence estimates of the population number living with dementia in Europe, including Czechia, as it is stated by Alzheimer Europe report (2019) using their updated prevalence estimates and EuroCoDe estimates for the total population: Total age specific prevalence rates of dementia: age range 60–64 (prevalence 0.6%); 65–69 (1.3%); 70–74 (3.3%); 75–79 (8.0%); 80–84 (12.1%); 85–89 (21.9%); 90+ (40.8%). Alzheimer Europe estimates were provided for 2050, whereas current prevalence rates were to remain the same in each of the years. When applying the 2019 prevalence estimates and EuroCoDe prevalence rates to population data for European countries, there is a significant difference in the estimated number of people living with dementia in 2018 (the difference comes to more than 1 million people with dementia). Applying the EuroCoDe prevalence estimates, 10,935,444 people exist with dementia, compared to 9,780,678 when using 2019 Alzheimer Europe estimates. The difference shows more than 1 million people in 2018. Despite this shift from the EuroCoDe estimates, the number of people living with dementia will continue to increase rapidly. Assuming no change in prevalence rates appears in future years, the number of people with dementia in Europe will almost double by 2050 (up to 18,846,286 people with dementia using Alzheimer Europe 2019 prevalence rates; 3% of population). In Czechia, the overall number of people with dementia (population aged 30–90+) will almost double from 149,633 in 2018 to 279,983 in 2050 (Alzheimer Europe, 2019). According to results in our study, there will be 313,000 people living with dementia by 2050 (population aged 30+). Studies indicate a trend towards a decline in the prevalence of dementia in recent years, and findings of Alzheimer Europe 2019 align with this assessment (compared with our results that indicate a higher number of people with dementia by 2050; difference is 33,017 people with dementia).

Results of the estimation of women with dementia above 60 years of age are shown in Figure 1. Results are also presented in table format (see Appendix).

Results of the estimation of women with dementia above 30 years of age are shown in Figure 2.

Projection results regarding the number of men with dementia above 60 years of age are situated below (Figure 3).

Projection results regarding the number of men with dementia above 30 years of age are situated below (Figure 4).

b) Estimates for the number of individuals with dementia aged 65+ in Czechia by 2050 are based on data from the Population census and on the population forecast prepared by the Czech Statistical Office (CZSO, 2013b). For screening, it was important to distinguish between mortality rates of people living with/without dementia. We constructed our own mortality tables for men having dementia and women with dementia (see Appendix).

Figure 1. Projection of Number of Women with Dementia Aged 60+
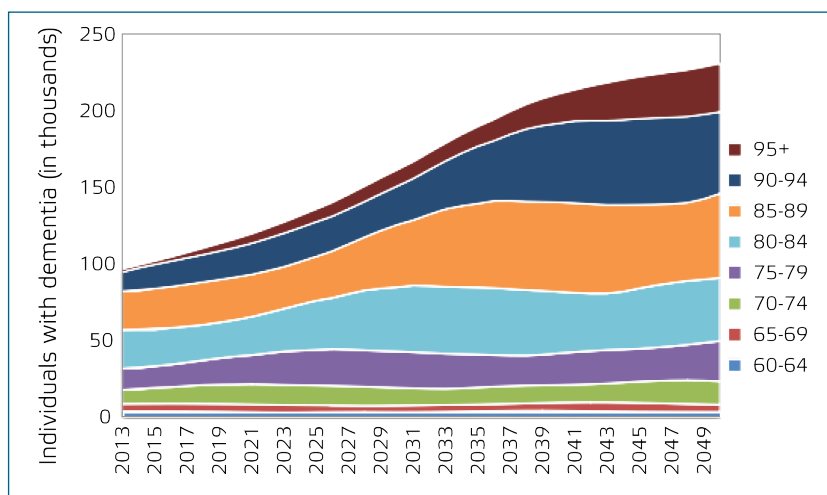
Source: data Czech Statistical Office, EuroCoDe 2009, own calculations.

Figure 2. Projection regarding the Number of Women with Dementia Aged 30+
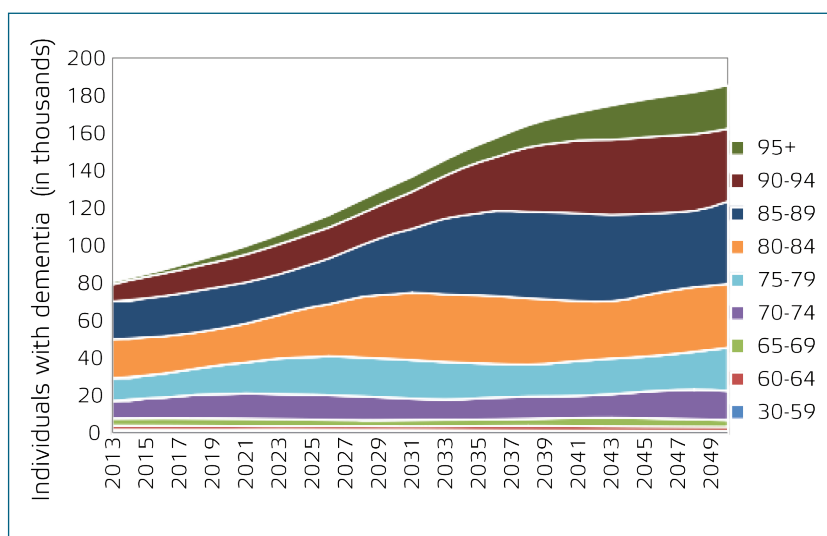
Source: data Czech Statistical Office, EURODEM 1991, own calculations.

When calculating mortality rates for people with dementia, we drew source data from the Czech Statistical Office (the number of deaths by causes of death) and from the National Registry of Hospitalized Patients, available in the database of the Institute of Health Information and Statistics of the Czech Republic and the report Hospitalization in hospitals in the CR. (IHIS [The Institute of Health Information and Statistics of the Czech Republic], 2011).

These are numbers of hospitalized in inpatient facilities classified by major a diagnostic category, i.e., sex and age. Calculations for the diagnostic category "*01-Diseases and disorders of the nervous system*" and "*19-Mental diseases and disorders*" in 2010 were chosen (IHIS, 2011). Migration was not included in the model. In 2006–2010, the total number of hospitalizations for dementia increased by 22% (from 6,549 to 7,981 hospitalizations). The highest increase occurred in Alzheimer's disease (by more than 41%; 489 hospitalizations) (IHIS, 2011).

An indirect indicator of prevalence is the number of patients hospitalized with a particular disease, as well as visiting the doctor. However, it should be remembered that this is an indirect method of estimation because it remains difficult to distinguish whether it is a single visit (hospitalization) during the period or a recurrent one. It is equally important to remember that not all patients with a given disease visit a doctor and are included in statistics. These studies also take into account the age composition of the population (IHIS, 2011).

The basic input data of the CZSO projection (2013b) is the population of the Czech Republic by gender and age at 1.1.2013. The medium variation of the projection is generally considered the most likely, but the results need to be interpreted in terms of the definition of the expected development of the extreme variants (low and high variants) (CZSO, 2013b). The results of the projection must be understood in relation to entry parameters, sudden unpredictable changes in the economic and social system, or the epidemic of diseases can significantly affect the level of fertility and mortality and overall population development. The expected future development of the age structure will be dynamic in the direction of the population's intense aging. The biggest changes will occur in the age group 65+.

Results of the projection are interpreted for the age category 65 and older. Number of seniors aged 65+ will rise from 1.8 million in 2015 to 3.2 million in 2050 (1.7 million women and 1.5 million men), representing a nearly double increase. Thus, a significant increase in the share of men 65+ is expected. The projection assumes further increase in life expectancy. Changes in life expectancy at birth are most likely to improve the mortality rate of men aged

Figure 3. Projection regarding the Number of Men with Dementia Aged 60+
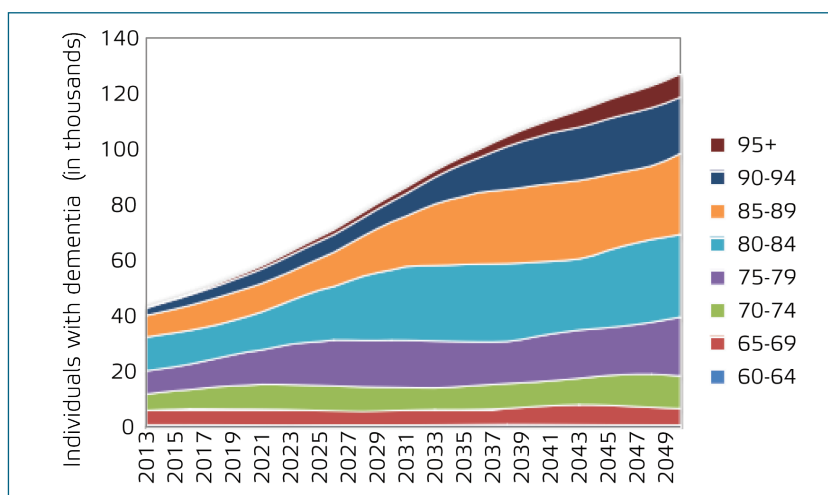
Source: data Czech Statistical Office, EuroCoDe 2009, own calculations.

Figure 4. Projection regarding the Number of Men with Dementia Aged 30+
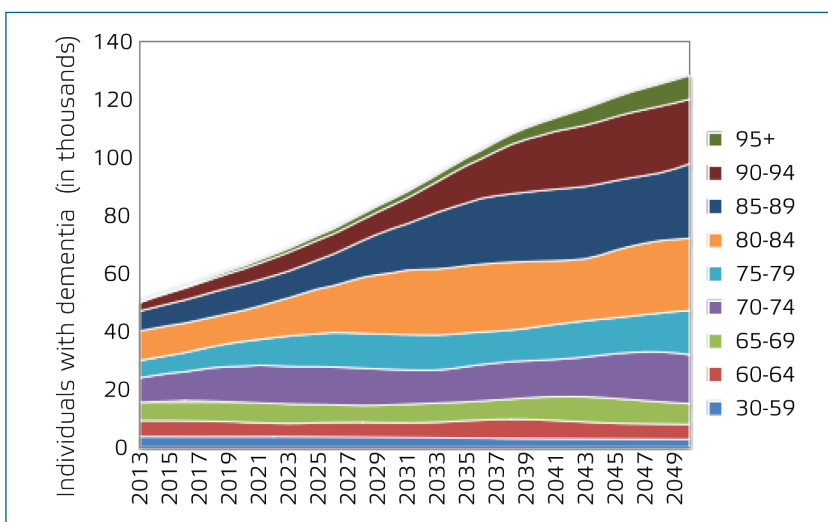
Source: data Czech Statistical Office, EURODEM 1991, own calculations.

60+ (for women especially at age 80+). A more significant improvement in mortality is expected for men (CZSO, 2013a).

Figure 5 and 6 show an increase in the number of men and women with dementia aged 65+ based on three variants of possible development. The share of people with dementia will increase according to all variants of the projection. The number of women with dementia aged 65+ is estimated to be over 61 thousand (in view of increase in life expectancy at the age of 65). Contribution of women in this age group with dementia aged 65+ will almost double by 2050.

The number of men with dementia aged 65+ is expected to increase from 28,000 in 2015 to nearly 60,000 in 2050. The contribution of males with dementia by 2050 is 114% more compared to 2015.

Answering our main research questions – how many men and women will suffer from dementia until 2050 comparing results according to methods used in this study – in our research we proceeded in the same way as professional publications, and data for predicting the number of people

Figure 5. Estimation of Men with Dementia Aged 65+ by 2050

Source: dataCzechStatistical Office, IHIS, own calculations.

Figure 6. Estimation of Men with Dementia Aged 65+ by 2050

Source: dataCzechStatistical Office, IHIS, own calculations.

with dementia have been modeled using various prevalence studies or other approaches. For the Czech Republic, data on the number of people suffering from dementia can be traced. For example, estimates are available for dementia from Alzheimer's Europe (2013) based on the European population on which most other studies, including those from the Czech Alzheimer's Society, are based. The Czech Alzheimer's Society published estimates for 2020 of 183,000 people with Alzheimer's disease or another type of dementia and for 2050 of 383,000 people with dementia. The Interior Ministry of the Czech Republic states that in 2050 this number could more than double: i.e., almost 400,000 people with dementia.

We focused on the age category 65+ in section b) *Estimates of the number of individuals with dementia*, and according to this projection there will be more than 120,000 people suffering from dementia by 2050 in Czechia. This relatively low number may be affected by the selected diagnostic categories (see Methods) in our study. Different results may be obtained when using for example the diagnostic category G30: *Number of deaths caused by Alzheimer's disease.* It is important to notice that in b) we constructed our own mortality tables for people with dementia and calculated mortality rates according to our selected criteria. From this reason the results vary from results when using generally known prevalence rates in a). According to a) *Projection of the prevalence of dementia*, we obtained 357,000 people with dementia aged 60+ (using EuroCoDe, 2009) and 313,000 people with dementia aged 30+ (EURODEM). Both approaches a) and b) were compared. For the Czech Republic, to our knowledge, no validated prevalence study for Alzheimer's disease and other forms of dementia is yet available. Results may vary significantly due to the character of the disease, the proportion of which is more or less based on estimates.
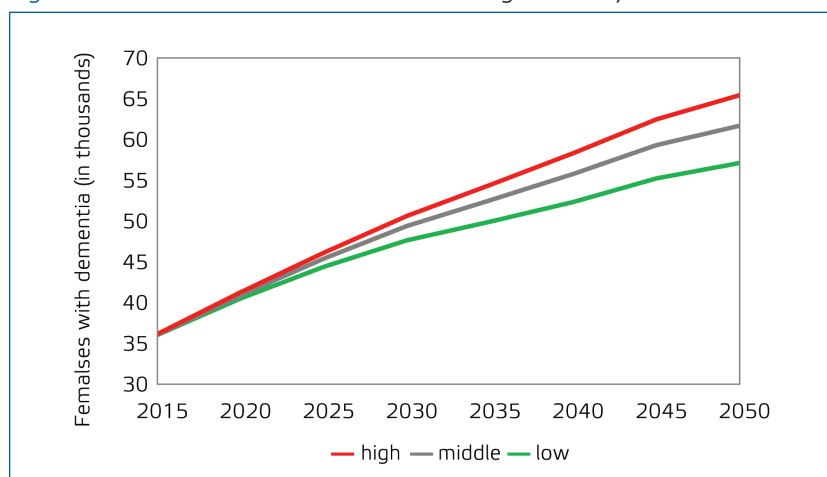
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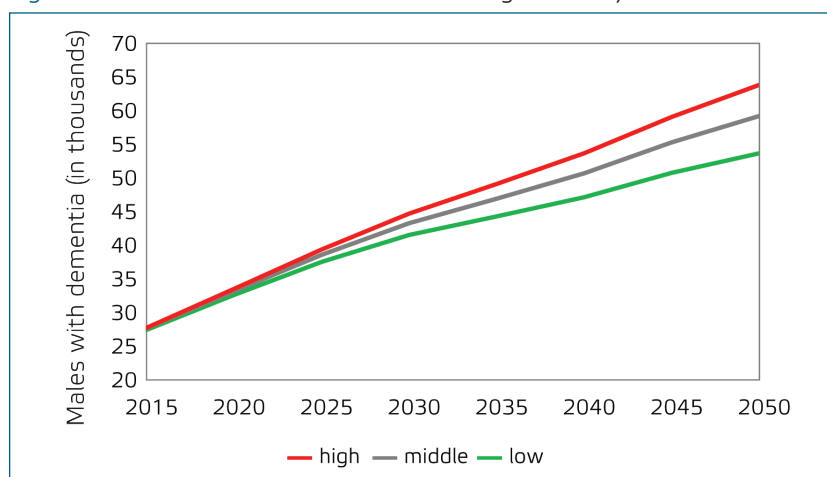
Discussion

Preparing for the upcoming situation Czechia has to face makes it important, moreover, necessary to estimate the number of people with dementia. Applying prevalence rates of dementia based on European studies (EURO-DEM and EuroCoDe) on the Czech Republic's population projection results is necessary due to the fact that the Czech Republic does not have specific prevalence rates. Some current studies suggest that international prevalence rates of dementia may be slightly lower than previously thought. Even if the existing prevalence rates of dementia were overestimated, the number of people with dementia seems likely to at least double in the Czech Republic during the next 35 years.

As noted by Stephan and Brayne (2010, as cited in Zeilig et al., 2014) in the study *Prevalence and projections of dementia,* due to cultural, ethnic and demographic variability in the incidence and prevalence of dementia, a need for further studies at national and international level exists (Stephan & Brayne, 2010, as cited in Zeilig et al., 2014). Regardless of the methods used, it remains necessary to calculate an element of uncertainty being present until the moment of the projection horizon occurs. This is because the projection involves too many determinants and random influences (Ziegler, 2010). The projection aims to point to the likely development should all the factors that may affect future developments be considered (Vaupel et al., as cited in Ziegler, 2010). Estimating the specific prevalence rate of dementia in each country is essential to appropriately plan prevention strategies, since potential differences in the prevalence of dementia could be due to differences in potentially modifiable risk factors (Bacigalupo et al., 2018). Risk factors in early life under 45 years (education; RFP [Risk factor prevalence] 40.0%), midlife age 45–65 years (hypertension RFP 8.9%, obesity RFP 3.4%, hearing loss RFP 31.7%, traumatic brain injury RFP 12.1%, alcohol consumption RFP 11.8%) and later life above 65 years (smoking RFP 27.4%, depression RFP 13.2%, physical inactivity RFP 17.7%, social isolation RFP 11.0%, diabetes RFP 6.4%, air pollution RFP 75.0%) may contribute to an increased risk of dementia (Livingston et al., 2020). Risks are particularly higher in low-and-middle income countries compared to high income countries. Dementia risk reduction can be affected by: childhood education, social public health policies reducing hypertension risk, policies encouraging social, cognitive, and physical activity, reducing the risk of brain trauma in employment and transport, and reducing air pollution (Livingston et al., 2020).

Since dementia is intensely rising with age, projections include the assumptions about the development of life expectancy. According to Ziegler (2010), the projection results primarily depend on assumptions about life expectancy. According to Romero et al. (2014), it is necessary to know the extent of dementia as a cause of death from the death certificate. Respiratory problems are listed as the most frequently reported cause of death among people who were demented, yet were not reported as demented on death certificates. The use of death certificates for studying dementia grossly underestimates dementia's occurrence in the population (Romero et al., 2014). This difficulty in using death certificates to determine the number of deaths from Alzheimer's and other dementias has been referred to as a "blurred distinction between death with dementia and death from dementia". One in three seniors dies with Alzheimer's or another dementia (Alzheimer's Association, 2022). Among people over the age of 65, one in thirteen suffers from dementia (Musílek et al., 2019).

One of the main problems in Czechia is the necessity to increase current social and health service capacities to take care of the dependent part of patients. Population aging and the increase in the number of elderly individuals aged 65+ evoked a need to address this issue, since age remains the major risk factor for dementia and severe cognitive impairment. The increase in the number of people aged 65+ will reflect the age structure's irregularities and the expected future prolongation of the mean length of life (Cséfalvaiová, 2017).

Strength and Limitations

It is important to point out the accuracy of the estimates for the number of people with dementia in relation to the nature of the available input data. Statistics on dementia in the Czech Republic have significant shortcomings in comparison with, for example, Germany, where data analyses are based on the statutory health insurance system that provides these data.

Knowledge about risk factors and potential prevention as well as diagnosing dementia is improving although significant gaps remain. The current state of knowledge is complicated by the fact that not all people with dementia have a diagnosed disease. Population aging with particular emphasis on a more than twofold increase in the number of people living with dementia must be understood as a call for public and private institutions to act. In addition to the necessary medical care, the goal for an aging society must be to increase long-term care capacity.

Conclusion, Implications, and Future Directions

In this paper, we estimated the number of individuals living with dementia: a) projection of dementia prevalence using prevalence rates from the EURODEM and EuroCoDe studies; b) dementia projection based on mortality tables of individuals with dementia. Our aim was to apply the prevalence rates from two foreign studies – EURODEM and EuroCoDe – and to compare these dementia prevalence projection results with the results of the dementia projection using the available data for the Czech Republic and our own mortality tables of individuals living with dementia. According to the projection results, the number of men and women living with dementia will more than double by 2050. The ongoing trend leads towards a decline in the prevalence of dementia (the number of people with dementia above 30+ by 2050 in our study is 313,000 people using EURODEM and 357,000 when EuroCoDe estimates were used). A number of factors exist which may explain this decrease: i.e., improvements in public health and efforts to decrease some risk factors of dementia (smoking, alcohol consumption, lifestyle changes, cardiovascular diseases). The most endangered category consists of people in the older age groups; a very important group in terms of population aging will be people aged 65+ and 80 and older. For this reason, we selected the age category 65+ in the section b) estimation of people with dementia by 2050. According to this projection, there will be more than 120,000 people suffering from dementia by 2050 in Czechia.

Governments must be aware of age structural changes that will not only lead to increasing numbers of people with dementia and increased costs associated with the care of patients and their treatments, but also unwanted gains in associated problems, such as the varying population structure and burdens on the family caregiver or institutional care. From the public health perspective, interventions, including how to organize care facilities for such a complex physical illness and its attendant social needs, to support people affected by dementia, can have a huge effect.

Our future study will analyze risk factors of dementia (obesity, depression, alcohol consumption, hypertension, smoking, social contacts, education, etc.) from the perspective of the Czech Republic. Data from the SHARE database (Survey of Health, Aging and Retirement in Europe) will be used.

Author contributions

Kornélia Svacinova: conceptualization, design, methodology, funding acquisition, investigation, project administration, data management, formal analysis, interpretation, supervision, writing original draft, writing review and editing. Markéta Pechholdova: conceptualization, design, methodology, funding acquisition, project administration, interpretation, supervision, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement

The authors have no conflicts of interest to disclose.

Ethical statement

This manuscript is the authors' original work.
Human participants have been not involved in this study.
No ethical approvement, informed consent or data handling policy was needed.

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Appendix

Appendix 1: Mortality tables of men with dementia

2015	lx	Lx	Tx	ex
0-4	100 000	498 495	7 407 933	74,08
5-9	99 398	496 499	6 909 438	69,51
10-14	99 201	491 893	6 412 939	64,65
15-19	97 556	485 247	5 921 046	60,69
20-24	96 543	477 080	5 435 799	56,30
25-29	94 289	468 737	4 958 720	52,59
30-34	93 206	462 065	4 489 983	48,17
35-39	91 620	454 679	4 027 917	43,96
40-44	90 251	446 002	3 573 238	39,59
45-49	88 149	433 116	3 127 237	35,48
50-54	85 097	415 579	2 694 121	31,66
55-59	81 135	398 094	2 278 543	28,08
60-64	78 103	381 346	1 880 448	24,08
65-69	74 435	363 805	1 499 103	20,14
70-74	71 087	346 675	1 135 298	15,97
75-79	67 583	328 845	788 624	11,67
80-84	63 955	309 833	459 778	7,19
85+	59 978	149 945	149 945	2,50

2020	lx	Lx	Tx	ex
0-4	100 000	498 525	7 431 313	74,31
5-9	99 410	496 568	6 932 788	69,74
10-14	99 217	492 054	6 436 220	64,87
15-19	97 604	485 539	5 944 165	60,90
20-24	96 611	477 530	5 458 626	56,50
25-29	94 401	469 347	4 981 096	52,77
30-34	93 338	462 800	4 511 749	48,34
35-39	91 782	455 550	4 048 948	44,11
40-44	90 438	447 030	3 593 398	39,73
45-49	88 374	434 372	3 146 368	35,60
50-54	85 375	417 135	2 711 996	31,77
55-59	81 479	399 937	2 294 861	28,17
60-64	78 496	383 447	1 894 924	24,14
65-69	74 883	366 162	1 511 477	20,18
70-74	71 582	349 265	1 145 315	16,00
75-79	68 124	331 662	796 050	11,69
80-84	64 540	312 869	464 388	7,20
85+	60 607	151 518	151 518	2,50

2025	lx	Lx	Tx	ex
0-4	100 000	498 555	7 454 350	74,54
5-9	99 422	496 637	6 955 796	69,96
10-14	99 233	492 213	6 459 159	65,09
15-19	97 652	485 826	5 966 946	61,10
20-24	96 678	477 972	5 481 120	56,69
25-29	94 511	469 946	5 003 148	52,94
30-34	93 468	463 522	4 533 202	48,50
35-39	91 941	456 406	4 069 680	44,26
40-44	90 622	448 040	3 613 274	39,87
45-49	88 594	435 606	3 165 234	35,73
50-54	85 648	418 665	2 729 628	31,87
55-59	81 818	401 750	2 310 963	28,25
60-64	78 882	385 516	1 909 212	24,20
65-69	75 324	368 486	1 523 697	20,23
70-74	72 070	351 821	1 155 211	16,03
75-79	68 659	334 443	803 390	11,70
80-84	65 119	315 872	468 946	7,20
85+	61 230	153 075	153 075	2,50

2030	lx	Lx	Tx	ex
0-4	100 000	498 583	7 477 046	74,77
5-9	99 433	496 704	6 978 463	70,18
10-14	99 248	492 368	6 481 758	65,31
15-19	97 699	486 107	5 989 391	61,30
20-24	96 744	478 406	5 503 284	56,89
25-29	94 618	470 534	5 024 878	53,11
30-34	93 595	464 230	4 554 345	48,66
35-39	92 097	457 245	4 090 115	44,41
40-44	90 802	449 031	3 632 870	40,01
45-49	88 811	436 819	3 183 838	35,85
50-54	85 917	420 170	2 747 019	31,97
55-59	82 151	403 534	2 326 849	28,32
60-64	79 262	387 553	1 923 315	24,27
65-69	75 759	370 776	1 535 762	20,27
70-74	72 551	354 343	1 164 986	16,06
75-79	69 186	337 190	810 643	11,72
80-84	65 690	318 839	473 453	7,21
85+	61 846	154 614	154 614	2,50

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2035	lx	Lx	Tx	ex
0-4	100 000	498 612	7 499 403	74,99
5-9	99 445	496 770	7 000 792	70,40
10-14	99 263	492 520	6 504 022	65,52
15-19	97 744	486 382	6 011 502	61,50
20-24	96 808	478 831	5 525 120	57,07
25-29	94 724	471 110	5 046 289	53,27
30-34	93 720	464 924	4 575 179	48,82
35-39	92 250	458 069	4 110 255	44,56
40-44	90 978	450 005	3 652 186	40,14
45-49	89 024	438 010	3 202 181	35,97
50-54	86 180	421 649	2 764 170	32,07
55-59	82 479	405 290	2 342 521	28,40
60-64	79 637	389 559	1 937 232	24,33
65-69	76 187	373 032	1 547 673	20,31
70-74	73 026	356 830	1 174 640	16,09
75-79	69 706	339 902	817 811	11,73
80-84	66 255	321 773	477 909	7,21
85+	62 455	156 136	156 136	2,50

2040	lx	Lx	Tx	ex
0-4	100 000	498 640	7 521 425	75,21
5-9	99 456	496 835	7 022 786	70,61
10-14	99 278	492 668	6 525 951	65,73
15-19	97 789	486 652	6 033 283	61,70
20-24	96 872	479 247	5 546 630	57,26
25-29	94 827	471 675	5 067 383	53,44
30-34	93 843	465 606	4 595 708	48,97
35-39	92 400	458 878	4 130 102	44,70
40-44	91 152	450 961	3 671 224	40,28
45-49	89 233	439 181	3 220 263	36,09
50-54	86 440	423 103	2 781 082	32,17
55-59	82 801	407 016	2 357 980	28,48
60-64	80 005	391 534	1 950 963	24,39
65-69	76 609	375 256	1 559 429	20,36
70-74	73 494	359 282	1 184 174	16,11
75-79	70 219	342 578	824 891	11,75
80-84	66 812	324 671	482 313	7,22
85+	63 057	157 642	157 642	2,50

2045	lx	Lx	Tx	ex
0-4	100 000	498 667	7 543 114	75,43
5-9	99 467	496 898	7 044 448	70,82
10-14	99 292	492 814	6 547 550	65,94
15-19	97 833	486 917	6 054 735	61,89
20-24	96 934	479 656	5 567 818	57,44
25-29	94 929	472 229	5 088 162	53,60
30-34	93 963	466 274	4 615 933	49,13
35-39	92 547	459 672	4 149 659	44,84
40-44	91 322	451 899	3 689 987	40,41
45-49	89 438	440 330	3 238 087	36,20
50-54	86 694	424 532	2 797 757	32,27
55-59	83 118	408 715	2 373 225	28,55
60-64	80 367	393 478	1 964 511	24,44
65-69	77 024	377 446	1 571 032	20,40
70-74	73 955	361 701	1 193 586	16,14
75-79	70 726	345 220	831 885	11,76
80-84	67 362	327 536	486 665	7,22
85+	63 652	159 130	159 130	2,50

2050	lx	Lx	Tx	ex
0-4	100 000	498 693	7 564 474	75,64
5-9	99 477	496 960	7 065 780	71,03
10-14	99 307	492 958	6 568 821	66,15
15-19	97 876	487 177	6 075 863	62,08
20-24	96 994	480 057	5 588 686	57,62
25-29	95 028	472 773	5 108 629	53,76
30-34	94 081	466 930	4 635 856	49,28
35-39	92 691	460 451	4 168 926	44,98
40-44	91 489	452 821	3 708 475	40,53
45-49	89 639	441 459	3 255 655	36,32
50-54	86 945	425 937	2 814 195	32,37
55-59	83 430	410 385	2 388 259	28,63
60-64	80 724	395 392	1 977 874	24,50
65-69	77 433	379 604	1 582 482	20,44
70-74	74 409	364 085	1 202 878	16,17
75-79	71 225	347 827	838 793	11,78
80-84	67 906	330 365	490 965	7,23
85+	64 240	160 600	160 600	2,50

Appendix 2: Mortality tables of women with dementia

2015	lx	Lx	Tx	ex
0-4	100 000	498 814	7 874 934	78,75
5-9	99 526	494 735	7 376 120	74,11
10-14	98 368	490 944	6 881 385	69,96
15-19	98 009	489 417	6 390 441	65,20
20-24	97 758	487 573	5 901 025	60,36
25-29	97 271	484 389	5 413 452	55,65
30-34	96 484	480 859	4 929 062	51,09
35-39	95 859	477 821	4 448 203	46,40
40-44	95 269	472 086	3 970 382	41,68
45-49	93 565	464 963	3 498 297	37,39
50-54	92 420	457 555	3 033 334	32,82
55-59	90 602	445 639	2 575 779	28,43
60-64	87 654	429 951	2 130 140	24,30
65-69	84 327	412 865	1 700 189	20,16
70-74	80 819	395 637	1 287 323	15,93
75-79	77 436	375 311	891 686	11,52
80-84	72 689	349 049	516 376	7,10
85+	66 931	167 327	167 327	2,50

2020	lx	Lx	Tx	ex
0-4	100 000	498 838	7 890 823	78,91
5-9	99 535	494 840	7 391 985	74,27
10-14	98 401	491 124	6 897 145	70,09
15-19	98 049	489 627	6 406 021	65,34
20-24	97 802	487 819	5 916 394	60,49
25-29	97 326	484 698	5 428 575	55,78
30-34	96 554	481 236	4 943 877	51,20
35-39	95 941	478 256	4 462 641	46,51
40-44	95 362	472 630	3 984 385	41,78
45-49	93 690	465 642	3 511 754	37,48
50-54	92 567	458 371	3 046 112	32,91
55-59	90 782	446 673	2 587 741	28,50
60-64	87 887	431 263	2 141 068	24,36
65-69	84 618	414 467	1 709 805	20,21
70-74	81 169	397 518	1 295 339	15,96
75-79	77 838	377 502	897 821	11,53
80-84	73 162	351 612	520 319	7,11
85+	67 483	168 707	168 707	2,50

2025

age	lx	Lx	Tx	ex
0-4	100 000	498 861	7 906 453	79,06
5-9	99 544	494 943	7 407 592	74,42
10-14	98 433	491 301	6 912 649	70,23
15-19	98 087	489 833	6 421 348	65,47
20-24	97 846	488 061	5 931 515	60,62
25-29	97 378	485 000	5 443 455	55,90
30-34	96 622	481 605	4 958 454	51,32
35-39	96 021	478 683	4 476 849	46,62
40-44	95 453	473 165	3 998 166	41,89
45-49	93 813	466 309	3 525 001	37,57
50-54	92 710	459 173	3 058 692	32,99
55-59	90 959	447 688	2 599 519	28,58
60-64	88 116	432 551	2 151 831	24,42
65-69	84 904	416 042	1 719 280	20,25
70-74	81 512	399 368	1 303 238	15,99
75-79	78 235	379 660	903 870	11,55
80-84	73 629	354 141	524 210	7,12
85+	68 028	170 069	170 069	2,50

2030

age	lx	Lx	Tx	ex
0-4	100 000	498 884	7 921 828	79,22
5-9	99 553	495 044	7 422 944	74,56
10-14	98 464	491 474	6 927 900	70,36
15-19	98 126	490 035	6 436 426	65,59
20-24	97 889	488 297	5 946 391	60,75
25-29	97 430	485 297	5 458 094	56,02
30-34	96 688	481 968	4 972 797	51,43
35-39	96 099	479 102	4 490 829	46,73
40-44	95 542	473 689	4 011 727	41,99
45-49	93 934	466 963	3 538 038	37,67
50-54	92 852	459 960	3 071 075	33,08
55-59	91 132	448 684	2 611 115	28,65
60-64	88 341	433 817	2 162 431	24,48
65-69	85 186	417 590	1 728 614	20,29
70-74	81 851	401 190	1 311 024	16,02
75-79	78 625	381 786	909 834	11,57
80-84	74 089	356 635	528 048	7,13
85+	68 565	171 413	171 413	2,50

2035

age	lx	Lx	Tx	ex
0-4	100 000	498 906	7 936 950	79,37
5-9	99 562	495 143	7 438 044	74,71
10-14	98 495	491 644	6 942 902	70,49
15-19	98 163	490 233	6 451 258	65,72
20-24	97 930	488 530	5 961 025	60,87
25-29	97 481	485 587	5 472 495	56,14
30-34	96 754	482 323	4 986 908	51,54
35-39	96 176	479 513	4 504 584	46,84
40-44	95 629	474 203	4 025 072	42,09
45-49	94 052	467 605	3 550 869	37,75
50-54	92 990	460 732	3 083 264	33,16
55-59	91 303	449 663	2 622 532	28,72
60-64	88 562	435 061	2 172 869	24,53
65-69	85 462	419 113	1 737 808	20,33
70-74	82 183	402 982	1 318 695	16,05
75-79	79 009	383 879	915 713	11,59
80-84	74 542	359 095	531 834	7,13
85+	69 096	172 739	172 739	2,50

2040

age	lx	Lx	Tx	ex
0-4	100 000	498 928	7 951 824	79,52
5-9	99 571	495 240	7 452 896	74,85
10-14	98 525	491 810	6 957 656	70,62
15-19	98 199	490 427	6 465 846	65,84
20-24	97 972	488 757	5 975 418	60,99
25-29	97 531	485 873	5 486 661	56,26
30-34	96 818	482 672	5 000 789	51,65
35-39	96 251	479 915	4 518 117	46,94
40-44	95 715	474 707	4 038 202	42,19
45-49	94 168	468 234	3 563 494	37,84
50-54	93 126	461 490	3 095 260	33,24
55-59	91 470	450 624	2 633 770	28,79
60-64	88 779	436 283	2 183 146	24,59
65-69	85 734	420 610	1 746 863	20,38
70-74	82 510	404 745	1 326 253	16,07
75-79	79 388	385 941	921 509	11,61
80-84	74 989	361 520	535 568	7,14
85+	69 619	174 048	174 048	2,50

Appendix 3: Czech population by age and sex 2018 and 2050

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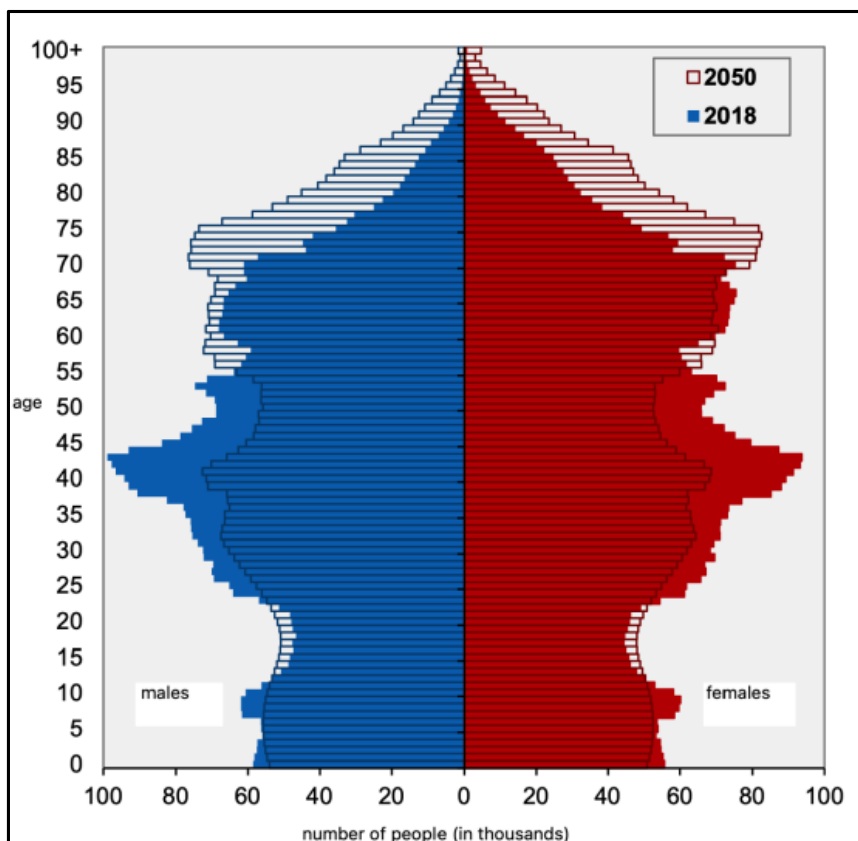
Appendix 4: Results of the projection of prevalence of dementia by 2050 using EuroCoDe and EURODEM prevalence rates

Females	EuroCoDe							
Age	2015	2020	2025	2030	2035	2040	2045	2050
60-64	3 415	3 019	2 858	2 914	3 509	3 837	3 159	3 001
65-69	5 083	5 091	4 521	4 301	4 400	5 314	5 825	4 811
70-74	10 339	12 859	12 976	11 612	11 131	11 437	13 884	15 279
75-79	14 044	18 267	23 085	23 653	21 402	20 705	21 409	26 195
80-84	24 723	24 002	32 346	42 067	43 994	40 275	39 592	41 364
85-89	26 039	27 828	28 753	40 739	54 726	58 459	54 547	55 102
90-94	15 641	19 395	22 630	25 175	37 451	51 527	56 178	53 273
95+	2 214	5 574	8 316	10 671	12 815	19 224	27 385	31 635
Total	101 498	116 035	135 484	161 132	189 429	210 779	221 980	230 661

Females	EuroCoDe							
Age	2015	2020	2025	2030	2035	2040	2045	2050
30-59	2 007	1 996	1 977	1 890	1 751	1 628	1 565	1 496
60-64	1 783	1 577	1 492	1 522	1 832	2 004	1 650	1 567
65-69	3 994	4 000	3 552	3 379	3 457	4 176	4 577	3 780
70-74	10 502	13 062	13 181	11 795	11 307	11 618	14 103	15 520
75-79	12 325	16 031	20 260	20 759	18 783	18 171	18 790	22 990
80-84	20 351	19 758	26 626	34 629	36 215	33 153	32 591	34 049
85-89	20 795	22 223	22 962	32 534	43 704	46 685	43 561	44 005
90-94	11 361	14 088	16 437	18 286	27 203	37 427	40 805	38 695
Total	84 753	96 846	112 622	132 666	153 706	169 043	177 843	185 440

Females	EuroCoDe							
Age	2015	2020	2025	2030	2035	2040	2045	2050
60-64	696	630	615	634	761	824	688	652
65-69	5 561	5 711	5 237	5 178	5 383	6 493	7 059	5 925
70-74	6 721	8 639	9 034	8 428	8 453	8 839	10 739	11 735
75-79	8 623	11 962	15 795	16 912	16 049	16 310	17 207	21 136
80-84	12 273	12 786	18 548	25 350	27 823	26 839	27 851	29 778
85-89	8 527	10 161	11 331	17 294	24 485	27 584	27 219	29 147
90-94	3 436	4 857	6 203	7 343	11 782	17 314	20 080	20 259
95+	406	1 007	1 575	2 106	2 666	4 437	6 827	8 378
Total	46 242	55 752	68 337	83 244	97 401	108 640	117 670	127 009

Females	EuroCoDe							
Age	2015	2020	2025	2030	2035	2040	2045	2050
30-59	3 701	3 682	3 634	3 462	3 209	2 999	2 895	2 787
60-64	5 496	4 976	4 855	5 005	6 010	6 509	5 437	5 152
65-69	6 704	6 885	6 313	6 242	6 489	7 828	8 510	7 143
70-74	9 682	12 445	13 015	12 141	12 177	12 734	15 471	16 905
75-79	6 208	8 613	11 372	12 176	11 555	11 743	12 389	15 218
80-84	10 259	10 687	15 503	21 189	23 257	22 433	23 280	24 891
85-89	7 527	8 969	10 002	15 266	21 615	24 350	24 029	25 730
90-94	3 777	5 340	6 819	8 072	12 953	19 034	22 074	22 271
Total	53 750	62 579	73 049	85 608	99 863	111 955	120 738	128 262

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RESEARCH PAPER

Quality of Life in Personal Social Ecosystems: Further Psychometric Evaluation and Hungarian Adaptation of the Experience in Personal Social Systems Questionnaire

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Introduction: Hunger et al. (2014, 2015, 2017) developed the Experience in Personal Social Systems Questionnaire (EXIS.pers) to assess individuals' perceived functioning in their personal ecosystems.

Aims: The present study aims to 1) provide further data regarding this instrument's psychometric characteristics that have not yet been investigated, as well as 2) describe the scale's Hungarian adaptation.

Methods: The present data set consisted of 400 questionnaires of 182 individuals recruited from the general population (83.8% female, M_{age} = 39.8 years, SD_{age} = 9.3 years) participating in repeated assessments. The Brief Symptom Inventory, the SCOFF screening test, the Patient Health Questionnaire-15, the Meaning in Life Questionnaire, and the WHO Wellbeing Index were used to investigate construct validity.

Results: A bifactor structure of the EXIS.pers fitted the data best according to the confirmatory factor analytic models. The results confirmed the scalar invariance of the best fitting bifactor model across both sex and time. Internal consistency of both the subscale and total scores was good according to both traditional (Cronbach's alpha) and more advanced (omega) indicators. Test-retest reliability with one- and five-month time lag was appropriate, as well. EXIS.pers scores showed significant inverse association with all 13 indicators of psychopathology and positive associations with both indicators of positive mental health suggestive of appropriate validity.

Conclusions: The results indicate that the EXIS.pers can be used with confidence when comparing men and women or in studies involving repeated-measures designs, and that the Hungarian version serves as a reliable and valid adaptation of the original instrument.

Keywords: personal social systems, confirmatory factor analysis, validity, reliability, cultural adaptation

Introduction

Even though many psychotherapy interventions directly or indirectly aim to change how people function and feel in their narrower social environment (e.g., current family, family of origin, or circle of close friends), relatively little effort has been devoted in effectiveness and efficacy research to assessing individuals' perceived functioning or quality of life strictly within these personal ecosystems. This may be at least partly due to the scarcity of relevant assessment tools in that area (Hunger et al., 2017). The Experience in Personal Social Systems Questionnaire (EXIS.pers) was developed to fill this gap, allowing researchers to assess the actual status and changes in how individuals perceive their fit and comfort level within their important social systems (Hunger, 2015; Hunger et al., 2017; Hunger, Bornhäuser, Weinhold, and Schweitzer, 2014).

When developing the questionnaire's original item pool, two prominent figures of the German systemic psychotherapy scene were interviewed. Their reports about the possible outcomes of their work and their perceptions of systemic change were then compared to and integrated into the literature of systemic family therapy as well as the broader fields of applied psychology (Hunger et al., 2017). In a pilot study (N = 179), exploratory factor analysis was used to investigate the first prototype of the EXIS questionnaire, which included 10 items for all five factors (Belonging, Autonomy, Accord, Confidence, and Clarity). The number of factors to retain was determined using parallel analysis and final item selection relied on both statistical and theoretical considerations (e.g., to be as short as possible without compromising reliability) (Hunger et al., 2017). These analyses resulted in the development of a reduced-length and final version, which included four factors (Belonging, Autonomy, Accord and Confidence) captured by three items each, and an additional question about who the respondent was thinking of while completing the questionnaire (i.e., parents, partner, offspring, friends or others). All subscales, as well as the total scale, had good internal consistency in this study, with Cronbach's alphas ranging from .79 to .83 (Hunger et al., 2017).

The dimension of *Belonging* can be described as the feeling of being part of the given social system both emotionally and instrumentally (Hunger et al., 2017). *Autonomy* is defined as being assertive in the social system by demarking boundaries and standing for one's needs, while believing that discussing and reconsidering certain roles, rights, and responsibilities remain possible. *Accord* refers to the concept of accepting one's social system the way it exists, including both negative and positive aspects and experiences. Finally, the dimension of *Confidence* reflects perceived self-efficacy, referring to the trust in the individual's and their social system's coping capabilities.

In a second study, the scale developers investigated the psychometric properties of the EXIS.pers questionnaire on an independent German- (N = 634) and English-speaking (N = 310) sample (Hunger et al., 2017). Using confirmatory factor analysis, a good fit has been observed both with a first-order, a four-factor, and a bifactor model including the same four domain-specific factors and a general factor, although the latter model's fit indices were slightly better. Internal consistency for the total score was excellent in both languages (Cronbach's alpha = .91 and .92), while that of the subscale scores came to good or very good in both samples (Cronbach's alphas between .74 and .88).

In terms of the convergent and divergent validity for the EXIS.pers, relatively little data have been published to date. The main study on the assessment tool only provided data on the association between EXIS.pers scores and sociodemographic variables, thus giving little support for the scale's validity (Hunger et al., 2017). From an earlier, brief description of the scale (Hunger, 2015), it is also known that scores on the instrument showed a significant, strong correlation with measures of social support (Perceived Social Support Questionnaire, F-SozU) and general psychopathology (Outcome Questionnaire, OQ-45), providing some support to the convergent and divergent validity of the assessment tool.

Since the instrument's publication, the EXIS.pers has already been used in several studies published by the main test developer's team. The first one consisted of a randomized controlled trial exploring the efficacy of family constellation seminars, in which the EXIS.pers operationalized one of the primary outcomes. The scale was used both in the short- (Hunger, Bornhäuser, Link, et al., 2014; Weinhold et al., 2013) and long-term (Hunger-Schoppe, 2020; Hunger et al., 2015) follow-up of participants and data with its use indicated stable positive changes in social functioning up until five years after the intervention. In these studies, the EXIS.pers invariably displayed excellent internal consistency (Cronbach's alpha ≈ .90).

In a psychometric study (Hunger et al., 2016), the EXIS.pers was used to investigate the construct validity of the Burden Assessment Scale (BAS), German version, which is a measurement tool designed to assess the level of burden experienced by relatives who care for mentally ill patients. The authors found that BAS scores

negatively predicted a statistically significant portion of relatives' experiences in their social systems measured by the EXIS.pers. Meanwhile, BAS scores have also negatively predicted incidents of relatives' experiences in their workplace community assessed by the organization-specific version of the EXIS (EXIS.org). In this study as well, the total score of the EXIS.pers could be characterized by excellent internal consistency (Cronbach's alpha = .94).

In a further study on the mediating role of family functioning and personality traits regarding the relationship between attachment style and eating disorders, the EXIS.pers was deployed to measure the quality of social functioning within the family (Münch et al., 2016). Here, a Cronbach's alpha of .97 was observed and the results indicated significantly lower EXIS.pers scores in the eating disorder group compared to the control group. Furthermore, EXIS.pers scores partially mediated the association between attachment style and eating disorder status.

Finally, in a recent study comparing the efficacy of cognitive behavioral therapy and systemic therapy in reducing the symptoms of social anxiety disorder (Hunger et al., 2020), the EXIS.pers was used as a secondary outcome to measure the participants' social functioning level. In this study again, internal consistency of the EXIS.pers total score stood very high (Cronbach's alpha of .94–.96, depending on the assessment point). The results showed that participants in both treatment conditions improved significantly according to the EXIS.pers, with a wide range of effect sizes across groups (Cohen's d: 0.23–1.06), indicating that the scale can be characterized by good sensitivity to change.

The above summary shows that the EXIS.pers has been used in several studies in the short time that has elapsed since its publication. The data accumulated to date is mostly based on the German-language version of the scale, with the exception of the main psychometric study on the scale using an English-language adaptation, as well. While the internal consistency of the total scale score has consistently been reported as excellent, we know little about the scale's validity and reliability assessed by more advanced indicators than Cronbach's alpha (e.g., omega). The present study's aim, therefore, was twofold. Our first goal was to describe the adaptation process of the instrument's Hungarian translation (which, to the best of our knowledge, represents the first language adaptation developed independently of the original authors) and investigate its basic psychometric characteristics (factor structure, temporal stability, and internal consistency). In our second goal, we intended to provide further data in relation to the instrument's psychometric characteristics regarding aspects never investigated before (measurement invariance across sex and time, convergent and divergent validity in terms of additional positive, and negative mental health indicators).

Methods

Sample and procedure

This study's protocol has been approved by the Research Ethics Board of Károli Gáspár University of the Reformed Church in Hungary (25/2017/P). We recruited the present study's participants from the general population for the purposes of a preregistered effectiveness study (https://clinicaltrials.gov/ct2/show/NCT03233958) to examine the effects of a brief group therapy intervention to improve general psychological functioning and quality of life. All respondents were intervention participants: the study did not include control subjects. After the baseline assessment (T1), participants were followed-up at one- (T2) and six months (T3) post-intervention. The present study's data set consisted of 400 completed questionnaires from 182 individual participants (Table 1). Participation was voluntary, and after participants gave their informed, written consent, they could choose whether to complete the questionnaires online or in hard copy. Most often, married women with postgraduate education comprised the participants (Table 1).

Measures

Sociodemographic variables

To assess sociodemographic characteristics, we administered questions pertaining to the participants' sex, age, relationships/marital status, and educational attainments (Table 1 displays response options).

Table 1. Sociodemographic Characteristics of the Study Sample

	T1	*T2*	*T3*
N	182	118	100
Sex (*N*, %)			
Male	30 (16.5)	18 (15.3)	17 (17.0)
Female	152 (83.5)	100 (84.7)	83 (83.0)
Age (*M, SD*)	39.9 (9.5)	39.7 (9.2)	39.7 (9.1)
Educational level (*N*, %)			
Secondary	37 (20.3)	30 (25.4)	26 (26.0)
Postsecondary	145 (79.7)	88 (74.6)	74 (74.0)
Marital status (*N*, %)			
Single	56 (30.8)	35 (29.7)	30 (30.0)
In relationship without cohabiting	26 (14.3)	18 (15.3)	14 (14.0)
Married / common law	73 (40.1)	47 (39.8)	40 (40.0)
Separated / divorced	27 (14.8)	18 (15.3)	16 (16.0)

Experience in Personal Social Systems Questionnaire (EXIS.pers)

Hunger et al. developed the EXIS.pers in order to assess the status and potential changes involving subjective experiences in the individual's personal social system(s) (Hunger, 2015; Hunger, Bornhäuser, Weinhold, et al., 2014). Two versions of the EXIS questionnaire have been developed: (1) the EXIS.pers measures experiences in an individual's personal social system (e.g., family, circle of friends), while (2) the EXIS.org assesses experiences in an organizational context (e.g., workplace). The two versions differ only in the instructions given to participants, but in the present paper's empirical section, we exclusively focus on the EXIS.pers.

As the questionnaire's original publication included information on both the German and English language versions of the tool, as well as data regarding their psychometric characteristics (Hunger et al., 2017), the present authorial team decided to primarily rely on the English language version during the translation process due to an easier access to competent translators in that language. Accordingly, two independent translators with backgrounds in clinical / health / counseling psychology translated the questionnaire's English language version into Hungarian. Then, further two independent translators back-translated the consensual version into English. As the review of the back-translations revealed inconsistencies regarding Item #8, the author team this time considered the German-language version of the questionnaire (by consulting two additional independent experts fluent both in German and Hungarian) and revised the item's Hungarian wording accordingly. The final version of the Hungarian EXIS.pers can be found in the Appendix of the present article.

Brief Symptom Inventory (BSI)

The BSI (Derogatis & Spencer, 1993) serves as an economic way to measure an individual's overall psychopathology and distress level; it is a brief form of the SCL-90-R (Derogatis, 1977). The BSI consists of 53 items pertaining to the following nine symptom dimensions of the SCL-90-R: (1) Somatization, (2) Obsessive-compulsive symptoms, (3) Interpersonal sensitivity, (4) Depression, (5) Anxiety, (6) Hostility, (7) Phobic anxiety, (8) Paranoid ideation, and (9) Psychoticism. Out of the three global measures of pathology and distress, we used the General Severity Index (GSI, mean of all items) in the present study. According to this indicator, our sample ($M = 0.82$, $SD = 0.51$) fell between the norms of the general population ($M = 0.30$, $SD = 0.31$) and psychiatric outpatients ($M = 1.32$, $SD = 0.072$) according to the standards published by the instrument's developers (Derogatis & Melisaratos, 1983). The questionnaire items can be answered on a Likert-type scale ranging from 0 ("Not at all") to 4 ("Extremely"). Urbán et al. (2014) psychometrically investigated the questionnaire's Hungarian version. BSI subscales' internal consistency in the present sample ranged from suboptimal (Phobic Anxiety: $\alpha = 0.562$) through good (Somatization: $\alpha = 0.776$; Obsession-compulsion: $\alpha = 0.746$; Interpersonal sensitivity: $\alpha = 0.755$; Anxiety: $\alpha = 0.734$; Hostility: $\alpha = 0.756$; Paranoid ideation: $\alpha = 0.744$; Psychoticism: $\alpha = 0.727$) to excellent (Depression: $\alpha = 0.857$; General Severity Index: $\alpha = 0.953$).

SCOFF

The Hungarian version (Dukay-Szabó et al., 2016) of the SCOFF screening test (Morgan et al., 2000) was used to measure non-disorder-specific risk level for eating disorders. This assessment tool consists of five yes-or-no type questions assessing eating disorders symptoms. At least two positive answers indicate a high likelihood of an eating disorder [100% sensitivity and 85% specificity characterized this cut-off in a clinical sample, while 50% sensitivity and 87.62% specificity was registered in a subclinical sample (Dukay-Szabó et al., 2016)]. In the present study, the Cronbach's alpha coefficient for the SCOFF was .558.

Patient Health Questionnaire-15 (PHQ-15)

The Hungarian version (Stauder et al., 2021) of the PHQ-15 (Kroenke et al., 2002) was used to evaluate the intrusiveness of somatic symptoms and a tendency toward somatization. The assessment tool contains 15 items, each addressing a somatic symptom referring to various frequently occurring mild symptoms, such as back pain or trouble sleeping. Respondents could answer on a Likert-type scale ranging from 0 ("Not bothered at all") to 2 ("Bothered a lot"). Internal consistency of PHQ-15 was good in the present sample ($\alpha = 0.757$).

Meaning in Life Questionnaire (MLQ)

The MLQ was developed by Steger et al. (2006) to assess *presence of meaning* and *search for meaning* in the respondent's life (Steger et al., 2006). The scale consists of 10 items (five items measuring both subconstructs) scored on a 7-point Likert scale ranging from 1 ("Absolutely untrue") to 7 ("Absolutely true"). Martos and Konkolÿ Thege developed and validated the Hungarian version (MLQ-H) used in the present study, which showed excellent psychometric properties (Martos & Konkolÿ Thege, 2012). Both the *Presence* ($\alpha = 0.923$) and the *Search* ($\alpha = 0.855$) subscales displayed a very high internal consistency in the present sample.

WHO Well-being Index (WBI-5)

The Hungarian, five-item version of the WHO Well-being Index (Bech et al., 1996) was used to measure participants' overall subjective well-being. Respondents could rate their level of agreement on a 4-point Likert-type scale ranging from 0 ("Not at all true") to 3 ("Absolutely true"). The Hungarian adaptation has been developed and psychometrically investigated by Susánszky et al. (2006). Internal consistency of the scale proved to be excellent in the present study ($\alpha = 0.88$).

Statistical analyses

In order to identify the factor structure that best fits the data, a series of confirmatory factor analyses were performed on the T1 sample using the Mplus 7.1 software (semantic representation of the competing models is displayed on Figure 1). The data set did not contain missing values, and considering the very close to normal distribution of the EXIS.pers item scores (skewness $<|0.5|$), the maximum likelihood estimation was used. Model 1 consisted of a single-factor solution with one general factor responsible for all 12 item responses. Model 2 consisted of a four-factor solution representing four correlating contributing factors of the questionnaire: Belonging, Autonomy, Accord, and Confidence. Model 3 comprised of a slightly revised form of Model 2 where, in addition to the four first-order factors, a second-order global factor was also incorporated.

In addition to the previous three traditional models, the appropriateness of a bifactor model (Model 4) was also tested. This latter kind of model allows for separating the role of the general and domain-specific factors as – contrary to traditional second-order models – it allows all items to load directly onto a general and a domain-specific factor *simultaneously*. Studies suggest that this measurement structure may be a more effective approach to model construct-relevant multidimensionality (Brunner et al., 2012; Reise et al., 2010; Reise et al., 2012) and can inform test users, for instance, whether subscale scores can be used in a meaningful way over and above the total score when predicting external variables.

Model fit was evaluated based on the 1) chi-square test [non-significant results indicate an adequate fit; however, this indicator is not particularly reliable with larger samples; cf. (Marsh et al., 2004)]; 2) Tucker-Lewis and Comparative Fit Indexes (TLI and CFI, respectively; values between 0.90 and 0.95 indicate an acceptable fit while values greater than 0.95 suggest good fit); 3) root mean square error of approximation (RMSEA; values

Figure 1. Sematic Graphical Representation of the Competing Factor Structure Models
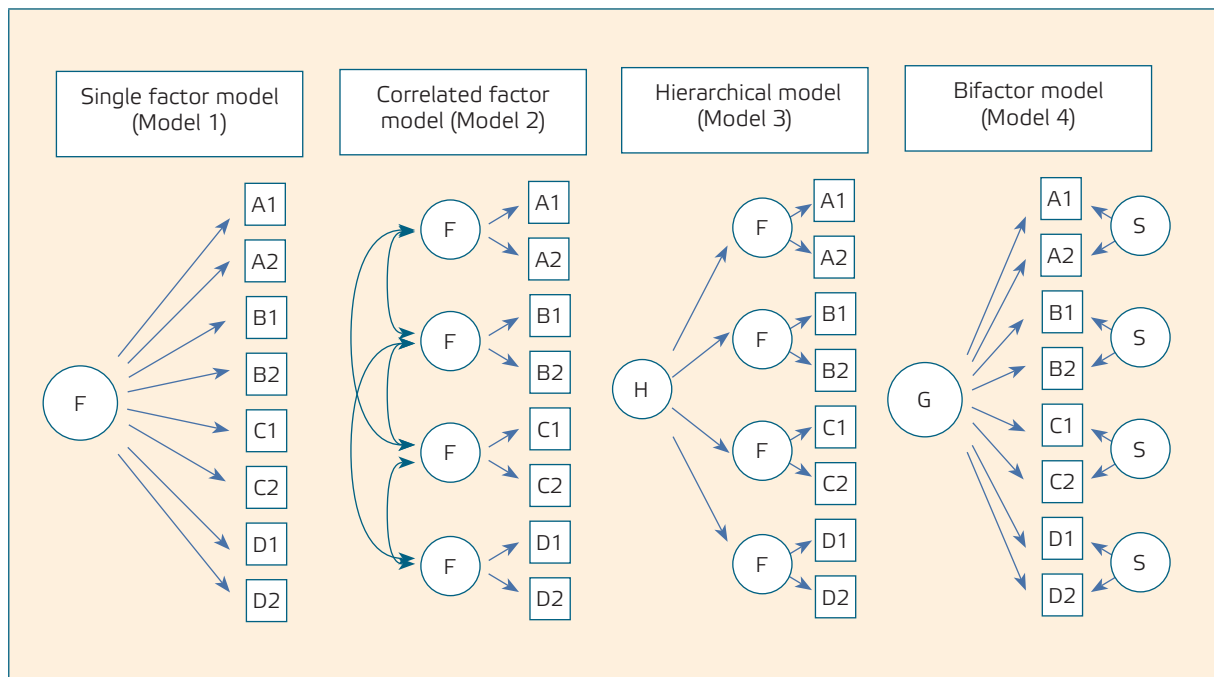
Note: A1-A2, B1-B2, C1-C2, D1-D2 = items; F = first-order factor; H = higher/second-order factor; S = specific factor in a bifactor model; G = global factor in a bifactor model.

below 0.08 indicate an acceptable fit, while values below 0.05 show a good fit); and 4) standardized root mean square residual (SRMR; values less than 0.08 indicate an appropriate fit) (Hu & Bentler, 1999). Finally, Bayesian information criteria were also reported, which do not have a clear cut-off; lower values mean a better fit when comparing alternative models (Hooper et al., 2008).

Internal consistency was evaluated by calculating Cronbach's alpha, omega total, and omega hierarchical coefficients (Zinbarg et al., 2005) for both the whole instrument and its dimensions according to the best-fitting model. Omega total estimates the reliability of a latent factor combining the general and specific factor variance, while omega hierarchical estimates the reliability of a latent factor with all other latent construct variance removed (Brunner et al., 2012) – thus providing useful information on whether scores for a specific factor can be interpreted with confidence or only the total score (general factor score) should be used. Both kinds of omega coefficients were calculated using the Omega software (Watkins, 2013).

Measurement invariance of the final model across sex (male or female) and time (Time 1, Time 2, or Time 3) has also been tested on the combined sample from all three data points (N = 400) by comparing models representing 1) configural invariance (same factor structure imposed across groups); 2) metric invariance (configural invariance + factor loadings and intercepts are constrained to be equal across groups); and 3) scalar invariance (metric invariance + latent means are constrained to be equal across groups). When comparing the nested models forming the sequence of invariance tests, guidelines for samples with adequate sample size ($N \geq 300$) were considered suggesting that models can be seen as providing a similar degree of fit as long as changes in CFI remain under .010 and alterations in RMSEA remain under .015 between a less and a more restrictive model (Chen, 2007).

Convergent and divergent validity of the EXIS.pers' Hungarian version was evaluated on the T1 sample (N = 182) by examining the relationship between the total scale score and the indicators of psychopathology (Global Severity Index and all subscale scores of the BSI, SCOFF, and PHQ-15), overall well-being (WBI-5), as well as presence and search for meaning in life (MLQ).

The relationship between the EXIS.pers scores and categorical variables was evaluated using independent-samples t-tests (sex, educational attainment), and one-way analysis of variance (marital status), while those with continuous variables (age, indicators of psychopathology, well-being, and meaning in life) were investigated – due to their strong deviation from the normal distribution – using Spearman correlation coefficients. Finally, the current and international EXIS.pers total scores were compared using a set of one-sample t-tests. All descriptive and bivariate analyses were carried out using the SPSS 28.0 software.

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Results

Factor structure, internal consistency, and item analysis

The factor structure of the 12-item, Hungarian version of the EXIS.pers was investigated by a series of confirmatory factor analyses. Model 1 resulted in suboptimal model fit indices according to all fit indicators (Table 2). Models 2 and 3 produced acceptable (TLI) or good (CFI, SRMR) fit indices according to most goodness of fit indicators. The best-fitting model, however, proved to be the bifactor model (Model 4), the fit of which stood significantly better than any of the other three models (Table 2); however, the differences in fit indices between Model 4 versus Models 2 and 3 were trivial. For the best-fitting bifactor model, all factor loadings were significant and the standardized factor loadings for the items ranged between 0.49 and 0.75 in relation to the global factor and between 0.33 and 0.76 in relation to the domain-specific factors (Table 3).

Results of the analyses regarding measurement invariance showed that adding invariance constraints on the

Table 2. Model Fit Indices for the Competing Confirmatory Factor Analytic Models of the Hungarian Version of the EXIS.pers

	χ^2, p	TLI	CFI	RMSEA (90% CI)	SRMR	SSA BIC	Difference from Model 4
Model 1 - Single factor	575.1, $p<.001$	.572	.650	.230 (.213-.247)	.113	6,471.2	χ^2=477.1, $p<.001$
Model 2 - Four first-order, correlating factors	111.4, $p<.001$	.941	.957	.085 (.065-.106)	.043	6,019.7	χ^2=13.4, p=.037
Model 3 - Four first-order factors with a second-order factor	123.7, $p<.001$	.935	.950	.090 (.070-.110)	.056	6,027.9	χ^2=25.7, p=.001
Model 4 - Bifactor model	98.0, $p<.001$	.941	.962	.086 (.064-.108)	.046	6,018.5	N/A

TLI: Tucker-Lewis Index, CFI: Comparative Fit Index, RMSEA: Root Mean Square Error of Approximation, SRMR: Standardized Root Mean Square Residual, SSA BIC: Sample-Size Adjusted Bayesian Information Criterion.

Table 3. Item Characteristics of the Hungarian EXIS.pers from the Item- and Confirmatory Factor Analysis (bifactor model, N=182)

Item	M	SD	Item-total correlation	Standardized factor loadings (standard error) from the factor analysis				
				Global Factor	Belonging	Autonomy	Accord	Confidence
1	3.38	1.29	.683	.715 (.049)	.543 (.074)			
2	3.20	1.26	.678	.688 (.052)	.450 (.077)			
3	3.79	1.31	.694	.754 (.045)	.440 (.072)			
4	4.03	1.49	.684	.724 (.051)		.376 (.089)		
5	4.05	1.33	.716	.752 (.049)		.712 (.091)		
6	4.19	1.23	.697	.739 (.048)		.325 (.085)		
7	3.70	1.24	.655	.645 (.056)			.398 (.074)	
8	3.77	1.24	.626	.592 (.060)			.504 (.077)	
9	3.65	1.29	.579	.524 (.065)			.763 (.081)	
10	4.09	1.36	.585	.503 (.066)				.679 (.057)
11	4.27	1.33	.656	.580 (.059)				.676 (.057)
12	3.98	1.40	.553	.485 (.067)				.581 (.060)

Note. All factor loadings and item-total correlation coefficients significant at $p < .001$.

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factor structure did not cause a decrease in model fit larger than the recommended cut-off scores for changes in fit indices (ΔCFI = 0.007, ΔRMSEA = 0.011), suggesting configural invariance across sex. The same stayed true when adding further invariance constraints on factor loadings and intercepts (ΔCFI = 0.006, ΔRMSEA = 0.002), and finally on latent means (ΔCFI = 0.007, ΔRMSEA < 0.001). Similar data emerged regarding measurement invariance across assessment points: adding invariance constraints on the factor structure (ΔCFI = 0.004, ΔRMSEA = 0.007), factor loadings and intercepts (ΔCFI = .007, ΔRMSEA = 0.002), and latent means (ΔCFI = 0.008, ΔRMSEA = 0.001) did not cause a significant decrease in model fit, suggesting scalar invariance across assessment points as well.

Internal consistency and test-retest reliability

Cronbach's alpha values were very good (> .84) regarding both the total and the subscale scores (Table 4). The omega total coefficients (≥ .86), based on the bifactor model, indicated similarly outstanding internal consistency (Table 4). Omega hierarchical coefficients – estimating reliabilities with the effects of all other factors removed – stood high for the total score and ranged between .27 and .53 for the domain-specific factors. Data concerning variances showed a very similar pattern: while the general factor accounted for 57.8% of the common variance, the specific factors accounted for 7.9 – 14.3% of the common variance (Table 4). Intercorrelations (all $ps < .001$) between the total and the subscale scores ranged between .76 (Confidence) and .83 (Autonomy), while those among the subscales ranged between .43 (Belonging – Confidence) and .66 (Belonging – Autonomy).

The temporal stability of the Hungarian adaptation was good; the test-retest analysis revealed a strong correlation coefficient ($r_{1\text{-month}} = .64$, $p < .001$, $r_{5\text{-month}} = .71$, $p < .001$) between the total scores across the measurement occasions (*Table 4*). The same test-retest reliability coefficients for the subscales stood slightly lower and ranged from .50 to .63 for the one-month reassessment (all $ps < .001$), and .59-.74 for the five-month re-assessment (all $ps < .001$), still indicating good temporal reliability.

Convergent- and divergent-validity and international comparison of descriptive data

EXIS.pers total scores were significantly (all $ps \leq .001$) and inversely associated with all indicators of negative mental health ($r_{\text{BSI/Global symptom severity}} = -.62$, $r_{\text{BSI/Somatization}} = -.42$, $r_{\text{BSI/Obsession-Compulsion}} = -.43$, $r_{\text{BSI/Interpersonal sensitivity}} = -.47$, $r_{\text{BSI/Depression}} = -.52$, $r_{\text{BSI/Anxiety}} = -.59$, $r_{\text{BSI/Hostility}} = -.49$, $r_{\text{BSI/Phobic anxiety}} = .38$, $r_{\text{BSI/Paranoid ideation}} = -.51$, $r_{\text{BSI/Psychoticism}} = -.53$, $r_{\text{Eating disorders(SCOFF)}} = -.28$, $r_{\text{Somatization (PHQ)}} = -.44$, $r_{\text{Search for meaning (MLQ)}} = -.19$). In contrast, EXIS.pers total scores

Table 4. Descriptive and Reliability Characteristics of the Hungarian Version of the EXIS.pers and its Domains (N = 182)

	M	*SD*	Skewness (SE)	Kurtosis (SE)	Cronbach's Alpha	Common variance	Omega total	Omega hierarchical	1-month test-retest correlation (*N*=118¥)	5-months test-retest correlation (*N*=100 ¥¥)
Belonging	3.46	1.17	−0.25 (0.18)	−0.01 (0.36)	0.90	0.079	0.899	0.275	*r*=.50, *p*<.001	*r*=.74, *p*<.001
Autonomy	4.09	1.23	−0.15 (0.18)	−0.69 (0.36)	0.90	0.086	0.919	0.266	*r*=.63, *p*<.001	*r*=.61, *p*<.001
Accord	3.71	1.10	−0.04 (0.18)	−0.30 (0.36)	0.84	0.114	0.859	0.405	*r*=.55, *p*<.001	*r*=.66, *p*<.001
Confidence	4.12	1.22	−0.29 (0.18)	−0.62 (0.36)	0.87	0.143	0.871	0.526	*r*=.56, *p*<.001	*r*=.59, *p*<.001
Total score	3.84	0.94	−0.18 (0.18)	−0.34 (0.36)	0.91	0.578	0.956	0.811	*r*=.64, *p*<.001	*r*=.71, *p*<.001

¥ Data are from an effectiveness study where the intervention occurred between the two assessments (baseline vs. post-intervention);
¥¥ Data are from the follow-up period of the same effectiveness study without intervention occurring between the two assessments (post-intervention vs. follow-up).

showed a significant (both ps < .001), moderate or strong, positive association with both indicators of positive mental health ($r_{\text{Presence of life meaning (MLQ)}} = .52$, $r_{\text{General well-being (WBI)}} = .66$).

Descriptive statistics for the total and subscale scores are displayed in Table 4. No statistically significant association existed between the EXIS.pers total scores and sex ($M_{\text{females}} = 3.99$, $SD_{\text{females}} = 1.07$; $M_{\text{males}} = 4.25$, $SD_{\text{males}} = 0.95$; $t = 1.81$, $p = .072$, $d = 0.25$), age ($r = -.05$, $p = .321$), and marital status ($M_{\text{single}} = 4.09$, $SD_{\text{single}} = 1.12$; $M_{\text{relationship}} = 3.86$, $SD_{\text{relationship}} = 0.97$; $M_{\text{cohabiting}} = 4.14$, $SD_{\text{cohabiting}} = 1.01$; $M_{\text{separated}} = 3.80$, $SD_{\text{separated}} = 1.09$; $F = 2.15$, $p = .094$, $\eta^2 = 0.02$). Regarding educational attainment, though, those having postsecondary education ($M = 3.95$, $SD = 1.03$) showed significantly lower EXIS.pers total scores ($t = 2.95$, $p = .003$, $d = 0.35$) than those having only a secondary education ($M = 4.31$, $SD = 1.08$).

Comparisons with the international data indicated that almost all subscale and total scores stood significantly lower in the current sample (p values ranging from < .001 to .005) than the scores in the German or UK samples published by the test-developers (Hunger et al., 2017). The only exception involved the Confidence subscale, which did not show a significant difference ($p = .088$) from the scores reported for the sample from Germany.

Discussion

This study had a two-fold aim: 1) to describe the adaptation process of the EXIS.pers, Hungarian version, and examine its psychometric characteristics, and 2) to provide further psychometric data on issues never investigated before regarding this psychological assessment tool developed only a few years ago (i.e., measurement invariance across sex and time and investigation of reliability via methods more sophisticated than the calculation of Cronbach's alpha). It is also worthy of note that, to the best of our knowledge, this constitutes the first study on the EXIS.pers not conducted by the questionnaire's original authors, thus providing further independent data on the psychometric properties of this assessment tool.

Similarly to the original test developers' results (Hunger et al., 2017), a bifactor structure of the Hungarian EXIS.pers version fit the data best; however, even a correlated-first-order-factors model and a second-order model showed a good fit. In line with extant published data, the internal reliability of both the subscale and total scores stood excellent according to the traditional indicator of Cronbach's alpha. The questionnaire's test-retest reliability was appropriate considering the time-lag applied; however, these coefficients registered somewhat lower than those reported for the original, German-language version (Hunger, 2015). It is worthy of note, though, that temporal reliability data from Germany were based on assessments conducted with different time lags (two and four weeks), reliability indicators (Norman's S_{2week}: 0.78–0.92; Norman's $S_{\text{4 month}}$: 0.71-0.85), and study design (repeated assessments without an intervention occurring between assessment points).

The present findings confirming the instrument's convergent and divergent validity were also similar to those of the original test developers' results (Hunger, 2015): total scores on the EXIS.pers' Hungarian version indicated moderate or strong negative associations with the different indicators of psychopathology. The only exception involved the eating disorder indicator (not yet investigated in the literature); however, the very narrow range of the SCOFF (0–5) might also have contributed to the less strong but still statistically significant association between this psychopathology indicator and the EXIS.pers scores. In addition, we also found indicators of positive mental health to be related with EXIS.pers scores, in accordance with our theoretical assumption that a higher level of satisfaction regarding one's functioning in their narrower social environment is closely related to their overall well-being and perceived level of meaning in life (Debats, 1999).

The comparisons of the data resulting from the questionnaire's administration in Germany, Hungary, and the United Kingdom indicated that mean scores in the current Hungarian sample registered generally lower than in the two Western European countries. Considering the low sample size and unrepresentative nature of the samples, we cannot draw firm conclusions regarding these between-country differences; however, they stand in line with other surveys indicating long-lasting trends of lower happiness levels in Hungary across many indicators compared to Western democracies (Róbert, 2019). A parallel finding of this study is that those with higher educational attainment reported slightly poorer experiences in their personal social systems than their less educated counterparts. While this finding looks somewhat counterintuitive, considering the generally low acceptance and accessibility of psychotherapeutic interventions in Hungary, it is likely that participants with lower educational attainment in this sample represented a very special segment of this social stratum (cf. the sample of the current study was recruited among attendees of a group psychotherapy intervention who paid for the service).

Strengths and Limitations

A significant contribution of the present study to the international literature – beyond describing the Hungarian adaptation – is the investigation of factorial invariance of the EXIS.pers. The results confirmed the scalar invariance of the best-fitting bifactor model both across sex and time, indicating that the questionnaire can be used with confidence when investigating or comparing males and females or in studies with repeated-measures designs.

Limitations of the present study also need to be acknowledged. First of all, the sampling method only reached a relatively small number of individuals who are unique in many ways (participating in a psychotherapeutic intervention on a fee-for-service basis). The low number of male participants and the overrepresentation of highly educated respondents reflected this sample's unrepresentativeness; therefore, the generalizability involving some of the findings is questionable. Second, even though the adaptation process into Hungarian employed multiple translators, back-translations, and the consideration of two resource languages (English and German), the procedure did not satisfy all criteria developed to support the highest quality of cultural adaptation (Gudmundsson, 2009). Third, the analyses were based on data from an effectiveness study, that is, an intervention – assumed to influence the construct measured by the EXIS.pers – occurred between the first and second assessment points. As a result, our findings most likely underestimate the one-month temporal reliability of the EXIS.pers' Hungarian version, which is supported by the unusual fact that the five-month test-retest coefficients registered higher in this study than the one-month estimates. Fourth, the analyses on sex invariance were completed using the pooled data set of T1, T2, and T3 data, treating repeated-measures data as independent. The alternative, though, would have been to test sex invariance on the largest (T1) sample only, in which case the number of males would have been merely 30, making the analyses for a 12-item questionnaire unreliable (Harrington, 2008). Finally, some of the measures used to investigate the construct validity of the EXIS.pers (Phobic anxiety domain of the BSI and the SCOFF) could be characterized as having a suboptimally low internal consistency; therefore, results obtained through deploying these measures should be interpreted with caution.

Conclusion, Implications and Future Directions

Despite the above limitations, the present study's overall results suggest that the Hungarian version of the EXIS.pers is an appropriate adaptation of the assessment tool's original version; thus, it can serve as a reliable and valid measure to assess an individual's subjective experiences within his or her individually defined personal social system. It is recommended that authors of future efficacy and effectiveness studies of psychosocial interventions consider the inclusion of this measure into their assessment battery.

Author contributions

Barna Konkolÿ Thege: conceptualization, design, methodology, project administration, formal analysis, interpretation, supervision, writing original draft, writing review and editing.
Benedek Somogyi: investigation, data management, writing original draft.
Gergely Sándor Szabó: conceptualization, design, methodology, funding acquistion, investigation, project administration, data management, supervision, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement

The authors have no conflicts of interest to disclose.

Ethical statement

This manuscript is the authors' original work.

The study was reviewed and approved by the Research Ethics Board of Károli Gáspár University of the Reformed Church in Hungary, Budapest, Hungary, license number: 25/2017/P

All participants participated in the research voluntarily, and provided their written informed consent to participate in this study.

Data are stored in coded materials and databases without personal data, and the authors have policies in place to manage and keep data secure.

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Appendix: Hungarian version of the EXIS.pers

A következő kérdőív olyan állításokat tartalmaz, melyek az embereknek a személyes kapcsolataikban (például szülők, párkapcsolat, gyermekek, barátok) megélt élményeire vonatkoznak. Kérjük, alaposan gondolja végig a kapcsolatait azokkal a személyekkel, akik fontosak Önnek! Kérjük, hogy a következő kérdéseket az UTÓBBI KÉT HÉT alapján válaszolja meg! Minden egyes állításnál azt a választ jelölje meg, amelyik a legközelebb áll saját tapasztalataihoz! Ha bizonytalan, azt a választ jelölje meg, amelyik legelőször eszébe jut!

A számomra fontos személyes kapcsolataimat illetően azt tapasztaltam az elmúlt két hét során, hogy…	Egyálta-lán nem	Alig	Mérsé-kelten	Többnyire	Nagyon	Teljes mérték-ben
1. … elégedett vagyok	1	2	3	4	5	6
2. … összhangban vagyok a dolgok alakulásával.	1	2	3	4	5	6
3. … békében vagyok a többiekkel.	1	2	3	4	5	6
4. … úgy érzem, tartozom valahová.	1	2	3	4	5	6
5. … odafigyelnek rám.	1	2	3	4	5	6
6. … örülnek a jelenlétemnek.	1	2	3	4	5	6
7. … képes vagyok arra, hogy tiszteletben tartsam a szükségleteimet.	1	2	3	4	5	6
8. … képes vagyok eldönteni, hogy mennyire és hogyan legyek aktív a kapcsolataimban.	1	2	3	4	5	6
9. … képes vagyok megfelelő határokat tartani magam és mások közt.	1	2	3	4	5	6
10. … bízom abban, hogy van elég erőm meg-küzdeni a felmerülő kihívásokkal.	1	2	3	4	5	6
11. … bízom a dolgok további pozitív alakulásában.	1	2	3	4	5	6
12. … bízom abban, hogy el tudom fogadni azokat a dolgokat, amiken nem tudok változtatni.	1	2	3	4	5	6

13. Kire gondolt, amikor megválaszolta a fenti állításokat (több lehetőséget is megjelölhet)?

❒ Szülők   ❒ Partner   ❒ Gyerekek   ❒ Barátok   ❒ Más személyek: . . . .

REVIEW ARTICLE

Targeting the Needs of Self-Determination Theory: An Overview of Mental Health Care Apps

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Introduction: Smartphone apps are a highly accessible tool to supplement self-treatment for mental health challenges, such as depression, and are underrepresented in research. While many studies have performed content analyses of health apps, few studies have reviewed their adherence to behavior theory.

Aims: The objective of this study is to assess mHealth depression apps through the lens of the Self-Determination Theory and identify if app functions target the three basic needs: autonomy, competence, and relatedness.

Methods: All depression apps available from iTunes and Google Play that met inclusion criteria were analyzed (N = 194). Apps were reviewed for price options, store availability, download rates, and how functions targeted the three basic needs for intrinsic and sustained health behavior change outlined in the Self-Determination Theory.

Results: Findings showed that most of the apps targeted at least one of the basic needs (158/194, 81.4%). However, only a few of these apps targeted all three basic needs to some degree (15/194, 7.7%), and no single app targeted all three basic needs fully. Furthermore, neither store availability, price option nor download rates were accurate predictors that apps targeted the three basic needs.

Conclusions: The results suggest that some depression apps targeted autonomy, competence, and relatedness but this was limited to a small number of apps through few functions available in each app. People who want access to more functions targeting the needs would need to download a suite of apps.

Keywords: mHealth, depression, mobile applications, the Self-Determination Theory, SDT

Introduction

The number of mHealth apps continues to grow and is predicted to be over 325,000 (Larson, 2018). While there are some efforts to provide consumers with guidance on which apps have an evidence base (e.g., NHS App Library; McCartney, 2013), overall, governmental regulators do not recognize mHealth apps as medical devices and impose no authority over dissemination. This means that developers can develop and distribute apps through apps stores as treatment tools for depression without regulation. This leaves consumers vulnerable to poor quality health apps. However, due to the benefits of mobile apps as a platform to supplement self-treatment of depression, many apps have been developed and are competing to capture the market transitioning to the mHealth platform. The afford-ability of mHealth apps, coupled with the accessibility, practicality, and expectations of privacy, provides a viable healthcare option for private and stigmatized health concerns (Deng et al., 2014). As a result, this makes mHealth apps a viable option for people with depression. However, most of these apps are not developed by health profes-sionals (Powell et al., 2016), and there are cases of apps misreporting organizational affiliations and content (Shen

et al., 2015). These apps need to demonstrate some level of clinical foundation to be safe and effective (Powell et al., 2016), yet wide-spread dissemination means there are unfounded apps in circulation and non-specialist apps masking themselves as depression apps (Shen et al., 2015). Additionally, these apps could have adverse effects and worsen depression (Leigh & Flatt, 2015). Newspaper reports have claimed that most mHealth depression apps are unproven (Knapton, 2015) and many apps foster depression and depressive symptoms and do not offer any effective treatment (Ryu, 2012). Without guidance, finding a research-based mHealth depression app would be challenging (Shen et al., 2015), particularly as few mHealth depression apps incorporate health behavior theory into their designs (Sama et al., 2014). This study hopes to offer suggestions for suitable apps with a human behavior theory basis. mHealth has strong potential for mental health intervention yet more formal assessments around mHealth are needed (Grossman et al., 2020). This study exists to review mHealth depression apps for in-app functions that operate to target basic needs for health behavior change outlined by the Self-Determination Theory (SDT) (Ryan et al., 2008). An SDT-based approach to treatment of depression is empirically supported (Britton et al., 2008) and is well-suited to the app platform (Umaefulam & Premkumar, 2020). Furthermore, it is important for us to conduct this type of research around enabling change in a context of depression due to the barriers to health behavior change that depression enacts (Williams, 2014). Despite this, there is minimal research around SDT treatment approaches to mental health issues through apps (Fish & Saul, 2019).

The Self-Determination Theory

This study assesses mHealth depression apps using SDT as a theoretical basis. SDT acknowledges the fulfillment of three basic needs: autonomy, competence, and relatedness. These needs are crucial to create and support intrinsic, long-term motivation for behavioral change, and a lack of needs satisfaction can result in depression (Bartholomew et al., 2011) and depressive symptoms (Ryan et al., 2008) Furthermore, controlled motivation, as opposed to intrinsic motivation, can be associated with depression (Levesque et al., 2007). In light of this, the sample of apps in this study are reviewed for functions that target the three basic needs configured by SDT. Other popular health behavior theories, including the Health Belief Model and the Theory of Reasoned Action, are limited in their ability to explain health behavior change (Rothman, 2000). Conversely, SDT offers keen insight into understanding health behavior through apps (Monney et al., 2015). and depression treatment (Ryan & Deci, 2008).

Autonomy

The need for autonomy is the need for self-direction of behavior that is motivated by value, satisfaction, and interest in the behavior to the exclusion of external stimuli (Ryan et al., 2008). It is self-management of health with limited to no support from others (Ryan et al., 2008). In SDT, the motivation to change behavior is dependent on autonomy; when motivation is autonomous, people are more willing to sustain health behavior change than when motivation is forced (Ryan et al., 2008). Furthermore, a lack of autonomy in the face of difficult situations can be an indicator of depressive onset (Mazure et al., 2000), and low autonomy levels are associated with depressive symptoms (Schiffrin et al., 2019). This suggests that autonomy absence is a trigger for issues concerning mental health. Fostering health behavior change through supported autonomy can be identified as follows. Firstly, providing meaningful reasons for behavior change. Secondly, providing alternative behaviors or activities to enact that require active participation. Thirdly, supporting individual initiatives through personalization. Fourthly, recognizing alternative opinions or approaches to content. In light of this, it is assumed that mHealth depression apps with these qualities would support depression self-treatment.

Competence

The need for competence is the need to feel adept or skillful towards a behavior or the feeling that a skill or behavior change is improving (Ryan et al., 2008). It is different to autonomy, as it reflects personal ability rather than personal control. Experiencing the feeling that you are capable of changing a behavior is a component of motivation and maintenance of long-term behavior change. Furthermore, lower levels of competence are associated with depressive symptoms (Schiffrin et al., 2019). This supports findings that self-efficacy and competence foster effective depression treatment (Ryan & Deci, 2008). Feelings of competence come from tools, advice, and feedback that encourage behavioral changes and overcome barriers (Ryan et al., 2008). In light of this, apps that foster competence for depression self-treatment would provide sources of information that support depression treatment. Additionally, apps would include supportive tools that enable change and feedback mechanisms.

Relatedness

The need for relatedness is the need to feel connected to others (Ryan et al., 2008). In SDT, feelings of relatedness are important for establishing motivation as it allows people to adopt social influences from meaningful relationships. Social influence is an important component to health behavior change (Fogel et al., 2002), including treating depression (Logsdon et al., 2009). Furthermore, relatedness and social influence are increasingly important aspects of our digital lives and online presence. This is also true for our digitization of health behavior and management. For instance, online communities, forums, and chat rooms enable social engagement with likeminded people with relatable health issues (Fogel et al., 2002). mHealth apps that enable social connection with peers and feelings of relatedness would likely contribute to positive health behavior change around depression.

To sum up, in accordance with SDT, the needs for autonomy, competence, and relatedness are central to innate and sustained motivation to make behavioral changes. mHealth depression apps that recognize these needs are likely to make greater positive changes for people with depression than those apps which overlook these needs and other aspects of behavior and treatment theories. In light of this, this study investigates the following question: Do mHealth depression apps host functions to target user needs for autonomy, competence, and relatedness in line with SDT? From this investigation, the study makes suggestions of mHealth depression apps.

Methods

Sample Selection

For this app review study, mHealth depression apps are recognized as apps that claim to treat, manage, educate, or help with depression and depressive symptoms. Generic mental health treatment apps were included only if they met this criterion. Apps focusing on symptom assessment and mood monitoring were excluded. With granted ethics clearance, two popular app stores (Google Play and Apple iTunes) were checked for any apps using the words "depression" and "depressive" in either the titles, keywords or descriptions of their app store webpages during March 2020. All search results from both stores were reviewed to assess if the apps qualified for study inclusion. A range of specialist apps were reviewed, including, but not limited to, chat apps, workbook apps, mindfulness-based apps and faith-based apps. Several apps, for instance hypnosis and acupuncture apps, were excluded because they cannot be appropriately analyzed within the context of this research. Social chat and communication apps were also excluded as they are generic communication apps without a focus on depression. Apps that were not in English were also excluded. From this sampling approach, 221 apps were reviewed: 144 from Google Play and 77 from iTunes. After correcting for twenty-seven duplicates, the sample was reduced to 194. As developers will occasionally give an app different names across app stores, both app names and developer names were recorded during data collection. By sorting the original 221 apps by app names, then developer names, all duplicates were identified by comparing descriptions, imagery and content. Any apparent duplicate apps were compared between the two app stores concurrently for confirmation.

Coding of Apps

App and Download Details

Apps were coded for market type (Google Play, iTunes, or both stores) and price type (free or paid). Download rates were included for apps available from Google Play only as iTunes does not report download information. Apps were reviewed according to titles, descriptions, and imagery; a supported method of data collection in mHealth research (Pinheiro et al., 2019; Wali et al., 2019). The coding scheme was developed by using the conceptualization of the SDT variables outlined earlier. As a quality check, 20% of included apps were randomly selected and recoded by the author to confirm consistency in the coding. Functions that targeted the three basic needs were observed and coded appropriately. Some apps gave instructions that align with SDT; however, they did not provide functions to support it and were coded appropriately. For example, some apps advised users to make to-do lists while others hosted to-do list functions which enable the behavior and target the need for competence. Additionally, to target the need for autonomy, an app must provide in-depth, objective information about depression (e.g., psychoeducation approach, Harrer et al., 2021) as opposed to a brief, undiscerning description.

Autonomy

Autonomy was assessed through functions in apps that supported autonomous behavior of users through: 1) providing meaningful reasons for change, 2) providing alternative behaviors, and 3) supporting individual initiatives through personalization. Coding was based on the presence or absence of these functions in the apps. First, apps were assessed for relevant, sound information that supports reasons for behavior change, such as objective and clinical information on depression and depressive symptoms and valid reasons for treatment. Valid reasons are justifications that treating depression improves health and life quality. The second aspect of autonomy considers choices and behavior alternatives. Apps were reviewed for activities and exercises with active participation that redirect concentration towards treatment, such as workbooks, guided meditation, writing, learning games, and mindfulness practices. Apps with a dedicated treatment approach, such as mindfulness and CBT exercises, likely have a strong overlap with elements of SDT. The third aspect of autonomy is to support individual initiatives. Here, apps were reviewed for functions that enable change through behavior plans or schedules, such as a personalized depression management plan outlining how to act and react for future situations and how to achieve behavior goals. The last aspect of autonomy considers individual perspectives. This can only be assessed in interpersonal communication. Therefore, this aspect of autonomy was not coded for this study.

Competence

Competence is enabled by skill development, supportive tools for development and feedback on behavior change (Ryan et al., 2008). Coding was dependent on whether apps hosted functions that target the need for competence through: 1) resources, 2) supporting change, and 3) providing feedback. Firstly, apps were reviewed for informational resources on skills for change, such as treatment guidelines and insights and stories from lived experience. Practical resources to educate app users, such as FAQs, hotlines, educational quizzes, and games were also identified. The second aspect of competence can be seen in app functions that actively support change, such as reminders and push notifications, goal settings and to-do list functions, and mood assessments and journaling. Finally, apps were reviewed for evidence of providing feedback, such as personalized reviews of progress based on mood and behavior tracking and journaling.

Relatedness

Relatedness is determined by feelings of connectedness to peers (Ryan et al., 2008). Therefore, apps were reviewed for relatedness by observing functions that connect users with peers and chatbots to enable social support and with clinicians to enable more formal correspondence. Functions such as chat rooms, forums, bulletin boards, messaging functions, and connection to social media were identified as evidence of mHealth depression apps supporting relatedness and coded appropriately.

Results

App and Download Details

Out of 194 apps, the majority were uniquely available to Google Play (118/194, 60.8%) while around one-quarter (50/194, 25.8%) were exclusive to iTunes. As a result, a minority of apps were available from both app stores (26/194, 13.4%). In terms of price type, 135 of the 194 apps reviewed (69.6%) were free, and the remaining apps (59/194, 30.4%) required some form of payment. Price type did not predict download rates in Google Play as the highly downloaded apps were a combination of free and paid. iTunes does not disclose download rates for apps meaning download rate could not be used either. Google Play download rates are provided as approximations, so no exact numbers can be given in this study. However, based on these approximations, it is clear that all 144 mHealth depression apps from Google Play have been downloaded at least once. One million downloads was the highest rate which was represented by eight apps. Approximately 80,000 was the average rate despite the majority of apps having low rates and the popular minority, less than twenty percent, having more downloads than the average. However, download rates were not a reliable indicator that apps targeted the basic needs of SDT as highly downloaded apps did not appear to consistently meet the basic needs.

Table 1. Apps Functions Corresponding to the Needs of the Self-Determination Theory (*N*=194)

| The Self-Determination Theory Needs through Functions	Distribution, *n* (%)
Autonomy	73 (37.6)
Meaningful Reasons for Behavior Change	36 (18.6)
Function - Information on Depression	36 (18.6)
Function - Reasons for Treating Depression	0 (0)
Providing Choices and Behavior Alternatives	42 (21.6)
Function - Activities that Involve Active Participation	42 (21.6)
Supporting Individual Initiatives	6 (3.1)
Function - Personalized Depression Management Plan	6 (3.1)
Competence	95 (49)
Information Resources on Skills for Change	17 (8.8)
Function - Treatment Guidelines or Tips	5 (2.6)
Function - Practical Resources for Education	12 (6.2)
Supportive Tools for Behavior Change	88 (45.4)
Function - Reminders or Notifications	9 (4.6)
Function - Goal Setting or To-Do List	9 (4.6)
Function - Mood Tracker or Journaling	84 (43.3)
Feedback	31 (16)
Function - Personalized Review of Progress or Change	31 (16)
Relatedness	49 (25.3)
Interaction with Others	49 (25.3)
Function - Connection with Peers, Chatbots or Clinicians	47 (24.2)
Function - Connection with Social Media	5 (2.6)

Note. The distribution does not add up in cases where apps have multiple functions within a single need.

Functions Satisfying the Basic Needs

This study aims to investigate whether mHealth depression apps, through their functions, satisfied needs for autonomy, relatedness, and competence as characterized by SDT. Analysis showed that while no apps hosted all functions identified in the coding criteria, most apps (158/194, 81.4%) hosted a function that satisfied at least one need, and only fifteen apps (15/194, 7.7%) hosted functions that targeted all three basic needs. However, thirty-six apps (19%) did not host any functions outlined, meaning that they did not target any of the basic needs.

Just over one-third of the apps satisfied the need for autonomy (73/194, 37.6%). Four app functions were observed in this study to target the need for autonomy. First, providing information on depression (36/194, 18.6%). Second, activities that involve active participation (42/194, 21.6%). Third, assisting with creating a personalized depression management plan (6/194, 3.1%). Lastly, no apps provided reasons for treating depression. Almost half of the apps targeted the need for competence (95/194, 49%). Few apps provided information resources on skills for change towards competence; five apps (2.6%) offered treatment guidelines or tips, and twelve apps (6.2%) provided practical resources for education on depression and treatment. The other functions that target the need for competence are as follows. The two functions, 1) reminders or notifications and 2) goal setting or to-do lists, were each seen in nine apps (4.6%) while mood tracking or journaling functions were found in close to half (84/194, 43.3%). Functions that gave feedback, including personalized reviews of progress and behavior change, were observed in thirty-one apps (16%). The need for relatedness was addressed by one-quarter of the apps (49/194, 25.3%) making it the least-targeted need outlined by SDT. The most common function that targeted this need allowed users to communicate with peers, clinicians, and even chatbots. Five apps (2.6%) hosted a function for social media connection that allowed users to link their app behavior to social media.

Figure 1. Youper
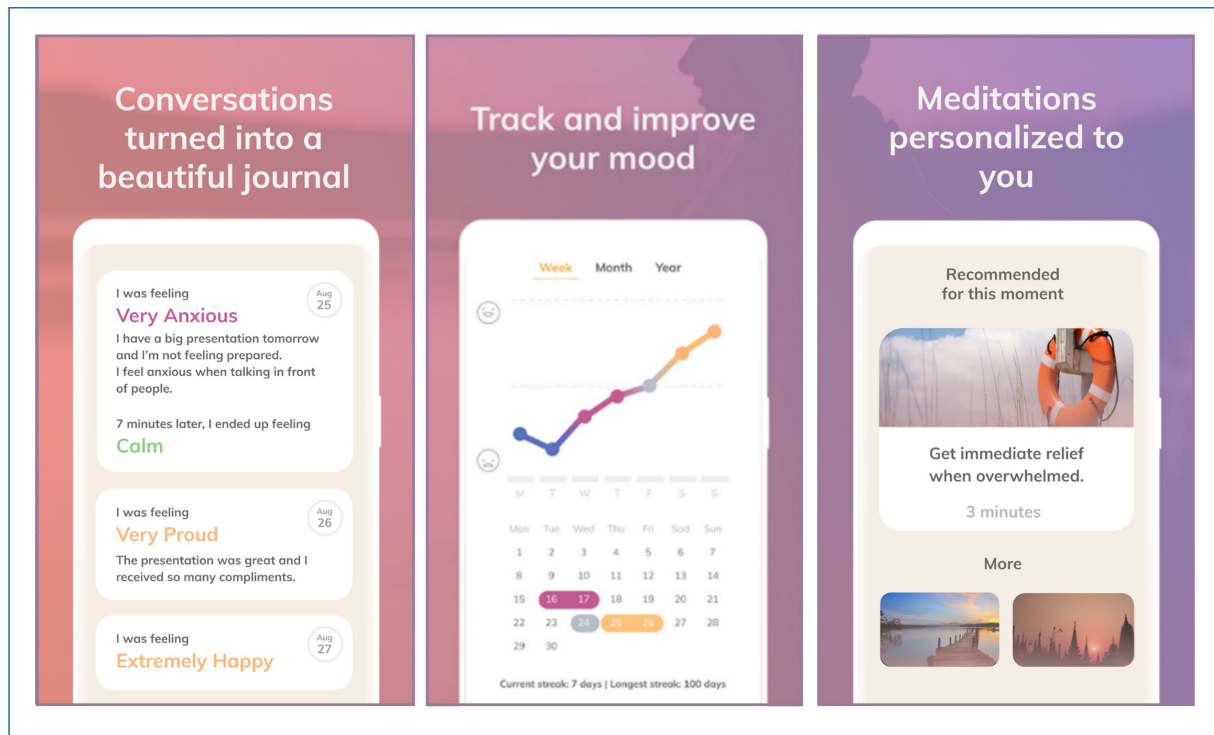
## Suggested Apps Based on Popularity and Basic Needs

Of the three most downloaded mHealth depression apps, two apps, Youper (Youper, 2020) (Figure 1) and Mood-path (ReachOut Australia, 2020) (Figure 2), targeted the needs for autonomy, competence, and relatedness through five functions, the highest number of observed functions in any app in this study. Furthermore, both of these apps were free and available in both app stores making them an attractive starting point for anyone seeking apps for depression self-treatment. Youper is an artificial intelligence app where users can connect with a chatbot designed to use empathetic language while they complete therapy exercises on their device. Moodpath describes itself as a clinical app. It provides a mood journal for users and analyzes their health assessments to develop individualized progress reports and suggestions for self-reflections and activities. Based on how these apps targeted the needs for autonomy, competence, and relatedness, their stand-out concepts and aesthetics, and their popularity based on download rates, this study suggests two particular apps, Youper and Moodpath, as a starting point for anyone seeking an mHealth depression app. Both apps scored highly in a study conducting quality evaluation of mHealth depression apps and each have produced positive results in clinical trials (Burchert et al., 2021; Mehta et al., 2021).

Discussion

Main Findings

Using SDT as a theoretical basis, this study reviewed mHealth depression apps (*N* = 194) available from the Google Play and iTunes app stores. Research into applications of SDT to mHealth apps appears to be minimal (see Eysenbach et al., 2020). Hence, the objective in this study was to identify functions in apps that target the needs for autonomy, competence, and relatedness to identify apps with a SDT basis. These needs are outlined by SDT as crucial for creating and supporting intrinsic, long-term motivation for health behavior change (Ryan et al., 2008). The analysis proposes that the minority of the apps hosted features to target the basic needs outlined by SDT. In particular, one-quarter (49/194, 25.3%) of the apps satisfied the need for relatedness, and less than half targeted autonomy (73/194, 37.6%) and competence (95/194, 49%). This suggests that finding an app for self-treatment of depression that targets the needs would not be immediate for people using Google Play or iTunes. Furthermore, neither the price type nor download rates are reliable indicators; apps that targeted the three basic

Figure 2. Moodpath
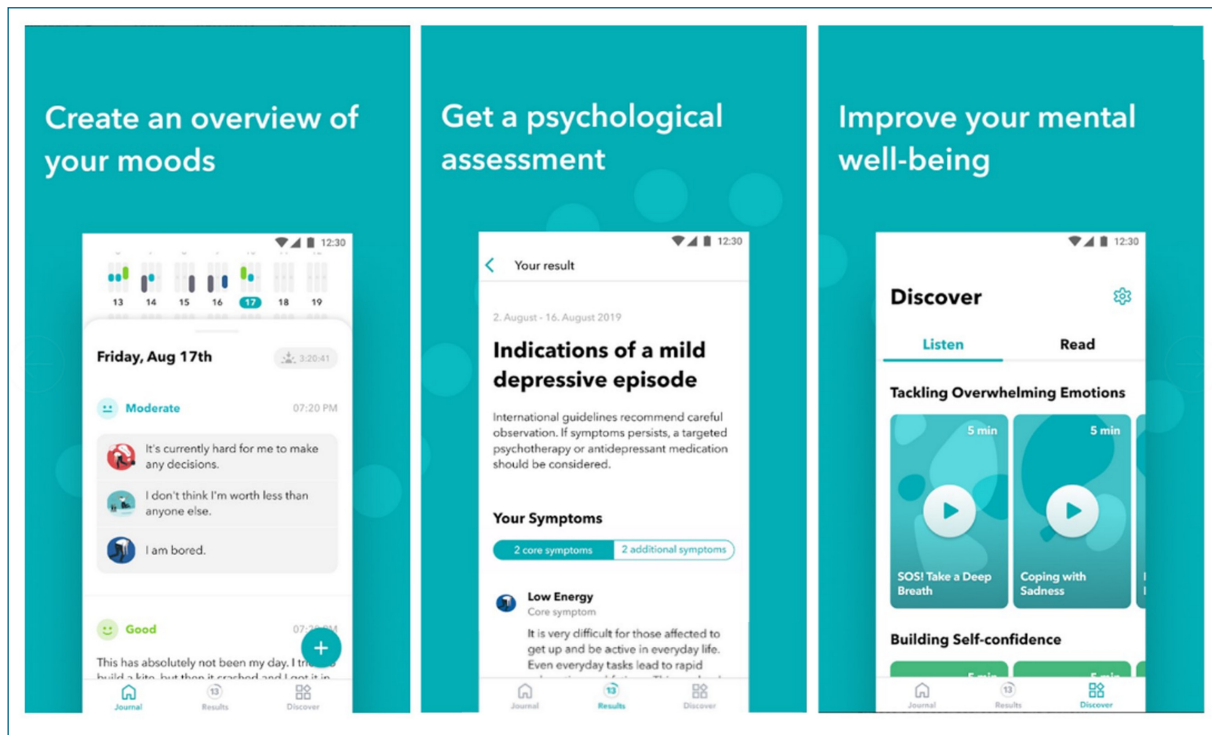
needs were reflected similarly in both paid (91/194, 46.9%) and free apps (103/194, 53.1%) and had varying download rates.

The study found that while a small portion of the apps (36/194, 19%) did not target any of the basic needs, a smaller portion (15/194, 7.7%) hosted functions that targeted all three basic needs. Research demonstrates that addressing the three basic needs of SDT is a prerequisite to building and maintaining intrinsic motivation for behavioral change (Ryan et al., 2008). In light of this, it can be argued that mHealth depression apps that do not target the three basic needs would produce limited results. In contrast, the few apps that target all three needs might foster motivation and positive, long-term health behavior change. Although few of the apps targeted all three needs, people are able to build intrinsic motivation for behavior change by targeting the three basic needs by using a single mHealth depression app. Therefore, individuals would not need to access a suite of apps which would be a more costly and less practical approach. Despite this, the effectiveness of mHealth depression apps that target all three basic needs would depend correspondingly on other factors not covered here, including but not limited to, users' subjective evaluation of app engagement techniques (i.e., gamification and aesthetics) and technology acceptance and usage drivers (i.e., perceived ease of use and usefulness).

Strengths and Limitations

The strength of this study is that it presents a theory-driven overview of mHealth depression apps that are available and highly accessible in the market and is bolstered with empirical analysis. This study also has limitations. Firstly, the apps reviewed were limited to Google Play and iTunes. Consequently, other relevant apps available only in other competing app stores, e.g., Amazon Appstore and Windows Appstore, may likely have been excluded. Furthermore, apps reviewed in this study were limited to apps with content delivered in English further truncating the selection of mHealth depression apps. Secondly, as iTunes does not disclose download rates, all analyses and discussion around download rates are based solely on the information provided by Google Play. Thirdly, by focusing solely on SDT, this study has overlooked many other behavior change theories and therapies, such as operant conditioning theory and cognitive behavior therapy, that may have more relevance to mHealth and mental health management spaces.

Conclusion, Implications and Future Directions

To summarize, this study reviewed mHealth depression apps to identify functions that target the basic needs for autonomy, competence, and relatedness which foster intrinsic motivation for behavioral change as outlined in SDT. To some extent, the apps that were reviewed targeted these needs and may be useful. Nonetheless, most of the apps offered limited functions to satisfy these needs and few apps targeted all three needs. This corresponds with other findings that mental health support apps are not at an acceptable standard (Larsen et al., 2016). The study reviewed all mHealth depression apps available from the Google Play and Apple iTunes app stores that claimed to treat, support, manage, or help people with depression and depressive symptoms. With this in mind, it is suggested that significant potential remains for improvement to these apps by refining and introducing functions guided by health behavior theory. However, the findings from the study coupled with the accessibility of apps makes mHealth depression apps, at the very least, an ideal platform to begin treatment. Of course, experimental research is needed to measure the efficacy of mHealth depression apps.

While this research is not assessing the effectiveness of mHealth depression apps based on user outcomes, it offers a review. There are some implications to this. Firstly, although some apps may target the three basic needs, it is possible that these apps are limited in their ability to engender sustained behavioral change as this rudimentary research overlooks many other relevant factors. Secondly, health professionals should consider a suite of studies on the topic and make their own assessment before prescribing mHealth depression apps to patients. Thirdly, users of these apps may not have the capacity to access or use academic literature on the topic, so future research should investigate how to best give people the skills and materials to make their own assessment of mHealth depression apps. Furthermore, future research that clinically assesses whether these apps and functions target needs of depressive individuals would be a contribution to the field. Lastly, it is unknown how many healthcare-developed apps are offered or in use today, and there is limited research on treatment of depression through apps and how apps can be used safely without the support of a clinician. Also, why people turn to apps and whether the healthcare system encourages this movement is underrepresented in research.

Author contribution
Luke Brownlow: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, writing original draft, writing review and editing.
The author gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement
The author has no conflicts of interest to disclose.

Ethical statement
This manuscript is the author's original work.
Human participants have been not involved in this study.
No ethical approvement, informed consent or data handling policy was needed.

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REVIEW ARTICLE

Main Debates on the Management of Mental Illness: 1990-2020. A narrative review

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Introduction: Since the introduction of newer psychiatric treatment methods during the 20th century, debates about the effectiveness and appropriateness of such treatment have featured. Advocates among those who promote the sociological, biological, psychological and spiritual understandings of mental illness and its treatment have created tangible tensions with those supporting each position commonly indulging in fierce attacks on the others.

Aims: The aim of this paper is to explore some of the principal treatment viewpoints that characterized the late 20th century (1990 onwards) and early 21st century (up till 2020). Ultimately, these debates guided contemporary practice towards a biopsychosocial-spiritual view of mental illness in a move towards holistic person-centered care, which nowadays is the advocated model in many health systems.

Methods: The authors undertook a literature search in order to locate published debates on psychiatric treatment during the late 20th century (1990 onwards) and the early 21st century (up till 2020).

Results: Debates emerging from 36 articles were identified and synthesized in a narrative review.

Conclusions: Exploring the various debates that have characterized mental health care serves as a crucial reflective exercise on what needs to be considered when claiming that contemporary care is based on a holistic and person-centered approach. In this view, critical evaluation is needed so as to avoid repeating the coercive and inhumane mistakes of the past.

Keywords: psychiatric treatment, critical psychiatry, medical model, individual-community model, person-centered approach

Introduction

Advances in psychopharmacology and psychological therapies have been significant in improving the quality of life for some of the individuals who were experiencing symptoms synonymous to a mental illness (Choo et al., 2019). A multitude of clinical trials as well as convincing patient narratives have shown that mainstream psychiatric treatment – mainly drugs such as antipsychotics, antidepressants, anxiolytics and mood stabilizers – conferred a significant beneficial effect (see Reid, 2013; Leucht et al., 2012; Jamison, 1995). Medical guidelines, such as those issued by the National Institute for Health and Care Excellence (NICE), recommend and guide the use of

drugs and psychological therapies in most of the psychiatric conditions found in the *DSM* and *ICD*. Furthermore, there seems to be a consensus on the move towards less restrictive community care, with hospitalization being left as a last resort (WHO, 2018). Still psychiatric treatment has been characterized by a history of opposing views, theories, debates and a confusing and non-conclusive ocean of clinical trials.

The aim of this paper is to explore some of the historical perceptions related to the treatment of symptoms that mental illness causes. We have divided the paper into two parts – the first segment (1) concerns opposing views on the appropriateness and effectiveness of psychiatric treatment. The second section (2) explores some contemporary alternative person-centered and holistic approaches in mental health. This paper includes debates linked to the Medical Model as well as those that characterize the Individual-Community Model. The terms used by the authors during the different debates shall reflect those used by the particular source that is being cited in that specific debate. However, the authors of this paper lean towards the Individual-Community Model as a theoretical framework.

Methods

The authors undertook a literature search in order to locate published debates related to psychiatric treatment that featured during the late 20th century (1990 onwards) and early 21st century (up till 2020). This was an era characterized by the introduction of new psychiatric medication and methods of treatment – some of which are still in use in contemporary psychiatry and mental health care. Key terms were identified by carrying out focussed and expanded searches on the MeSH On Demand interface. The key terms used were *mental disorders, survivor movement, mental health treatment, mental illness management, psychiatric medication, critical psychiatry, mental illness debates* and *mental health services*. These were then entered in selected databases, namely The Cochrane Central Register of Controlled Trials, EMBASE, MEDLINE and PsycINFO. We used filters and limiters accordingly to limit the results in terms of relevance and the time limit of the search was set to 1990–2020. The Critical Psychiatry Network article database was also searched manually to identify additional sources. These debates emerging from the final 36 articles that were filtered from the results according to set inclusion and exclusion criteria were then synthesized in a journey, which shall be presented in the following section.

Results and Discussion

The Effectiveness of Psychiatric Drugs

A Crusade Against Drug Effectiveness

During the mid-late 20th century, the introduction of psychiatric drugs marked what is often considered to be the new era for mental health. Bestowed with the title "pharmacological revolution", it stood as a remarkable technological achievement and played a role in downsizing psychiatric asylums. In his review of the "psychiatric revolution", Scull (2010) noted that the introduction of these new medications was not the only factor responsible for the demise of the traditionally oppressive psychiatric system. Others such as fiscal considerations and deliberate adjustments in state policy significantly drove deinstitutionalization. Psychiatric drugs, however, completely changed the practice of psychiatry as well as its status in society. Chlorpromazine and similar antipsychotic drug types were the first ones to be introduced, providing psychiatry with a treatment type that was simple to administer although it was ultimately responsible for iatrogenic illness. The phenothiazines lessened the severity of symptomatology and provided relief for some patients. In this view, these drugs received an eager welcome by professionals and patients especially when considering that before their introduction, psychiatric treatment had merely consisted of social restraint. Quickly, these drugs became a major source of profit for the industry notoriously termed "Big Pharma" which had discovered the benefits linked to the marketing of drugs that had the potential to change people's moods (Scull, 2010). The introduction of Prozac was another milestone in the revolution and such a successful one that it changed many perspectives on mental disorder. However, the new drugs were not magical cures that provided a permanent solution to psychiatric problems. Gradually, doctors and other reviewers raised critical stances which birthed the emergence of widespread debates in the medical and social world.

The effectiveness of psychotropic drugs has been one of the most controversial areas over the years. Figures like Moncrieff (2013a, 2013b), Healy (2016) and Breggin (2006) have presented research that contradicts the promoted and evidenced effectiveness of commonly used drug types in psychiatry. Bracken (2012) stated that the evidence that psychiatric drugs function through a placebo effect cannot be contradicted. The author cited two meta-analyses, carried out by Turner and Kirsch, which have concluded that in 80% of the cases explored through individual studies, the improvement seen was very much comparable to that experienced by participants in placebo groups.

Double (2001) acknowledged that reviewing the literature about the effectiveness of psychiatric drugs remains a complex task due to the vast number of studies, different methodologies, and the need to appraise the quality of studies located. Several researchers have endeavored to undertake this process. Double (2001) described how in 1974, Morris and Beck were amongst the first to synthesize the data available by looking at trials published over a 14-year period. Their results showed that in more than half the cases, antidepressants were more effective than placebo. However, Bracken and Thomas (2004) theorized that the main mode of antidepressants' function is through the generation of hope. Since hope may be generated through alternative, less invasive methods, the authors postulated that discourse in mental health should feature issues such as hope, meaning, and values.

Kirsch (2011) reported that a significant difference between placebo and antidepressants is only witnessed in very severe cases of depression. In 1995, Moncrieff had also explored the effectiveness of the mood stabilizer lithium and expressed dissatisfaction due to her observation that results obtained are neither clear nor significantly demonstrated:

> Differences between lithium and placebo treatment in several of the trials were probably attributable to discontinuation of lithium increasing the likelihood of manic relapse in placebo treated subjects. In the largest prospective trial, treatment conditions for the two groups were not comparable (Prien et al., 1973), and in another prospective trial only a select group of subjects were considered and results were presented in a way which impedes a proper understanding of the data. (Moncrieff, 1995, p. 571)

In a later trial by Bowden et al. (2000), which is considered as the largest clinical trial in this area, there was no significant difference in the participating individuals' response rates to lithium and to a placebo. In addition to the fact that the effectiveness of drugs has been placed under scrutiny, Evans (2004) also cautioned about the inadequacy of the double-blind methodology that is used in many clinical trials. This is due to several factors. For instance, participating individuals may note that the placebo tablets that they have been taking taste differently from the usual medication. Active medication may also be characterized by side effects that distinguish it from a placebo. Treatment that is regularly used to manage psychosis has also been under scrutiny. In 1998, Thornley and Adams explored the effectiveness of drugs used in the treatment of schizophrenia over the past 50 years. A total of 2000 trials were included in the review. The findings showed that the overall quality of the studies was poor and this may have led to inaccurate overly positive results in relation to the effectiveness of these drugs (Thornley & Adams, 1998). Thomas and Bracken (1999) discussed how rather than viewing drugs as the medical cure, it is advisable to talk and describe the experience of psychosis during a dialogue with the person:

> It is often assumed that in irrational states, such as psychosis, there are constraints on a person's ability to act autonomously. This view may be used as justification by a psychiatrist to disregard the patient's treatment preferences. But situations in which a person is irrational in all aspects of thought, will and action are rare. (p. 328)

In 2010, Irving Kirsch compiled his research around this area in a book called *Antidepressants: The Emperor's New Drugs*. His views were similar to that of other leading figures, and he outlined his concern that the drug industry may be a culprit in promoting the pseudo-effectiveness of psychiatric drugs:

> The drug effect seemed rather small to us, considering that these medications had been heralded as a revolution in the treatment of depression – blockbuster drugs that have been prescribed to hundreds of millions of patients, with annual sales totalling billions of pounds. (Kirsch, 2010, p.11)

This concern echoes the thoughts of critical psychiatrists in relation to the evidence base underlying the biomedical model. Notably, Kirsch did not shun the use of medical treatment as he realized that this may be of use in particular cases.

In 2013, Peter Breggin, another prominent figure in the effort to limit the abusive prescription of psychotropic drugs, presented a guided system to psychiatric drug withdrawal in his book: *Psychiatric Drug Withdrawal:*

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A Guide for Prescribers, Therapists, Patients and Their Families. The aim of the book was to offer guidelines to assist the prescriber and therapist in helping individuals to withdraw from psychiatric drugs. Breggin (2013) elucidated how research revealed the danger of long-term exposure to psychiatric drugs due to their relation to obesity, diabetes, heart disease, abnormal movements, and a detrimental effect on the quality of life. These dangers have led Breggin to advise that the best option in modern psychiatry is to encourage withdrawal from psychiatric drugs.

Counter Arguments

Despite the convincing nature of these arguments, which indeed research supports, it is interesting to note that the opposing side of the argument is similarly based on a multitude of studies which seemingly demonstrate the effectiveness of the commonly used drug types in psychiatry (Kohler et al., 2014; Maher et al., 2011; Vieta et al., 2010). Leading figures in this area, such as Leucht et al. (2012) have cautioned against the crusade opposing psychiatric drugs due to the consequences that it can have on patients: "In this context, many psychiatric drugs not only improve the acute episode but also prevent further episodes. Patients with severe, recurrent depression might have 20 episodes in their lifetime, which could be reduced by medication to 10" (p. 103). They argued that controversy about medication effectiveness can result in patients who decide to discontinue their medication – this can easily be a catalyst to suicide or relapse. These researchers devoted considerable effort to proving the effectiveness of psychiatric drugs through various randomized controlled trials and meta-analysis. One particular study involved an overview of 94 meta-analyses in an attempt to demonstrate that the degree of psychiatric drug effectiveness compares well to other drugs used in general medicine (Leucht et al., 2012). In an echo of Moncrieff and Cohen's views (2009), it has to be said that whilst the consequence of stopping effective medication is acknowledged, it may be equally harmful to mislead individuals into believing that psychiatric drugs are overly effective or can provide a cure. In a chain of publications, Moncrieff distinguished between a *drug centered model* and a *disease centered model* (See Moncrieff, 2013b; Moncrieff, 2010; Moncrieff, 2009). She described how the drug centered model may be more empowering as it views psychiatric medication as an extrinsic substance that mainly works through producing cognitive and emotional suppression:

> The disease centred model is captured by the idea that drugs act by correcting or partially correcting an underlying biological lesion, analogous to the way the action of most drugs in general medicine is understood. In contrast the drug centred model suggests that drugs work by inducing their own abnormal brain states. (Moncrieff, 2013b, p. 296)

This suppressed state may be beneficial in certain circumstances, such as in acute psychotic states. However, in an example brought by Moncrieff and Cohen (2009), once the acute episode has been controlled, the person may then decide to stop antipsychotic drug use and instead engage in alternative forms of maintenance treatments (p. 151). This is different and probably more beneficial than adherence to the disease centered model which assumes that psychiatric medication is physiologically corrective.

These debates on treatment models raged throughout the process of deinstitutionalization that saw the down-sizing of several psychiatric hospitals in the late 20th century. In Western industrialized nations, the number and size of asylums had increased dramatically over the nineteenth century. These were planned to be humane places where patients could live comfortably whilst receiving treatment, as opposed to the prison-like asylums of the past – a push towards "moral care". Despite these principles, these asylums became overworked, non-therapeutic, geographically isolated, and uncaring to patients (Wright, 1997). By the turn of the century, rising admissions had resulted in severe congestion, posing several challenges for mental facilities. Funding was often withdrawn, particularly during economic downturns and warfare. Patients were starved to death at asylums because of terrible living circumstances, lack of cleanliness, overcrowding, ill-treatment, and abuse (Fakhoury & Priebe, 2007). Although asylum numbers continued to rise until the 1950s, the first community-based solutions were proposed and provisionally adopted as early as the 1920s and 1930s. Supportive housing as well as specialized teams were among the community services that emerged. Although deinstitutionalization benefited the vast majority of patients, it is not without flaws. Some argued that it was a failed step in the right direction, claiming that contemporary society suffers from a "re-institutionalization" issue (Fakhoury & Priebe, 2007). Thus, deinstitutionalization left some homeless or without care (Eisenberg & Guttmacher, 2010), resulting in the formation of "psychiatric communities" instead of a successful move towards "community psychiatry".

Contemporary Alternative Approaches

The Psychosis Example

Dutch psychiatrist Marius Romme has been one of the early 21st century pioneers in developing alternative approaches which view symptoms characteristic of psychosis as meaningful, as phenomena that must be explored and understood rather than suppressed or disguised. He posited that accepting and coping with auditory hallucinations – a symptom that is often attributed to a state of psychosis – can enhance one's quality of life in a better way than simply ignoring the voices (Romme, 2009). Indeed, as a result of his empirical work, he concluded that struggling against the voices only causes them to become stronger. In his publications, such as *Accepting Voices* (Romme & Escher, 1993) and *Making Sense of Voices* (Romme & Escher, 2000), as well as others published in the journal *Mind*, Romme described an innovative approach involving the extraction of meaning from psychosis. This may be painful for some people due to the realization and facing of difficulties. Professionals aim to facilitate this process for the person and guide them by acknowledging that the individual's explanatory framework may be different from that of the professional's as seen in the following service user narrative presented by Romme (2007):

> Every time, when I was released from hospital and went back to normal life, there was this reduction of possibilities in my life. Nearly ten years later, I was not interested in anything anymore. It took me quite a while to see the relationship between my voices and my life, so I realized that when I was angry and did not express my anger the voices became angry at me. (section 3-4)

This approach is synonymous with the *Hearing Voices Network*, originally founded by Marius Romme in the Netherlands, which has been developed in other countries such as the UK. These movements are concerned with the normalization rather than the medicalization of the psychotic experience and are active in raising awareness about alternative ways of coping: "So, accepting is not concretely accepting everything of the voices as they are perceived, but is the beginning of looking differently at them; normalising them; being with many others who hear voices; creating hope and opening personal possibilities" (Romme, 2007, section 3).

The debate surrounding "medicalization" and "normalization" highlights two different concepts that manifest during the management of mental illness. Medicalization is commonly associated with the medical model, having the primary target of attaching a medical label to the presenting symptoms of mental illness and the provision of medications to eliminate them. In this view, success is measured by the level of symptom reduction. Contrastingly, normalization is concerned with ameliorating the individual's quality of life, something not necessarily brought about by the elimination of symptoms. Instead, the overarching philosophy is a focus on personal satisfaction and quality of life. Rather than singling out the symptoms as "abnormalities" that need to be medicated, they are viewed as normal variations within the human population that one can learn to manage and live with using various ways. Whilst medication is not excluded from a "normalization" point of view, it is perceived as a means to enhance quality of life rather than as a permanent end (solution) to a medical problem. On the plus side, normalization has been considered as more enabling and a positive move towards humane care as well as the lessening of stigma by increasing mental health awareness. However, it has also led to a rise in misdiagnoses, misperceptions and higher prevalence rates as a result of people mischaracterizing typical feelings like sadness as depression (Frances, 2010).

Psychologist Rufus May advocates a similar approach to Romme's; May's main focus is to introduce alternatives to medical labeling and management of psychiatric symptoms, particularly, psychosis. In the documentary *The Doctor who Hears Voices,* produced by Regan (2008), May provided an overview of the "voice dialogue technique" that can be used to engage in a therapeutic relationship with a person who is experiencing auditory command hallucinations. He explained that "supporting people in a force-free way through their spiritual and emotional crises takes resources. Not more resources, just a different emphasis in how they are used." (May, 2008, paragraph 11). Such symptoms would normally probably merit an admission to a psychiatric hospital were a mainstream approach to be applied:

> In terms of care for psychosis, force is at the centre of the state's approach to treatment. Neuroleptic drug treatment (under the pseudonym anti-psychotic medication) is presented as the treatment of choice for people with unusual beliefs, behaviours or experiences; Treatment of choice for those who have no choice. Most first admissions to psychiatric hospitals are characterised by a 'try this medication or if you don't we'll have to force you to take it' approach. Maybe we should rename mental health services 'psychiatric drugging services'! (May, 2005, paragraph 18)

Earlier in the 20th century, this phenomenon of medical force had been explored in depth by Parsons (1951) in his book "*The Social System*". His main claim was that social control is present in all social relations – this also

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applies to the doctor-patient relationship during which the doctor acts as an agent of control. In this relationship, the patient assumes the "sick role" and is expected to follow the doctor's guidance to recover. This becomes even more accentuated when an illness is more severe and the individual needs to rely on the doctor's expertise to a higher degree. Since the faking or mismanagement of illnesses can be detrimental to society, the doctor has been given the societal power to be in control of this "deviance" (sickness) and has a duty to assist the patient to return to normality. However, the move towards the 21st century brought with it greater access to information, especially through the virtual world. This has led to individuals who are more knowledgeable and who are ready to challenge medical authority, viewing the doctor-patient relationship as a "provider-consumer alliance" rather than as a sacred bond.

Other leading figures in this area include Sandra Escher (see Escher et al., 2003) who has worked with Marius Romme to produce various publications, Patricia Deegan (see Deegan, 2007), Tamsin Knight (See Knight, 2013) and Peter Lehmann (see Stastny & Lehmann, 2007).

The Recovery Movement and the Person-Centered Approach

Bracken (2012) noted that these controversial approaches may bring about changes in the way that psychiatrists and other professionals are trained since it seems as if the only skill needed to engage with those experiencing mental health challenges is the willingness to listen and to respect the individual. One of the most powerful contemporary movements, which may be viewed as lying midway between the critical psychiatry model and conventional psychiatry one is the *Recovery Model*. Warner (2010) explained that this refers to a focus on self-determination, empowerment, and interpersonal support – a focus on collaboration rather than adherence and compliance. Lieberman et al. (2008) added that educational programs, as well as structures such as user-run services and peer support, are important concepts in the recovery model, which constitutes a bio-psycho-social-spiritual model of care. As stated by Deegan (1996):

> The recovery model is rooted in the simple yet profound realization that people who have been diagnosed with a mental illness are human beings. Those of us who have been diagnosed are not objects to be acted upon. We are fully human subjects who can act and in acting, change our situation. We are human beings, and we can speak for ourselves. We have a voice and can learn to use it. We have the right to be heard and listened to. We can become self-determining. We can take a stand toward what is distressing to us and need not be passive victims of an illness. We can become experts in our own journey of recovery. (p. 92)

Ultimately, this is the spirit within the contemporary move towards a person-centered approach, which focuses on offering care that is personalized, coordinated and enabling whilst treating those seeking care (and their loved ones) as individuals and as equal partners (The Health Foundation, 2014). In the 1940s, Carl R. Rogers pioneered the "person-centered approach" in the United States through his realization that the practitioner's attitudes were just as crucial as his skills (Kirschenbaum, 2020). In this view, therapeutic interactions are potentially successful if the practitioner is able to really embrace the client in the moment, enter the client's frame of reference, and express an empathetic acceptance to the patient. Rogers used the phrase "client-centered" to define his approach to therapeutic interactions as a result of his intensive attention on the client's inner experience. His book "Client-Centered Therapy" (Rogers, 1951) bore a significant impact on the helping professions. In one of his writings, he stated that when a practitioner conveys unconditional positive regard and empathic understanding to the extent that the client feels the professional's genuineness, the "necessary and sufficient circumstances for therapeutic personality change" are present (Rogers, 1957, p. 95). Although Rogers used the term "client-centered", "person-centered" was considered by others as a better phrase to characterize the therapeutic connection, which is, after all, a relationship between two people and not just one (Kirschenbaum, 2020). After Rogers' death in 1987, the person-centered movement continued to spread over the globe and has now become one of the leading approaches to mental health treatment in some countries, particularly in Europe. This approach, and the rise of the recovery movement, provided alternatives to the Medical Model, leading the way to a more humane management of mental illness.

Strengths and Limitations

Whilst quality assurance efforts were employed during the design stage of this narrative account, a number of strengths and limitations characterized the process. The main strengths identified entail the robustness of the search strategy for locating literature on the topic, the critical evaluation of the resulting documents, and the inclusion

of debates emerging from different professional and philosophical viewpoints. Although search keywords were selected to target a wide range of potential articles emerging from different disciplines, it is acknowledged that other potentially important keywords may have been invariably omitted. Finally, whilst the 30-year time span selected was a vital period in the development of contemporary mental health services, important changes that took place during the 1950's could have added further perspective to the debates.

Conclusion, Implications and Future Directions

On reflection, it appears as if the alternative approaches to biomedical psychiatry that have just been described may add an interesting tangent to the range of psychiatric services and treatment options available in the 21st century. However, a paucity seems to exist in the empirical evidence-base related to a number of these approaches, especially when compared to mainstream treatment options such as pharmacotherapy and psychotherapy. This journey through the history of "modern" psychiatric treatment highlights the multifaceted characteristics of mental health and its illnesses, with explanations and treatments lying on a spectrum that features social explanations, biological ones, psychological understandings, and spiritual beliefs. In view of all these considerations, selecting appropriate treatment options depends on feasibility and meaningfulness and not simply on effectiveness and availability. Conclusively, whilst many service providers and health carers claim that their practice stands based on a holistic and person-centered approach, this may not always be the case. This is where the debates and theories that have been explored in the paper may serve as a reflective exercise on the historical debates on mental health care, in a bid to facilitate a critical evaluation of contemporary practice.

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Paulann Grech: conceptualization, design, methodology, investigation, project administration, data management, formal analysis, interpretation, writing original draft, writing review and editing.
Reuben Grech: conceptualization, design, methodology, investigation, formal analysis, interpretation, writing original draft, writing review and editing.
All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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This manuscript is the authors' original work.
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