

SAMUEL O. EBIMGBO, CHIEMEZIE S. ATAMA,
CHINYERE E. ONALU*, INYOMOMA A. OBASI-IGWE
& GABRIEL U. AGHAEDO

PREDICTORS OF LONELINESS AMONG OLDER ADULTS IN SOUTH-EASTERN NIGERIA

Implications for Social Workers**

(Received: 1 March 2020; accepted: 30 November 2020)

Old-age loneliness is a crucial public health issue with mortality consequences as well as other negative health conditions and lifestyles including depression, substance abuse, sedentary lifestyles, and suicide ideation. This study investigated the predictors of loneliness among older adults in Nigeria's southeast in order to articulate some interventions that will plummet the issue. A structured questionnaire (N = 516), in-depth interviews (N = 8), and focus group discussion (N = 16) were used to collect data from respondents aged 60 years or older. The quantitative data sets were subjected to chi-square and binary regression analysis, while a thematic analysis was adopted for the qualitative data. The study's findings show that some demographic factors such as the number of children ($p < .002$), health status ($p < .023$), and social support ($p < .014$), among others, were statistically significant in predicting loneliness among older adults. The study, therefore, recommends the consideration of community-based services to enable elderly adults to buffer the experience of loneliness. Social workers should also influence the various organs responsible for social policies to formulate and promote policies that address the well-being of older adults.

Keywords: loneliness; older adults; social policy; social workers; southeast Nigeria

1. Introduction

Population ageing remains a demographic issue that is prevalent in both developed and developing countries of the world (BÉLANGER et al. 2016). In 2017, estimates

* Corresponding author: Chinyere E. Onalu (M.Sc), Department of Social Work, Faculty of the Social Sciences, University of Nigeria, Nsukka, 410001; chinyere.onalu@unn.edu.ng.

** Ethical considerations: Ethical issues (including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

Conflict of interest: The authors declare that there is no conflict of interest.

show that the world's population of people in the ages of 60 and up stood at 962 million; this number is projected to increase to 2.1 billion by the year 2050 (United Nations Department of Economic and Social Affairs, Population Division [UN DESA] 2017). Similar to developing countries like Nigeria, the ageing population is gradually gaining currency. According to the report of the Population Reference Bureau (2020), Nigeria holds the highest number of people who are 60 years and above in Africa. The report of the UN DESA (2019) shows that the population of Nigerians in this age category is estimated to increase from 9.1 million in 2019 to 11.5 million in 2025, and to 25.5 million in 2050. With this, the population of Nigerian older adults may likely outgrow the total population of some African countries (such as Ghana and Senegal) in the next few years (TOGONU-BICKERSTETH & AKINYEMI 2014). This increase in the population of elderly adults in Nigeria is associated to a great extent with numerous challenges including old-age loneliness because the country lacks well-designed policies that address the well-being of this sub-population.

Old-age loneliness has been documented as an issue of concern many countries are facing across the globe (DAHLBERG & MCKEE 2014; TAUBE et al. 2014). About 12% to 46% of older adults across the globe have reported the experience of loneliness (DAHLBERG & MCKEE 2014; HOLWERDA et al. 2014). Consequently, old-age loneliness has been dubbed a public health problem (Department of Health 2012). As a concept, loneliness lacks a unified acceptable definition, however, thereby generating discrepancies in opinions among scholars (OJEMBE & KALU 2019). For instance, loneliness is described as being or staying alone (VICTOR et al. 2000); also, loneliness is seen as a state of feeling lonely (FOKKEMA & KNIPSCHER 2007). However, despite the variations in conceptualizing loneliness, there is seemingly congruity regarding its impact on individuals, especially older adults (OJEMBE & KALU 2019). Loneliness affects the mental and physical health of the elderly (DAHLBERG et al. 2015; DINAPOLI et al. 2014). It is also a crucial risk factor for developing cardiovascular diseases such as coronary heart disease and stroke (VALTORTA et al. 2016), elevated blood pressure (SHANKAR et al. 2011), and responsible for mortality (LUO 2012). Old-age loneliness also associates with malnutrition, hospital admissions and readmissions, and substance abuse (CACIOPPO & HAWKLEY 2009).

Studies have shown that old-age loneliness is attributed to many factors. For instance, RAHMAN and colleagues (2019) found that gender, marital status, living status, depression, concern about falling, and hearing-visual impairment were found to have an influence on loneliness among Bangladesh's older adults. Also, VALTORTA and HANRATTY (2012) found that age, social environment, driving status, place of residence, and physical or mental health are associated with loneliness. OJEMBE and KALU (2018) equally found that disability, living alone, age, weak family ties, bereavement, poor social networks, and retirement causes old-age loneliness. In China, older adults of 75 years and above, who have a poor education status, are unmarried and living alone, have fair to a poor family and non-family relationships and chronic medical conditions (ZHONG et al. 2018), or are widows (CHEN & FEELEY 2014; CHEN et al.

2014a; CHEN et al. 2014b; GIERVELD et al. 2012) were found to experience more loneliness. Also, in Turkey, ARSLANTAŞ and colleagues (2015) revealed that the presence of diseases and physical handicaps, frequent intake of medication, and lack of hobbies, increased loneliness. Other factors include social support (QUEEN et al. 2014), spouse loss, decreasing functional ability, reduced social relations, and hospitalization (NIEDZWIEDZ et al. 2016; RICO-URIBE et al. 2016; SQUIRES 2015; VALTORTA & HANRATTY 2012). Also, family structure, including living arrangements, not having children, or having a smaller number of children were found to influence older adults' experiences of loneliness (BEUTEL et al. 2017; GRUNDY & READ 2012; KORINEK 2013; VAKILI et al. 2017). Older adults who are economically disadvantaged have been found to be lonelier than older adults who are economically advantaged (BOSMA et al. 2015; PINQUART & SÖRENSEN 2001).

In Nigeria, we reported studies that have investigated old-age loneliness using either qualitative (OJEMBE & KALU 2018; OJEMBE & KALU 2019) or quantitative approaches (IGBOKWE et al. 2020; OJAGBEMI & GUREJE 2019). However, a mixed-method approach adopted by the current study as well as the implication for social workers justifies its importance. The social convoy model was used to structure the study's framework (SHERMAN et al. 2015). Individuals go through life embedded in a personal network of individuals whom they give and from whom they receive social supports. The convoy includes a protective, dynamic network of close social ties that is responsible for the provision of personal, familial, cultural, and even professional supports and linkages for an older adult. In Nigeria, old-age loneliness is occasioned by the increasing urbanization of young family members and modifications in the traditional family system. In the 1970s and 1980s, the Nigerian elderly could boast of having large networks of people including spouses, siblings, in-laws, adult children, and grandchildren, among others, to interact and relate with (OJEMBE & KALU 2018). Communal living was the order in those days and it permitted the coexistence of older adults with other family and community members, thus constant interaction and communication were assured (OLADEJI 2011). With this type of family set-up in times past and the ample interactive relationships among the elderly and their family members, the experiences of loneliness were barely detected. However, older adults may still experience loneliness despite hitherto living together with their family members due to more working wives and their children's education (OKOYE et al. 2017), as well as excessive contact with social media (OJEMBE & KALU 2019).

In lieu of the above, the need for social work professionals becomes imperative. Social workers engage people and the social structures to address life challenges and enhance wellbeing (International Association of School of Social Work [IASSW] & International Federation of Social Work [IFSW] 2014). For those practicing social work, the implications of loneliness are particularly prevalent in the area of adult safeguarding, where practitioners may work with vulnerable adults who are self-neglecting, or who are victims of abuse as a result of lack of social networks (COOK 2017). Thus, social workers improvise preventative measures by identifying ways to engage people, build a network of relationships providing for social support, which

to a great extent will buffer old-age loneliness. They equally provide counselling to older adults whom loneliness affects. They focus on the strengths of older adults to promote resilience in times of loneliness. This they do by building on the resilience that the elderly have developed from coping with previous adversities, and they strive to place self-determination as the central value (The Irish Association of Social Workers' [IASW] Special Interest Group on Ageing [SIGA] 2011).

2. Materials and methods

2.1. Study area

The study was conducted in Nnewi, south-eastern Nigeria. Nnewi is made up of four communities (Otolo, Uruagu, Umudim, and Nnewichi) with an estimated population of 9,186 people (4,805 males and 4,381 females) aged 60 years and older (National Population Commission [NPC] 2010). Nnewi is home to many major indigenous manufacturing industries and other socio-economic activities. Thus, people from different cultural backgrounds reside in the town in order to work, be schooled, engage in trade, and pursue many other activities. Undoubtedly, these activities occupy the young family members daily involving little or no interactions with older adults; this can largely increase the likelihood of loneliness.

2.2. Study sample and sampling

Through accidental sampling, 516 respondents were selected for a quantitative study while 24 participants were selected for qualitative study through snowballing. We purposively selected all of the four communities for fair representation and selected six villages from each of the communities; hence, in all, 24 villages were selected out of a totality of 43. From the six selected villages in each of the three communities (Otolo, Uruagu, and Umudim), we selected 22 older adults because these communities are more populated than Nnewichi, where only 20 respondents were chosen in each of the six selected villages.

Furthermore, eight respondents (four males and four females) were selected for an in-depth interview (IDI) through snowball sampling. Four respondents (two males and two females) were selected from two villages (Otolo and Uruagu), but were not included in the questionnaire. In the same vein, two focus group discussions (FGDs) were conducted with older adults in the remaining two villages (Umudim and Nnewichi). The FGD was made up of one all-male group and one all-female group comprising of eight participants in each group.

2.3. Data types and source

For a high level of precision, thoroughness, and comprehensive insight, a questionnaire, IDI schedule, and FGD guide were used for data collection. We administered

132 questionnaires in Otolu, and administered the same number in Uruagu and Umudim; however, only 120 questionnaires were administered in Nnewichi. With the help of five trained research assistants who came from the area, the questionnaires were administered in the homes of the older adults. The respondents gave their consent before answering the questions and assurances of confidentiality were given to them. The questionnaire was divided into two parts; the first part investigated the demographic characteristics (sex, age, marital status, educational status, occupation, and number of children) while the second part of the questionnaire focused on the experience of loneliness. We adopted the eight-item short measure of the University of California, Los Angeles Loneliness Scale (ULS-8) (HAYS & DIMATTEO 1987) to measure the level of perceived loneliness. The scale was derived from the revised version of the 20-item UCLA (RUSSELL et al. 1980). The choice of adopting the ULS-8 was informed by its high level of validity and reliability (RUSSELL et al. 1980; WU & YAO 2008). The scale, which consists of eight items, allowed the study respondents to rate the degree of loneliness on a four-point Likert scale: (1) Never, (2) Rarely, (3) Sometimes, and (4) Always. The score for the scale ranged from 15 to 60. Higher total scores were perceived as higher levels of loneliness experienced by older adults.

For the qualitative study, the lead researcher moderated the interview and discussion sessions while one of the other researchers served as a recorder and another as note-taker. The IDI schedule and FGD guide contained unstructured questions to enable the stimulation of further queries, which were not included in the interview but stood within the study's scope (see *Table 1*). All the participants were informed and were given an appointment before the exercise to avoid taking them unawares. The discussion sessions lasted for 45 minutes per session while IDIs lasted for about 35 minutes. The discussions for older adults were held in village halls while the IDI with older adults (males and females) were carried out in their various homes. Aside from ascertaining the participants' demographic information, the interview schedule and discussion guide addressed issues related to their experience of loneliness as well as the perceived factors of loneliness among the elderly, such as living arrangements, availability of social support, health status, education and income level, number of children, etc.

Table 1
Focus group discussions guide and in-depth interview schedule

<i>Key questions</i>	
1	Describe the experience of loneliness among older adults.
2	What are the causative factors of loneliness among older adults?
3	What are the impacts of loneliness on older adults?

2.4. Data analysis

The data from the questionnaire were coded, computer-processed, and analysed using version 20 of the Statistical Package for the Social Sciences (SPSS). The independent variables (sex, age, marital status, educational status, etc.) were subjected to a chi-square (χ^2) test with experience of loneliness as the dependent variable at a < 0.05 level of significance. Also, the relationship between sex, age, marital status, educational status, number of children, income level, living arrangements, health status and experience of loneliness were analysed using binary logistic regression at a < 0.05 level of significance. Thematic analysis was adopted for the qualitative study; phrases with contextual connotations were pulled as illustrative quotes.

2.5. Results presentation and discussion

2.5.1. Demographic characteristics of the respondents

The analysis shows that there was an almost equal number of male 50.2% and female 49.8% of respondents as shown in *Table 2*. The greater proportion of them stood at less than 70 years while the majority of the respondents, 63.8%, were married. Also, 95.5%, being the majority, have children while 50.7% had more than six children.

Table 2
Demographic characteristics of the respondents

<i>Demographic data</i>	<i>Frequency</i>		<i>Percentage (%)</i>	
	<i>Quantitative (N = 516)</i>	<i>Qualitative (N = 24)</i>	<i>Quantitative</i>	<i>Qualitative</i>
<i>Sex</i>				
Male	259	12	50.2	50
Female	257	12	49.8	50
<i>Age</i>				
< 70 years	271	8	52.5	33.3
71-80 years	146	11	28.3	45.8
> 81 years	99	5	19.2	20.8
<i>Marital status</i>				
Married	329	16	63.8	66.7
Widowed	118	8	22.9	33.3
Separated	22	0	4.3	0
Divorced	17	0	3.3	0
Single	30	0	5.8	0

<i>Demographic data</i>	<i>Frequency</i>		<i>Percentage (%)</i>	
	<i>Quantitative (N = 516)</i>	<i>Qualitative (N = 24)</i>	<i>Quantitative</i>	<i>Qualitative</i>
<i>Occupation</i>				
None	55	1	10.7	4.2
Farmer	121	2	23.4	8.3
Formerly employed	81	3	15.7	12.5
Trader	190	16	36.8	66.7
Artisan	69	2	13.4	8.3
<i>Education</i>				
None	139	9	26.9	37.5
Primary	110	11	21.3	45.8
Secondary	137	2	26.6	8.3
Tertiary	130	2	25.2	8.3
<i>Number of children</i>				
None	23	0	4.5	0
< 5 children	243	15	47.1	62.5
> 6 children	250	9	48.4	37.5

The demographic characteristics in the qualitative study show equal percentages in gender while the majority (66.7%) were between the ages of 60 to 75 years. Also, the majority (66.7%) were traders while 45.8% completed first school education.

2.5.2. Factors of loneliness among older adults

This section explains the relationship between some selected factors and the experience of loneliness as presented in *Table 3*. Marital status, income level, educational level, number of children, living arrangements, social support, and state of health show a significant relationship with old-age loneliness. About 69.3% of the respondents who are married said they have not experienced loneliness. Also, the respondents (58.3%) with a high income reported less loneliness.

Table 3
Factors associated with the experience of old-age loneliness

<i>Variables</i>	<i>Had Experienced Freq. (%)</i>	<i>Never experienced Freq. (%)</i>	<i>Total</i>	χ^2
<i>Sex</i>				0.327
Male	90(47.4)	169(51.8)	259(50.2)	
Female	100(52.6)	157(48.8)	257(49.8)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Marital status</i>				0.000*
Single/separated/widowed	89(46.8)	100(30.7)	189(36.6)	
Married	101(53.2)	226(69.3)	327(63.4)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Income level</i>				0.016*
Lower income	165(52.6)	256(41.7)	421(81.6)	
Higher income	25(47.4)	70(58.3)	95(18.4)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Educational status</i>				0.008*
Lower education	155(81.6)	94(28.8)	249(75.0)	
Higher education	35(18.4)	232(71.2)	267(25.0)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Having children</i>				0.015*
Have children	176(35.9)	317(60.9)	493(95.5)	
Do not have children	14(64.1)	9(39.1)	23(4.5)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>493(100)</i>	
<i>Number of children</i>				0.000*
Below 5 children	79(41.5)	87(25.9)	166(32.2)	
More than 5 children	111(58.5)	239(74.1)	350(67.8)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Living Arrangement</i>				0.030*
Living with family members	35(39.5)	243(71.1)	118(22.9)	
Not living with family members	155(60.5)	83(28.9)	398(77.1)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>Social support</i>				0.003*
Adequate support	89(31.0)	201(55.4)	290(56.2)	
Inadequate support	101(69.0)	125(44.6)	226(43.8)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	
<i>State of health</i>				0.000*
Health challenge	141(57.6)	36(32.9)	431(100)	
No health challenge	49(42.4)	290(67.1)	85(100)	
<i>Total</i>	<i>190(100)</i>	<i>326(100)</i>	<i>516(100)</i>	

* Association is significant at $p < 0.05$.

Some of the findings were validated by the responses from our qualitative study. For instance, a male respondent in the IDI conducted in Otolu reflected on the significance of income level on old-age loneliness:

'Someone's income determines the extent of the relationship with other people. Some elite families because of their status in society have all the facilities that are required to make one healthy and happy. Also, people always visit them to interact and socialize with them. I recall when we were living at Abakaliki, some of the rich men with large compounds constructed some recreational facilities which attract many people to their homes.'

Also, this following quote reflects the opinion of a female respondent in the IDI conducted in Uruagu:

'The rich always show off and like the saying in my place, "big man talk to big man". They regularly meet together to enjoy and also assist one another. If someone like me goes to a rich man's house, he will say "where does this one come from?" But if a fellow rich person visits, once they see each other and have a need which only money can solve they start solving it immediately.'

The findings also showed a significant association ($P < 0.008$) between educational level and loneliness. Corroborating the information from our qualitative study, a female participant in the FGD conducted in Umudim reflected, *'Someone's education can help to refrain from loneliness because educated people have many connections and contacts, numerous friends either from them or from their children who often visit them'*. Also, a male respondent in the IDI conducted in Otolu said, *'Education gives opportunity to have many friends who can still relate with each other despite being kept afar because of space and time.'*

The findings further revealed a significant relationship ($P < 0.000$) between the number of children and the experience of loneliness. However, this finding contradicted the finding from our qualitative data which indicated that the number of children has no relationship with loneliness. For instance, a participant in the FGD conducted with male older adults at Nnewichi reflected on this as follows:

'The number of children is not necessary for keeping company with older adults. I am saying this because someone may have just one child and he or she feels happy more than someone with numerous children because that only child will always comfort, care and support the parents whereas many children may end up instigating pains in the life of their older parents. The most important thing is how the children are trained.'

2.5.3. Predictors of old-age loneliness

The following constituted the reference categories in the analysis as shown in *Table 4*: being single, with a lower educational status, having fewer than five children, without a monthly stipend, having inadequate social support or family members' awareness, and possessing health challenges. With a Beta coefficient of 0.494.

Table 4
Binary logistic regression analysis predicting old-age loneliness

<i>Independent variables</i>	<i>Beta Coefficient</i>	<i>Level of Significance</i>	<i>Odds Ratio</i>
<i>Marital status</i>	.494	.019*	1.638
<i>Level of education</i>	.724	.016*	2.062
<i>Number of children</i>	.629	.002*	1.879
<i>Monthly stipend</i>	-.155	.452	.857
<i>Living arrangements</i>	-.574	.052*	.564
<i>Social support</i>	-.541	.014*	.582
<i>Health status</i>	-.645	.023*	.525

* Significant at $p < 0.05$.

0.724, 0.629, -0.574, -0.541 and -0.645 respectively: marital status, level of education, number of children, living arrangement, social support and state of health recorded a positive relationship as predictors of the experience of old-age loneliness. The odds ratios for the independent variables are given as 1.638, 2.062, 1.879, .564, .582 and .525. All the variables were statistically significant ($p < 0.05$). However, variables such as income level did not affect the people's feeling of loneliness.

3. Discussion

This study investigated the predictors of loneliness among older adults and the social work implications in south-eastern Nigeria. Marital status was found to stand as one of the factors that influence the experience of loneliness. Married older adults were 69.3% less likely to have experienced loneliness as compared to unmarried older adults (30.7%). Across the globe, to a great extent marriage provides spouses the opportunity for companionship and interaction which buffers loneliness. This finding corroborates the study conducted in the county of Shanghai, China, in which older adults aver that their partners support them by keeping them company and talking with them all the time (CHEN et al. 2014a; CHEN et al. 2014b). In Eastern and Western Europe, however, living with adult children may provide some level of protection against loneliness, but not to the same extent as having a partner or spousal relationship (GIERVELD et al. 2012). Similar findings have been reported in other studies (NIEDZWIEDZ et al. 2016; RICO-URIBE et al. 2016; SQUIRES 2015). This finding strongly suggests the need for social workers who are chiefly involved in the welfare services of individuals, groups, and societies in order to influence government, institutions or organizations that provide welfare services to develop suitable welfare programmes such as community-based services. Considering providing community-based intervention programs such as supplementary care, and day care among others for the elderly in Nigeria will buffer some of the challenges faced by older adults

– especially unmarried older adults. OKOYE (2013) found that community-based services are crucial in helping older adults living alone in their homes, to maintain functionality and achieve successful aging. Community-based services were found to be instrumental in providing elderly adults with some social and emotional benefits that can help to lessen their feelings of loneliness, boredom and solitude, and improve their quality of life (JACOB 2007).

The findings of this study also revealed that the number of children is another factor influencing old-age loneliness. Older adults with a larger number of children, as shown in *Table 3*, were 74.1% less likely to experience loneliness as compared to the older adults with a lower number of children. Among Africans, especially in the south-eastern part of Nigeria, marriage is the most acceptable way of increasing the household size through procreation. Among the south easterners, childless couples and couples with fewer children usually feel dissatisfied and uneasy with life because children are seen as a source of social protection in later life. The finding validates a study in Eastern Europe where several children and grandchildren are associated with positive assessments of one's social relationships, thereby reducing loneliness in old age (KORINEK 2013). In Yazd, Iran, loneliness is more prevalent in older adults who have a smaller number of children because these children act as a source of support to their older parents (VAKILI et al. 2017).

On the contrary, our qualitative study disagreed with the finding above, that is, that a high number of children reduces old-age loneliness. The responses from the qualitative study revealed that the number of children does not determine the feeling of old-age loneliness. Bringing up children remains crucial because a single child with adequate training will eventually grow up to fill the vacuum of many children who possess inadequate upbringing. A popular adage among Igbo south-eastern Nigerians is that *'Ample children without adequate training are equivalent to none'*. Therefore, social workers should create an awareness for the need for couples to give birth to children they can train adequately instead of giving birth to many children without adequate training and thereby culminate in neglect and loneliness during old age. Also, in southeast Nigeria, despite the prevalence of migration and the gradual disintegration of the family system, older adults with a smaller number of children could still confine themselves to other family or community members and activities as a measure in overcoming old-age loneliness. Studies have shown that social and cultural activities in society – such as village meetings, marriage ceremonies, child naming or dedications, funerals, postpartum care – are a veritable means of support to older adults (EBIMGBO et al. 2019). Thus, social workers are needed to encourage older adults to participate in some of these activities in order to reduce their experience of loneliness.

Another finding of the study is that elderly adults' income level determines the extent of their loneliness. Older adults with higher levels of income are 58.3% less likely to experience loneliness than those with lower income levels. The obtained qualitative data have shown that older adults' income determines the relationships they will have with people. People will always visit wealthy families or households

for interaction and socialization. Wealthy families will always have the wherewithal to attract people, social, political, economic or commercial activities, thereby reducing the level of loneliness among their aged members. Similar conclusions validate our finding that older adults who are economically disadvantaged are lonelier than others who are economically buoyantly advantaged (BOSMA et al. 2015; PINQUART & SÖRENSEN 2001). A study by EBIMGBO and colleagues (2020) has revealed that the economic support for Nigerian older adults is poor and uncoordinated. Thus, through lobbying, social workers should facilitate the social security policies that will address the financial wellbeing of older adults in Nigeria. Currently, the bill that provides elderly adults the right to social protection, including income security, has passed the second reading in the Nigerian Senate (OKOYE 2020). Social workers should facilitate legislative actions to transform the bill for the benefit of Nigeria's older adults. Through advocacy, professionals should challenge the non-payment of pension benefits to retirees.

With a Beta coefficient of 0.494, 0.724, 0.629, -0.574, -0.541 and -0.645, marital status, level of education, number of children, living arrangement, social support and state of health were significant in predicting old-age loneliness. Further justifying these findings is the social convoy model (SHERMAN et al. 2015), which posits that people go through life in a personal network of significant others where both support giving and receiving are made possible. Thus, if spouses with adequate education and sound health, remain together with their children and significant others who provide support (health, financial, material etc.), old-age loneliness will be barely experienced. Similar findings were also obtained across other studies (DAHLBERG & MCKEE 2014; DAHLBERG et al. 2015; QUEEN et al. 2014). Thus, the findings suggest the need for professional social workers to embark on mass literacy through educating the populace on the importance of planning for old age. The awareness may include challenges associated with aging, of which loneliness is a part. This will help individuals possess the necessary knowledge to overcome loneliness in old age.

4. Conclusion

The study investigated the factors that predict loneliness among older adults in south-east Nigeria. Loneliness is recognized as a public health problem and also one of the issues of concern that many countries are facing across the globe. Old-age loneliness is responsible for a mental, physical and emotional breakdown in older adults. Loneliness in old age is also a crucial risk factor for cardiovascular disease, coronary heart disease and stroke; it leads to elevated blood pressure, heightened inflammatory and metabolic responses to stress with mortality consequences. From the finding, a majority of the respondents (50.4%) indicated that they have experienced loneliness; whereas some factors such as marital status, income level, state of health, having children, and the number of children, were significant factors of loneliness. Also, some demographic characteristics, including marital status, level of education, social support, number of children, health status, etc., stood as predictors of loneliness among

elderly adults in the study area. This study therefore recommends that community-based services should be introduced in Nigeria in order to enable social workers to have a good interaction with older adults, thereby reducing loneliness in old age. Also, social work professionals in Nigeria have crucial roles to play in order to prevent future occurrences of old-age loneliness. As professionals who promote the social cohesion of people, engaging people and structures to address life challenges and enhance wellbeing, social workers should address old age loneliness through advocacy, negotiation, mediation and brokering. Some countries, such as the United Kingdom, had established the Campaign to End Loneliness in 2011 as a network of national, regional, and local organizations working together to ensure that loneliness is acted upon as a public health priority at national and local levels (Campaign to End Loneliness 2011). Similarly, the New Zealand government has committed itself to a vision of positive aging principles which promote community participation and prevent social isolation (MSD 2001). Nigerian social workers should influence national policies and public campaign programmes that will target tackling old-age loneliness as obtained in the developed countries. Finally, social workers can facilitate the review of Nigerian education policies and systems in order to include the study of older adults in school curriculums at all levels. This will ensure that the study of the elderly cuts across every educational level (primary, secondary, tertiary) so as to help educate the younger ones, family members, and care givers on the process of aging and also to acquire basic knowledge that entails care and support for older adults.

References

- ARSLANTAŞ, H., F. ADANA, F.A. ERGIN, D. KAYAR & G. ACAR (2015) 'Loneliness in Elderly People, Associated Factors and Its Correlation with Quality of Life: A Field Study from Western Turkey', *Iran Journal of Public Health* 44(1), 43–50, retrieved 3 May 2021 from <https://ijph.tums.ac.ir/index.php/ijph/article/view/3729>.
- BÉLANGER, E., T. AHMED, A. VAFAEI, C.L. CURCIO, S.P. PHILIPS & M.V. ZUNZUNEGUI (2016) 'Sources of Social Support Associated with Health and Quality of Life: A Cross-Sectional Study among Canadian and Latin American Older Adults', *BMJ Open* 6, 1–10 (<http://dx.doi.org/10.1136/bmjopen-2016-011503>).
- BEUTEL, M.E., E.M. KLEIN, E. BRÄHLER, I. REINER, C. JÜNGER, M. MICHAL, J. WILTINK, P.S. WILD, T. MÜNZEL, K.J. LACKNER & A.N. TIBUBOS (2017) 'Loneliness in the General Population: Prevalence, Determinants and Relations to Mental Health', *BMC Psychiatry* 17, 97 (<https://doi.org/10.1186/s12888-017-1262-x>).
- BOSMA, H., M. JANSEN, S. SCHEFMAN, K.J. HAJEMA & F. FERON (2015) 'Lonely at the Bottom: A Cross-Sectional Study on Being Ill, Poor, and Lonely', *Public Health* 129(2), 185–87 (<https://doi.org/10.1016/j.puhe.2014.11.016>).
- CACIOPPO, J.T. & L.C. HAWKLEY (2009) 'Perceived Social Isolation and Cognition', *Trends in Cognitive Sciences*, 13(10), 447–54 (<https://doi.org/10.1016/j.tics.2009.06.005>).
- Campaign to End Loneliness (2011) *Safeguarding the Convoy: A Call to Action from the Campaign to End Loneliness*, retrieved 3 May 2021 from <https://www.campaigntoendloneliness.org/wp-content/uploads/Safeguarding-the-Convoy.-A-call-to-action-from-the-Campaign-to-End-Loneliness.pdf>.

- CHEN, Y. & T.H. FEELEY (2014) 'Social Support, Social Strain, Loneliness, and Well-Being Among Older Adults: An Analysis of the Health and Retirement Study', *Journal of Social and Personal Relationships* 31(2), 141–61 (<https://doi.org/10.1177/0265407513488728>).
- CHEN, Y., A. HICKS & A.E. WHILE (2014a) 'Loneliness and Social Support of Older People in China: A Systematic Literature Review', *Health and Social Care in the Community* 22(2), 113–23 (<https://doi.org/10.1111/hsc.12051>).
- CHEN, Y., A. HICKS & A.E. WHILE (2014b) 'Loneliness and Social Support of Older People Living Alone in a County of Shanghai, China', *Health & Social Care in the Community* 22(4), 429–38 (<https://doi.org/10.1111/hsc.12099>).
- COOK, S. (2017) 'Social Work and its Role in Tackling Loneliness', published 27 Oct 2017, retrieved 3 May 2021 from <https://www.plymouth.ac.uk/news/pr-opinion/social-work-and-its-role-in-tackling-loneliness>.
- DAHLBERG, L. & K.J. MCKEE (2014) 'Correlates of Social and Emotional Loneliness in Older People: Evidence from an English Community Study', *Aging and Mental Health* 18(4), 504–14 (<https://doi.org/10.1080/13607863.2013.856863>).
- DAHLBERG, L., L. ANDERSSON, K.J. MCKEE & C. LENNARTSSON (2015) 'Predictors of Loneliness among Older Women and Men in Sweden: A National Longitudinal Study', *Aging and Mental Health* 19(5), 409–17 (<https://doi.org/10.1080/13607863.2014.944091>).
- Department of Health (2012) *The Adult Social Care Outcomes Framework 2013/14*, retrieved 5 May 2021 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/141627/The-Adult-Social-Care-Outcomes-Framework-2013-14.pdf.
- DINAPOLI, E.A., B. WU & F. SCOGIN (2014) 'Social Isolation and Cognitive Function in Appalachian Older Adults', *Research on Aging* 36(2), 161–79 (<https://doi.org/10.1177/0164027512470704>).
- EBIMGBO, S.O., C.N. OBI-KEGUNA, N.E. CHUKWU, C.E. ONALU, S.E. ABONYI & U.O. OKOYE (2019) 'Culture-Based Social Support to Older Adults in Nnewi, South-East Nigeria', *African Population Studies* 33(2), 4891–900 (<https://doi.org/10.11564/33-2-1402>).
- EBIMGBO, S.O., P. AGWU, N. CHUKWU & U. OKOYE (2020) 'Appraising Sufficiency of Financial Support for Older Adults in Anambra State, Nigeria', *Ageing International* 2020 (<https://doi.org/10.1007/s12126-020-09379-6>).
- FOKKEMA, T. & K. KNIPSCHER (2007) 'Escape Loneliness by Going Digital: A Quantitative and Qualitative Evaluation of a Dutch Experiment in Using ECT to Overcome Loneliness among Older Adults', *Aging & Mental Health* 11(5), 496–504 (<http://doi.org/10.1080/13607860701366129>).
- GIERVELD, J., P.A. DYKSTRA & N. SCHENK (2012) 'Living Arrangements, Intergenerational Support Types and Older Adult Loneliness in Eastern and Western Europe', *Demographic Research* 27(7), 167–200 (<http://doi.org/10.4054/DemRes.2012.27.7>).
- GRUNDY, E. & S. READ (2012) 'Social Contacts and Receipt of Help Among Older People in England: Are There Benefits of Having More Children?' *The Journals of Gerontology: Series B* 67(6), 742–54 (<https://doi.org/10.1093/geronb/gbs082>).
- HAYS, R.D. & M. R. DIMATTEO (1987) 'A Short-Form Measure of Loneliness', *Journal of Personality Assessment* 51(1), 69–81 (https://doi.org/10.1207/s15327752jpa5101_6).
- HOLWERDA, T.J., D.J.H. DEEG, A.T.F. BEEKMAN, T.G. VAN TILBURG, M.L. STEK, C. JONKER & R.A. SCHOEVEERS (2014) 'Feelings of Loneliness, but not Social Isolation, Predict Dementia Onset: Results from the Amsterdam Study of the Elderly (AMSTEL)', *Journal of Neurology, Neurosurgery, & Psychiatry* 85(2), 135–42 (<http://dx.doi.org/10.1136/jnnp-2012-302755>).
- IGBOKWE, C.C., V.J. EJEH, O.S. AGBAJE, P.I.C. UMOKE, C.N. IWEAMA & E.L. OZOEMENA (2020) 'Prevalence of Loneliness and Association with Depressive and Anxiety Symptoms among

- Retirees in Northcentral Nigeria: A Cross-Sectional Study', *BMC Geriatrics* 20, 153 (<https://doi.org/10.1186/s12877-020-01561-4>).
- International Association of School of Social Work (IASSW) & International Federation of Social Work (IFSW) (2014) *Global Definition of Social Work*, retrieved 24 April 2021 from <http://ifsw.org/what-is-social-work/global-definition-of-social-work>.
- JACOB, M.E., V.J. ABRAHAM, S. ABRAHAM & K.S. JACOB (2007) 'Effect of Community Based Day Care on Mental Health and Quality of Life of Older in Rural South India: A Community Intervention Study', *International Journal of Geriatric Psychiatry* 22(5), 445–47 (<https://doi.org/10.1002/gps.1706>).
- KORINEK, K. (2013) 'Family Relations and the Experience of Loneliness among Older Adults in Eastern Europe' in S.A. MCDANIEL & Z. ZIMMER, eds., *Global ageing in the twenty-first century: Challenges, Opportunities and Implications* (Burlington: Ashgate) 267–90.
- LUO, Y., L.C. HAWKLEY, L.J. WAITE & J.T. CACIOPPO (2012) 'Loneliness, Health, and Mortality in Old Age: A National Longitudinal Study', *Social Science Medicine* 74(6), 907–14 (<https://doi.org/10.1016/j.socscimed.2011.11.028>).
- Ministry of Social Development (2001) *New Zealand Positive Ageing Strategy* (Wellington: Ministry of Social Policy).
- National Population Commission (NPC) (2010) *Federal Republic of Nigeria 2006 Population and Housing Census: Priority Table Volume IV, Population Distribution by Age & Sex (State & Local Government Area)* (Abuja: National Population Commission) retrieved 6 May 2021 from <https://catalog.ihsn.org/index.php/catalog/3340/download/48521>.
- NIEDZWIEDZ, C.L., E.A. RICHARDSON, H. TUNSTALL, N.K. SHORTT, R.J. MITCHELL & J.R. PEARCE (2016) 'The Relationship Between Wealth and Loneliness Among Older People Across Europe: Is Social Participation Protective?' *Preventive Medicine* 91, 24–31 (<https://doi.org/10.1016/j.ypmed.2016.07.016>).
- OJAGBEMI, A. & O. GUREJE (2019) 'Social Relationships and the Association of Loneliness with Major Depressive Disorder in the Ibadan Study of Aging', *World Social Psychiatry* 2019(1), 82–88, retrieved 24 April 2021 from <https://www.worldsocpsychiatry.org/text.asp?2019/1/1/82/267972>.
- OJEMBE, B.U. & M.E. KALU (2018) 'Describing Reasons for Loneliness among Older People in Nigeria', *Journal of Gerontological Social Work* 61(6), 640–58 (<https://doi.org/10.1080/01634372.2018.1487495>).
- OJEMBE, B.U. & M.E. KALU (2019) 'Television, Radio, and Telephone: Tools for Reducing Loneliness among Older Adults in Nigeria', *Gerontechnology* 18(1), 36–46 (<https://doi.org/10.4017/gt.2019.18.1.004.00>).
- OKOYE, U. O. (2013) 'Community-Based Care for Home Bound Elderly Persons in Nigeria: A Policy Option', *International Journal of Innovative Research in Science, Engineering and Technology* 2(12), 7086–91, retrieved 22 Apr 2021 from http://www.ijirset.com/upload/2013/december/4_Community.pdf.
- OKOYE, K. (2020) 'Bill to Protect Rights, Privileges of Older Persons Passes 2nd Reading at Senate', *NNN News Nigeria*, published 17 March 2017, retrieved 3 May 2021 from <https://nnn.com.ng/bill-to-protect-rights-privileges-of-older-persons-passes-2nd-reading-at-senate/>.
- OKOYE, U., S.O. EBIMGBO & J. ENE (2017) 'Social Work with Older Adults in Nigeria' in U. OKOYE, N. CHUKWU & P. AGWU, eds., *Social Work in Nigeria: Book of Reading* (Nsukka: University of Nigeria Press) 160–171.
- OLADEJI, D. (2011) 'Family Care, Social Services, and Living Arrangements Factors Influencing Psychosocial Well-Being of Elderly from Selected Households in Ibadan, Nigeria', *Education Research International* 2011, Article ID 421898, 1–6 (<https://doi.org/10.1155/2011/421898>).

- PINQUART, M. & S. SÖRENSEN (2001) 'Influences on Loneliness in Older Adults: A Meta-Analysis', *Basic and Applied Psychology* 23(4), 245–66 (https://doi.org/10.1207/S15324834BASP2304_2).
- Population Reference Bureau (2020) *Countries with the Oldest Population in the World*, retrieved 3 May 2021 from <https://www.prb.org/countries-with-the-oldest-populations/>.
- QUEEN, T.L., R.S. STAWSKI, L.H. RYAN & J. SMITH (2014) 'Loneliness in a Day: Activity Engagement, Time Alone, and Experienced Emotions', *Psychology and Aging* 29(2), 297–305 (<https://doi.org/10.1037/a0036889>).
- RAHMAN, S., A. RAHMAN & S. RAHMAN (2019) 'Prevalence and Determinants of Loneliness Among Older Adults in Bangladesh', *International Journal of Emerging Trends in Social Sciences* 5(2), 57–64 (<https://doi.org/10.20448/2001.52.57.64>).
- RICO-URIBE, L.A., F.F. CABALLERO, B. OLAYA, B. TOBIASZ-ADAMCZYK, S. KOSKINEN, M. LEONARDI, J.M. HARO, S. CHATTERJI, J.L. AYUSO-MATEOS & M. MIRET (2016) 'Loneliness, Social Networks, and Health: A Cross-Sectional Study in Three Countries', *PLoS One* 11(1), e0145264 (<https://doi.org/10.1371/journal.pone.0145264>).
- RUSSELL, D., L.A. PEPLAU & C.E. CUTRONA (1980) 'The Revised UCLA Loneliness Scale: Concurrent and discriminate validity evidence', *Journal of Personality and Social Psychology* 39(3), 472–80 (<https://doi.org/10.1037//0022-3514.39.3.472>).
- SHANKAR, A., A. MCMUNN, J. BANKS & A. STEPTOE (2011) 'Loneliness, Social Isolation, and Behavioral and Biological Health Indicators in Older Adults', *Health Psychology* 30(4), 377–85 (<https://doi.org/10.1037/a0022826>).
- SHERMAN, C.W., W.H. WAN & T.C. ANTONUCCI (2015) 'Social Convoy Model' in S.K. WHITBOURNE, ed., *The Encyclopedia of Adulthood and Aging* 1–5 (Hoboken: Wiley) (<https://doi.org/10.1002/9781118521373.wbeaa094>).
- SQUIRES, S.E. (2015) 'To a Deeper Understanding of Loneliness amongst Older Irish Adults', *Collegium Antropologicum* 39(2), 289–95.
- TAUBE, E., J. KRISTENSSON, M. SANDBERG, P. MIDLÖV & U. JAKOBSSON (2014) 'Loneliness and Health Care Consumption among Older People', *Scandinavian Journal of Caring Sciences* 29(3), 435–43 (<https://doi.org/10.1111/scs.12147>).
- The Irish Association of Social Workers' (IASW) Special Interest Group on Ageing (SIGA) (2011) *The Role of the Social Worker with Older Persons*, retrieved 3 May 2021 from <https://www.iasw.ie/download/367/d82b4fe7-b766-4792-83d7-75eefb001b6c.pdf>.
- TOGONU-BICKERSTETH, F. & A.I. AKINYEMI (2014) 'Ageing and National Development in Nigeria: Costly Assumptions and Challenges for the Future', *African Population Studies* 27(2), 361–71 (<https://doi.org/10.11564/27-2-481>).
- United Nations Department of Economic and Social Affairs, Population Division (2017) *World Population Ageing 2017 – highlights* (ST/ESA/SER.A/397) retrieved 6 May 2021 from https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Highlights.pdf.
- United Nations Department of Economic and Social Affairs, Population Division (2019) *World population prospects 2019*, retrieved 3 May 2021 from <https://population.un.org/wpp/Data-Query/>.
- VAKILI, M., M. MIRZAEI & M. MODARRESI (2017) 'Loneliness and its Related Factors among Elderly People in Yazd', *Elderly Health Journal* 3(1), 10–15, retrieved 22 April 2021 from <http://ehj.ssu.ac.ir/article-1-74-en.pdf>
- VALTORTA, N. & B. HANRATTY (2012) 'Loneliness, Isolation and the Health of Older Adults: Do we Need a New Research Agenda?' *Journal of Royal Society and Medicine* 105(12), 518–22 (<https://doi.org/10.1258/jrsm.2012.120128>).

- VALTORTA, N.K., M. KANAAN, S. GILBODY, S. RONZI & B. HANRATTY (2016) 'Loneliness and Social Isolation as Risk Factors for Coronary Heart Disease and Stroke: Systematic Review and Meta-Analysis of Longitudinal Observational Studies', *Heart* 102(13), 1009–16 (<http://dx.doi.org/10.1136/heartjnl-2015-308790>).
- VICTOR, C., S. SCAMBLER, J. BOND & A. BOWLING (2000) 'Being Alone in Later Life: Loneliness, Social Isolation and Living Alone', *Reviews in Clinical Gerontology* 10(4), 407–17 (<https://doi.org/10.1017/S0959259800104101>).
- WU, C.-H. & G. YAO (2008) 'Psychometric Analysis of the Short-Form UCLA Loneliness Scale (ULS-8) in Taiwanese Undergraduate Students', *Personal Individual Differences* 44(8), 1762–71 (<https://doi.org/10.1016/j.paid.2008.02.003>).
- ZHONG, B.L., X.J. LIU, W.C. CHEN, H.F.K. CHIU & Y. CONWELL (2018) 'Loneliness in Chinese Older Adults in Primary Care: Prevalence and Correlates', *Psychogeriatrics* 18(5), 334–42 (<https://doi.org/10.1111/psyg.12325>).

JAANA KRANTZ, MADELEN ERIKSSON & MARTIN SALZMANN-ERIKSON*

EXPERIENCES OF BURNOUT SYNDROME AND THE PROCESS OF RECOVERY

A Qualitative Analysis of Narratives Published in Autobiographies**

(Received: 6 August 2020; accepted: 20 April 2021)

Burnout syndrome limits work capacity and the ability to manage a social and family life. Such limitations may lead to alienation from oneself and can result in frustration and anger. The recovery process may include a search for quick fixes from professionals but responsibility is in the hands of the ill with support from professionals, family, and work. Learning about limitations, the need to rest and accepting illness, are vital in the recovery process, but they are also associated with feelings of shame and blaming oneself for causing one's own burnout by neglecting bodily signals.

Objective: Burnout syndrome affects the individual as a whole because it involves emotional exhaustion, depersonalization, and a low sense of personal accomplishment. Research into burnout syndrome has predominantly focused on treatment outcomes measured using quantitative methods. The existing qualitative research has deepened theoretical insights from a lifeworld perspective, although, methodologically speaking, previous qualitative studies have been restricted to interviews. The qualitative interview method is somewhat limited. Hence, the objective of the present study was to analyze how autobiographers narrate their experiences of burnout syndrome and to describe their recovery process.

Design: An inductive qualitative approach with a descriptive design was used to gain insights into the authors' experience of burnout and recovery process, as expressed in writing.

* Corresponding author: Martin Salzmänn-Erikson, R.N., PsychNurse, PhD., Associate Professor in Nursing, Faculty of Health and Occupational Studies, University of Gävle, 80176 Gävle, Sweden; martin.salzmänn@hig.se

** Author Contribution: All three authors were engaged in the design of the study, Jaana Krantz and Madelen Eriksson were responsible for data collection, data analysis and formulating the results. Martin Salzmänn-Erikson was responsible for writing the article and contributed critical reflections throughout the process.

Funding and Disclosures: The study did not receive any funding and ethical approval was not necessary. The authors report no conflict of interest.

Ethical Considerations: Because this research is not considered human subjects research, vetting by an ethics board was not necessary.

Setting/Subjects: The data comprised six autobiographies written by authors from Sweden.

Results: The results are presented in three categories: 1) descriptions of estrangement from one's own body, 2) descriptions of how the phenomenon is manifested in everyday life, and 3) descriptions of recovery processes.

Conclusion: Burnout syndrome intersects both work life and family life and reveals the individual as a whole, integrated being. It is vital for healthcare professionals to adopt a person-centered approach that sees the individual as an integrated whole, consisting of body, mind, and soul.

Keywords: burnout syndrome; health behavior; narrative; qualitative research; recovery; work-life balance

1. Introduction

The term 'burnout' was coined in the mid-1970s (FREUDENBERGER 1974; SCHAUFELI et al. 2009). The onset of burnout syndrome marks a protracted process that involves diffuse symptoms in three areas: emotional exhaustion, depersonalization/cynicism, and low sense of personal accomplishment (MASLACH et al. 2001). Burnout is closely linked to work-life environments, and correlated factors have been emphasized in previous research; for example, job demands, a sense of individual control at work, and social support from colleagues and managers (BAKKER & COSTA 2014; HÅKANSSON & AHLBORG 2017; LINDEBERG et al. 2011). Other significant variables are, for example, role conflicts and work role ambiguity (PIKÓ & MIHÁLKA 2017). Our assumption is grounded in integrative nursing and the unitary paradigm, which posit that human beings are whole systems, inseparable from their environments (KOITHAN et al. 2017). Based on the reflection that burnout syndrome affects the whole human being, in the present article, we have analyzed narratives written in the first-person perspective, as presented in autobiographies.

2. Background

SCHAUFELI (2018) investigated burnout in 35 European countries based on a random sample of almost 44,000 individuals. In that study, it was reported that in countries where the levels of burnout are high, people are less happy, feel less engaged at work, and are less satisfied with their jobs. In relation to those results, the study also stressed that higher levels of burnout were found in countries where work was considered to be highly valued and important. In an earlier paper, SHANAFELT and colleagues (2015) examined the prevalence of burnout and satisfaction with work-life balance among physicians. They reported that only 41% of participants felt that their work schedule left enough time for personal and family life. Similarly, other studies have also shown that work-related stress affects family and social life (HÅKANSSON & AHLBORG 2017; OSHIO et al. 2017). Moreover, a systematic review showed that the development of emotional exhaustion is more likely to be seen among individuals with jobs that involve high demands and service-related professions (SEIDLER et al. 2014). Healthcare staff are exposed on a daily basis to stressful situations, not only

due to high workload, but also because they cannot control patient flows, patients' rapidly deteriorating health and moral distress. Hence, many publications have investigated burnout among physicians (ROTENSTEIN et al. 2018), nurses (CAÑADAS-DE LA FUENTE et al. 2015), midwives (CREEDY et al. 2017), physiotherapists (PAVLAKIS et al. 2010), social workers (HRICOVÁ et al. 2020) and dentists (JIN et al. 2015).

Cross-sectional studies, longitudinal studies, and meta-analyses have led to important insights into the theoretical body of knowledge on burnout regarding, for example, prevalence and risk factors (ALARCON et al. 2009; GARROSA et al. 2011; MASLACH et al. 2001). However, considerably fewer studies have investigated burnout from a life-world perspective: the narrative of subjective experiences. Results from some qualitative studies have deepened our understanding of how individuals experience burnout from a first-person perspective. KAVALIERTOS and colleagues (2017) interviewed staff in palliative care about their experiences of burnout and how its symptoms affected their work with patients. Another qualitative study by SALMINEN et al. (2015) analyzed interviews to describe experiences of what participants considered to be beneficial to their recovery in burnout rehabilitation. Clients' insights into being responsible for their own well-being was a key finding, seen in metaphors such as 'my well-being in my own hands'. Moreover, ARMAN and colleagues (2011) adopted a hermeneutic approach and interviewed 18 people about their burnout experiences. They demonstrated the burnout crossroads in terms of a collapse: 'The breakdown is often experienced as a release. Suddenly, or in due time, the person enters a sphere of "disarming" or "leaving the scene".' (ARMAN et al 2011, 299).

Burnout rehabilitation falls into three categories: person-directed interventions, organization-directed interventions, or a combination of both intervention types (AWA et al. 2010; BORZA et al. 2012; PETERSON et al. 2008). Person-directed interventions focus on teaching the individual to recognize stressors and use coping techniques; for example, relaxation. Organization-directed interventions are more focused on changing the working environment and preconditions (MARINE et al. 2006). Regarding the reduction of emotional exhaustion, a review study on job burnout in mental health providers found that person-directed interventions were more effective than organization-directed interventions (DREISON et al. 2018). However, many studies have looked at the combination of these two approaches (BORZA et al. 2012; WESTERMANN et al. 2014). Care models in healthcare have undergone changes during the past fifty years in terms of philosophies and approaches; the transition has gone from being medically oriented, to patient-centered, and further to the contemporary approach of person-centered care (LOUW et al. 2017). Key features of the person-centered approach are to take the perspective of the patients' own beliefs and values (MCCORMACK & McCANCE, 2006) and to increase their agency (BANDURA 2000). Hence, the person-centered approach presupposes a shift in positions in which the care-provider needs to be skilled in effective communication so as to facilitate partnership and strive toward health promotion (CONSTAND et al. 2014). Thus, MCCORMACK and McCANCE (2006) emphasized the areas of sympathetic presence, engagement, sharing decision-making to create a therapeutic culture, providing a feeling of well-being and, thus,

promoting satisfaction with care. In summary, the bulk of the previous research has investigated burnout syndrome and treatment using quantitative methods, while some qualitative seminal works have deepened our insights through the analysis of interview narratives. However, the qualitative interview method is somewhat limited (ATIENO 2009). In the present inquiry, the aim was twofold: to analyze how autobiographers narrate their experiences of burnout syndrome and to describe their recovery process.

3. Methods

3.1. Design

We used an inductive qualitative approach that was adapted using a descriptive design (CRESWELL & POTH 2018), as we wanted to gain insight into people's experiences of burnout. The inductive approach was chosen because we wished to analyze the data without a theoretical filter. However, given our own previous theoretical knowledge and experiences of encountering patients with burnout syndrome as nurses, we acknowledge that it is not possible to fully set aside our pre-understandings. However, through internal discussions, we tried to illuminate our experiences and pre-understandings to better understand how these might impact the analysis. Our underlying epistemological assumptions are in agreement with SHAPIRO (2011), who stated that 'A patient's story is rarely "just a story," but is rather the conscious and unconscious representation and performance of intricate personal motives and dominant meta-narrative influences' (SHAPIRO 2011, 68).

3.2. Sample

In accordance with the qualitative approach and the purpose of the review, we chose to use a purposive sample. The inclusion criteria were: autobiographical books of a minimum of 100 pages, written in the first person, and recently published. Because our first language is Swedish, we wanted to include books written in Swedish or translated into Swedish. Considering the cultural variation across societies, we wished to include a rather homogeneous sample and, hence, restricted it to experiences from Europe, although to achieve heterogeneity in the sample, which is desirable in qualitative studies, we included books written by both men and women who have varying life histories, ages, and occupations (see *Table 1*).

Table 1
The analyzed autobiographies

<i>Title</i>	<i>Author</i>	<i>Year</i>	<i>Pages</i>	<i>Profession</i>	<i>Family</i>
Dare to be afraid: A book about burnout syndrome (Swedish title: <i>Våga vara rädd - en bok om utmattningssyndrom</i>)	Emma Holmgren	2015	154	Division head & student	Married & two children
Burnout: The way back as a person and an athlete (Swedish title: <i>Utbrändheten: och vägen tillbaka som människa och idrottare</i>)	Marcus Streiffert	2015	151	Business student & elite cyclist	Parent
Don't feed the monkey: My way out of burnout syndrome (Swedish title: <i>Mata inte apan: min väg ur ett utmattningssyndrom</i>)	Pia Andersson	2016	148	Child educator	Married & two children
An end, a beginning: A psychiatrist's thoughts about his own burnout syndrome (Swedish title: <i>Ett slut: en början - en psykiatrikers funderingar kring sitt utmattningssyndrom</i>)	Niklas Nygren	2017	144	Psychiatrist	Married & two children
With my bravery: Getting through burnout syndrome (Swedish title: <i>Med mitt mod genom utmattningssyndrom</i>)	Eva Svärd	2017	175	Entrepreneur & advisor	Married & two children
Help, I'm burned out (Swedish title: <i>Hjälp jag är utmattad</i>)	Clara Lidström & Erica Dahlgren	2018	190	Blogger/author Journalist/Swedish Public Radio	Married & two children Married & two children

3.3. Data collection

A thorough, but not systematic, search was conducted for books in library search engines, bookstores and on Google (www.google.se). The main Swedish key words were 'utmattning', 'utmattningssyndrom', 'utbränd' [burnout, burnout syndrome]. Books could be included even though a key word was not in the book title. We found 13 books that we considered as highly relevant to our purpose. Seven books were excluded from the first review: one was written by a journalist, two were a collection of poetry, two were shorter texts without a coherent narrative, one did not correspond to our purpose and the final excluded book was a self-help book. After excluding the seven books, we held a discussion and reached the conclusion that the remaining six books were all relevant to our study purpose and they met the inclusion criteria (described in the Sample heading). To further review the six books, we read ten pages from each book, some pages from the beginning, some from the middle, and some from the end. This final review was not determined by any specific criteria but rather formed a basis for a final decision, based on a consensus arrived at from joint

discussions. The strategy of reading parts of the books while thinking of the study's purpose verified that all the books were relevant to the aim of the review. After the final review of the books' relevancy, the entirety of the books were read.

3.4. Data analysis

The process of analysis followed the steps described by GRANEHEIM and LUNDMAN (2004). Thus, the first two authors initially read the six books as a whole individually twice to get an overview of the content. Then, both authors extracted shorter paragraphs and quotes relevant to the aim. These excerpts were the first units in our analysis, called 'meaning units' (see *Table 2*). GRANEHEIM and LUNDMAN define meaning units as 'constellation of words or statements that relate to the same central meaning' (2004, 106). Since meaning units are wordy, these were reduced in size without losing their quality (see the second column in *Table 2*). During this process, the condensed meaning units were discussed between all three authors. The condensed meaning units were large, and to analyze the data the text was abstracted, although without losing its intended meaning. The goal was to identify codes that described experiences of burnout syndrome and the autobiographers' recovery process. All the abstracted extracts were given a code. Next, codes were reviewed and discussed, allowing us to identify patterns in the plethora of codes. These patterns formed tentative subcategories. From the discussions and illustrations that emerged while using a white-board, subcategories were grouped into more abstracted pattern structures. To establish the credibility of the analysis, we critically reviewed how the subcategories were related to their over-arching category. Furthermore, we critically reviewed the internal homogeneity within each subcategory and the external heterogeneity between subcategories and categories. To establish transparency in the analysis, *Table 2* illustrates the analytic process of abstraction from meaning units, condensed units, codes, subcategories, and categories. In addition, *Figure 1* is an overview of the distribution of meaning units per category for each book. For example, in NYGREN's (2017) book, we found 110 meaning units in total. All three categories (see Result) were represented, and almost equally distributed. In comparison, in STREIJFFERT's (2015) book, the second category – descriptions of how the burnout manifests itself in everyday life – was identified to a lesser extent, while STREIJFFERT elaborated more voluminously on describing the estrangement of one's own body and the recovery process.

Table 2
Examples of the analyzed data

<i>Meaning units</i>	<i>Condensed meaning units</i>	<i>Codes</i>	<i>Subcategories</i>	<i>Categories</i>
When I eat, I eat. When I take a walk, I take a walk. When I'm with my kids, I'm with my kids. I keep my attention more on what is actually happening in life.	When I eat, I eat. When I take a walk, I take a walk. When I'm with my kids, I'm with my kids. My attention is on what is actually happening.	Being in the here and now.	Acceptance and learning about rest and recovery.	<i>Description of recovery processes</i>
While sick-listed I went to meditation one evening a week. I found a calm place there among others who also needed a moment of peace and quiet. A feeling of community was created in the silence.	Went to meditation. Found a calm place among others who needed peace and quiet. Created community in silence.	Stillness and quiet.	The healing power of nature and activity.	
In our first meeting, the insurance office asked if my kids were a burden or relief regarding my burnout. To me both are true, and feeling that way feels horrible. Naturally they give me enormous joy, but it's hard to be strong for my kids when I feel so small on the inside	The insurance office asked if my kids were a burden or relief. To me both are true, and feeling that way feels horrible. They give me great joy, but it's hard to be so small on the inside when I want to be strong.	Experiencing that one's children can be a burden.	Limited ability to maintain social relationships.	<i>Description of how the phenomenon manifests itself in everyday life</i>
One change I made early on was to create good routines and try to structure my days.	Create good routines and try to structure one's days.	Work toward a sustainable future, structure and routine.	Strategies and adjustments in everyday life.	
I did not take sick leave, but was back at work the next day. That is what it is like to be Superman. Little did I know that my strength was also my kryptonite.	I did not take sick leave, but was at work the next day. That's how it is to be Superman. My strength was also my kryptonite.	Narrow-mindedness made my strength my weakness.	The body's signals and disobedience.	<i>Description of alienation over one's own body</i>
Long before I got fatigue syndrome written in my medical certificate, I was sick in the body. Finding balance again has been, and still is, an ongoing process that takes much longer than I could have imagined.	Long before I got fatigue syndrome written in my medical certificate, I was sick in the body. Finding balance again is an ongoing process that takes much longer than I could have imagined.	The feeling that something is wrong in the body comes long before the diagnosis.	Bodily resistance	

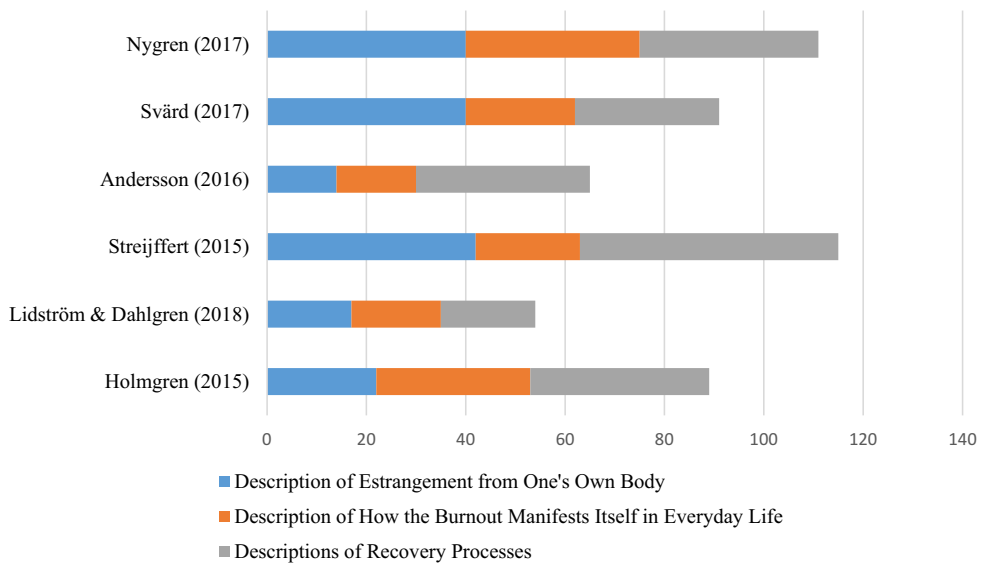


Figure 1

Overview of the distribution of meaning units per and category for each book

4. Results

The results are presented in three categories: 1) descriptions of estrangement from one's own body, 2) descriptions of how the phenomenon is manifested in everyday life, and 3) descriptions of recovery processes.

4.1. Descriptions of estrangement from one's own body

The body's signals and disobedience. All authors described the insidious signals of being constantly tired. Even though the brain was malfunctioning, they pushed themselves at high speed, resulting in feelings of exhaustion and a complete lack of energy. Other bodily signals were also described, such as a weakened immune system, headaches, numbness, shaking, and a sense of being cold in the extremities as well as a hot feeling in the head; also described were certain cognitive perceptions and the ability to focus on tasks. When the brain went on strike, they described a passivization of the body that they were not able to control. The feelings of no longer being able to control their own bodies they described as shocking. All of them described the body's signals and disobedience as being so strong that they wished they had been affected by a visible, physical illness instead of this bodily devastation (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017;

STREIFFERT 2015; SVÄRD 2017). Even though signals of burnout were imminent, one author wrote about her last attempts to override the signals by pushing herself.

I don't feel like I've walked or run into a wall, but like I'm still running and pushing the wall in front of me. It feels like I'm going to keep running, and if I just run a bit farther, I'll be able to run through the wall and come out on the other side. If I just try harder. If I just run faster. If I just go into a higher gear. (SVÄRD 2017, 19)

Perception and vulnerability to stimuli. The authors described a loss of patience and a crippling fatigue regarding all cognitive impressions. During the worst phases, everything was described as a struggle in quotidian life, such as the sound of a fan, background chatter, and the sound of traffic (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). NYGREN'S book depicted the inability to shut out cognitive impressions: 'It's like my filter function is gone or impaired. I can't "turn off" the sound around me' (2017, 95).

Emotional and mental imbalance. The physical symptoms began to slowly affect their brains, including increased memory loss and the feeling of no longer being able to function in social situations. The feeling of losing oneself led to anger and to constant feelings of inadequacy, worthlessness and failure, resulting in the feeling that everyday life was somehow unrealistic (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). Moreover, they described being very sensitive to setbacks; LIDSTRÖM and DAHLGREN (LIDSTRÖM & DAHLGREN 2018) recounted the desire to be helped by higher powers to relieve anxiety and to feel hope for the future.

4.2. Descriptions of how the burnout manifests itself in everyday life

Feelings of restrictions in everyday life. Several of the authors described an ambitious personality that has always existed, ever since childhood. The feeling of no longer being able to perform in the same way as before also caused the feeling of losing part of one's identity. The disease made them unable to perform the most basic tasks in everyday life, and they narrated the insidious insight that they had prioritized the needs of others while ignoring their own needs (ANDERSSON 2016; HOLMGREN 2015; NYGREN 2017; STREIFFERT 2015). Even the most basic needs and tasks were affected and sometimes neglected. The authors described how they were restricted in doing household tasks, such as watering flowers and cleaning. Being restricted in this way aroused feelings of shame. Upon reflection, maintaining a well-polished veneer was a contributing factor to the burnout syndrome. The 'invisible disease' and the expectations of those around them contributed to more demands, and the setbacks came more often than before. All attempts to overcome the restrictions, by keeping up with everyday tasks, led them deeper into the old behaviors that had caused the disease (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017).

Limited work capacity. The authors reported that work had been closely tied to their identities, resulting in a strong sense of responsibility and duty to work and colleagues. As a consequence of the severe symptoms, they went on sick leave, which physically separated them from work. Sick leave was perceived as somewhat transient. They conceived of themselves as irreplaceable at work, resulting in their continuing to work despite the symptoms (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017).

Limited ability to manage a social and family life. Maintaining social relationships while being affected by burnout was described as complex. Because they did not recognize themselves anymore, they feared that relatives would abandon them. Moreover, that same alienation from oneself could result in anger, which was sometimes directed toward relatives; this increased the fear of being abandoned, resulting in both fear and anxiety (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). Several authors described withdrawing themselves from social gatherings in general, but their social relationships with family members were also affected. Authors who had children described the problems they faced, for example NYGREN wrote: 'Being a parent puts demands on you that you can't escape through sick leave' (2017, 44). As a result of the burnout, the authors described experiences of emotional storms that affected their ability to be present and participate in family life. Due to their restricted ability to operate at full pace, they described feelings of frustration over family-related insufficiency and the need to live life at a much slower pace, thus leading to conflicts within the family. Moreover, there were narratives of feeling that the children were a burden and of not being able to give them love and care. They reported that the children had to take more responsibility, which led to feelings of guilt and a sense that they needed to compensate for their shortcomings.

Strategies and adjustments in everyday life. One recurring statement concerned the need to establish routines and structure in everyday life (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). One strategy was to verbalize or write about their feelings (NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). Additionally, setting boundaries they described as important, as was daring to say no (ANDERSSON 2016; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). Professional training in stress management was helpful in finding strategies to adjust everyday life (ANDERSSON et al. 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). NYGREN described this as follows:

The situation can be likened to carrying a backpack that officially weighs 15 kg, but that is constantly being filled with unofficial extra weight. Weight that doesn't count when the total burden is determined... Taking a course on working more efficiently might help me pack my backpack in a smarter way. Still, it's the same weight. (2017, 22)

4.3. Descriptions of recovery processes

Professional and non-professional support. Reassuringly, the authors described their need for support from healthcare professionals during their process of recovery. The way professionals approached them was considered important. They claimed that professionals who gave them time and included them in care plans increased their self-esteem and self-confidence (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; STREIFFERT 2015; SVÄRD 2017). Initially, they reported having wanted quick fixes from professionals, but along their path to recovery, they realized they were being given tools to help them rebuild a sustainable quotidian life (ANDERSSON 2016; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). Even though professional support was necessary, the sense of having a home and the behaviours physical presence of their family both strongly supported the recovery process. Support from relatives and everyday life's maintenance promoted the possibility of rest (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; SVÄRD 2017).

The healing power of nature and engagement in activities. Being out in nature became an important part of the recovery process. All of the authors described nature as offering opportunities to leave the outside world, and to think and reflect without external disturbances. Being alone with one's thoughts they considered vital to the recovery process (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017). HOLMGREN (2015, 122) put it like this: 'I see the things around me in another way; I can pause in the natural environment and become fascinated with a bumble bee collecting nectar from my currant bush.' Thus, spending time in nature and engaging in spontaneous activities, such as photographing, drinking coffee, or picking mushrooms, gave a sense of harmony and allowed one to rest both body and mind. Likewise, exercising by walking and exercising in general was said to benefit their recovery process as a way to reconnect with the body (ANDERSSON 2016; HOLMGREN 2015; NYGREN 2017; STREIFFERT 2015). Other kinds of group activities, such as yoga and meditation, were reported to have positive effects on their well-being and giving a feeling of community. Mindfulness and the realization that it was the brain that needed to rest, not the body, reoccurred upon awakening, and it became easier to accept one's current mood and facilitated the ability to take command of the illness (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; SVÄRD 2017).

Acceptance and learning about rest and recovery. The authors described a correlation between insights, learning about their need to rest and accepting the disease. However, accepting the disease was sometimes associated with feelings of shame and blaming oneself for causing the burnout to oneself by neglecting bodily signals. SVÄRD described such learning and growth in awareness as follows:

It's true that actually, despite my burnout, I'll have a passion for things my whole life, but thanks to my burnout syndrome, I'll be responsible and turn down the passion a bit, in everyday life, every day, taking care that I recover properly and regularly. (2017, 25)

Recovery was described as a non-linear process that included both progress and recession, which some authors found to be a tough experience. Having been burned out stood depicted as one of the most demanding events in life, but with these new experiences, they believed they were more prepared for the rest of their life (ANDERSSON 2016; HOLMGREN 2015; LIDSTRÖM & DAHLGREN 2018; NYGREN 2017; STREIFFERT 2015; SVÄRD 2017).

5. Discussion

The aim of the present study was to analyze how autobiographers narrate their experiences of burnout syndrome and to describe their recovery process. As mentioned in the literature review, burnout syndrome is a protracted process that manifests itself in emotional exhaustion, depersonalization, and a low sense of personal accomplishment (MASLACH et al. 2001). This also accords with our findings in that the authors clearly described an estrangement from their bodies in terms of bodily/corporal signals, being sensitive to stimuli and emotional imbalance. As we report in the findings, the symptoms of burnout encompass the whole person, and the inability to function as they had previously remains a highly restricting factor in their everyday life. In line with the unitary paradigm and a holistic perspective on the human being, the individual is a whole system that cannot be separated from their environment (FRISCH & RABINOWITSCH 2019; KOITHAN et al. 2017). Moreover, the principles of integrative nursing contend that human beings possess an innate capacity for health and wellbeing, and our results showed that one main barrier to be overcome was accepting the burnout syndrome and accepting the way its symptoms controlled and limited quotidian life, both in work and family. All of the authors had demanding jobs that included responsibility and required daily human interactions; they all felt they had to perform at the highest level. The results showed that their work gave them energy, and that this made them work even more. As previously mentioned, demanding jobs constitute a risk factor for burnout syndrome as performance is constantly in focus, being measure of ambition level (ARMAN et al. 2011). The job was seen as a risk factor no matter how the individuals loved their jobs – in fact, there was often a sense of inadequacy and a sense of duty linked to work. Therefore, many see the work as a contributing cause of their burnout (ARMAN et al. 2011). In addition to our findings regarding the narratives, we emphasize the importance of managers taking into account factors associated with burnout syndrome in the workplace when designing and reformulating workers' job descriptions; these factors include the level of job control, resources of recognition, feedback and participation (SCANLAN & STILL 2019).

We argue that with an awareness of these problems, managers can intervene via being sensitive to early warning signs exhibited among workers. For example,

a decrease in cognitive ability means a decrease in efficiency. In one study, psychiatrists' limitations at work were investigated as a result of initial burnout syndrome; it was shown that the number of patient visits was reduced and that psychiatrists were not working as effectively (GÜL et al. 2017). In our study, we presented similar findings in terms of how the authors described the loss of interest in their jobs, or how simple tasks could become overwhelmingly difficult. Moreover, similar descriptions are supported by several studies demonstrating that job dissatisfaction contributed to poorer health and well-being, but also in the long term to prolonged sick leave and negative impact in the recovery process (HÅKANSSON & AHLBORG 2017; HANSSON et al. 2006; HOLMGREN et al. 2009; LINDEBERG et al. 2011; MAGNUSSON HANSON et al. 2008; OSHIO et al. 2017). Hence, we argue that managers who adopt a preventive strategy may benefit their companies economically via enhanced employee workplace satisfaction and increased health.

For those experiencing burnout, the results emphasized the personal economic aspect in relation to fighting for employees' right to be on sick leave and receive compensation from the Social Insurance Office. Studies have shown that burnout-related economic stress affects family life negatively – both in social interactions and income (HÅKANSSON & AHLBORG 2017; HANSSON et al. 2006; HOLMGREN et al. 2009; LINDEBERG et al. 2011; MAGNUSSON HANSON et al. 2008; OSHIO et al. 2017).

Moreover, our results showed that the authors' attitudes toward family life were ambiguous. The family is held to be their main support and source of happiness, but at the same time, the presence of family members may also force the person to interact with others. One study from England examined how the pressure to be the perfect mother affects career and fatigue. These mothers were often highly educated and therefore had high career ambitions, which were seen as two risk factors for burnout (MEEUSSEN & VANLAAR 2018). Our results showed a continuous pattern of high ambitions and careers balanced with a well-functioning family life, where all individuals but one were married and had two children. In connection with fatigue syndrome, both career and family life broke down, and during the recovery process, they had to work to rebuild both parts from the ground up, but with different conditions and goals.

Little qualitative research has been done on burnout, although various research groups from both Finland and Sweden have collected data on the lived experiences of burnout through interviews (ARMAN et al. 2011; JÄRVIKOSKI et al. 2013; SALMINEN et al. 2015). These qualitative studies have further added an understanding of the lived experiences of suffering from burnout syndrome and the process of rehabilitation and recovery. Many similarities exist between those studies' results and the results presented here. Hence, at a thematic level, we were not able to add any new dimensions to our understanding of lived experiences, but rather the different analyses fortify the knowledge base. SALMINEN and colleagues (2015) conducted a two-year longitudinal study on narratives of burnout and recovery. They found that the most important factor for recovery was 'agency', which is also in line with the main theme outlined by KAVALIERATOS and colleagues (2017, 736) 'My well-being in my

own hands'. Similar to our findings, that view was displayed through a gradual understanding that a quick fix is not the answer; during the recovery process, the authors realized they had been given tools with which to rebuild a sustainable everyday life. Thus, individual responsibility stands out as a key feature. Personal responsibility has been emphasized in the recovery research (SLADE 2009). Lastly, burnout syndrome is an escalating and highly complex phenomenon affecting both the individual and community levels. Even though more research is needed, the present study has shed light on the many aspects of burnout grounded in the narrator's experiences. Our hope is that person-centered care will play a greater role among healthcare providers, helping them to improve the conditions for good communication and participation throughout the recovery process.

6. Strengths and limitations

This study is based on a qualitative content analysis of autobiographies written in the first-person. One special strength of this approach was the reflected narratives of people who had experienced and lived with the investigated phenomenon of interest. Qualitative studies in this field of research are scarce, but to further complete our understanding of the experiences, we chose to approach data collection slightly differently. We argue that autobiographies have the ability to complete the narrative in a way that interviews do not. In interview studies, participants are typically interviewed once, while much of the detail may be overlooked. One weakness is that we as researchers are not able to pose follow-up questions to the narrators and are limited to the written text. Hence, one possible addition to only analyzing the books would have been to also interview the authors. All of the examined autobiographies are written by people living in Sweden. This rather narrow perspective might entail a risk that the findings are not transferable to understanding the burnout syndrome of people living in other countries; however, it is inherent to qualitative methodology to not claim external validity, just as it is done in quantitative research.

7. Conclusion

The present study contributes to a deeper understanding of the lived experiences of burnout syndrome and the recovery process that follows. The study has relevance both to further understanding the complexity of the human being as a whole system, inseparable from their environment (KOITHAN et al. 2017) and to promoting the strength of the narrative (SHAPIRO 2011). We also conclude that recovery is a nonlinear process that takes time and effort. Healthcare professionals may use the present article to feel confident in approaching a patient's narrative and help them produce a story based on personal experience. Continuing research may therefore focus on producing a storyline in the nurse-patient relation and further investigating what is beneficial to the development of such a narrative.

References

- ALARCON, G., K.J. ESCHLEMAN & N.A. BOWLING (2009) 'Relationships Between Personality Variables and Burnout: A Meta-Analysis', *Work and Stress* 23(3), 244–63 (<https://doi.org/10.1080/02678370903282600>).
- ANDERSSON, P. (2016) *Mata inte apan: min väg ur ett utmattningssyndrom* [Don't feed the monkey: My way out of burnout syndrome] (Stockholm: Books on Demand).
- ANDERSSON, E., Z. SALICKIENE & K. ROSENGREN (2016) 'To Be Involved – A Qualitative Study of Nurses' Experiences of Caring for Dying Patients', *Nurse Education Today* 38, 144–49 (<https://doi.org/10.1016/j.nedt.2015.11.026>).
- ARMAN, M., A.S. HAMMARQVIST & A. REHNSFELDT (2011) 'Burnout as an Existential Deficiency - Lived Experiences of Burnout Sufferers', *Scandinavian Journal of Caring Sciences* 25(2), 294–302 (<https://doi.org/10.1111/j.1471-6712.2010.00825.x>).
- ATIENO, P.O. (2009) 'An Analysis of the Strengths and Limitation of Qualitative and Quantitative Research Paradigms', *Problems of Education in the 21st Century* 13, 13–18, retrieved 2 May 2021 from <http://oaji.net/articles/2014/457-1393665925.pdf>.
- AWA, W.L., M. PLAUMANN & U. WALTER (2010) 'Burnout Prevention: A Review of Intervention Programs', *Patient Education and Counseling* 78(2), 184–90 (<https://doi.org/10.1016/j.pec.2009.04.008>).
- BAKKER, A.B. & P.L. COSTA (2014) 'Chronic Job Burnout and Daily Functioning: A Theoretical Analysis', *Burnout Research* 1(3), 112–19 (<https://doi.org/10.1016/j.burn.2014.04.003>).
- BANDURA, A. (2000) 'Exercise of Human Agency through Collective Efficacy', *Current Directions in Psychological Science* 9(3), 75–78 (<https://doi.org/10.1111/1467-8721.00064>).
- BORZA, A., S. TEMENT, C. ZDREHUS & C. KORUNKA (2012) 'The BOIT Training: An Overview of a Burnout Intervention and Initial Survey Results', *Procedia – Social and Behavioral Sciences* 33, 523–27 (<https://doi.org/10.1016/j.sbspro.2012.01.176>).
- CAÑADAS-DE LA FUENTE, G.A., C. VARGAS, C. SAN LUIS, I. GARCÍA, G.R. CAÑADAS & E.I. DE LA FUENTE (2015) 'Risk Factors and Prevalence of Burnout Syndrome in the Nursing Profession', *International Journal of Nursing Studies* 52(1), 240–49 (<https://doi.org/10.1016/j.ijnurstu.2014.07.001>).
- CONSTAND, M.K., J.C. MACDERMID, V. DAL BELLO-HAAS & M. LAW (2014) 'Scoping Review of Patient-Centered Care Approaches in Healthcare', *BMC Health Services Research* 14, 271 (<https://doi.org/10.1186/1472-6963-14-271>).
- CREEDY, D., M. SIDEBOTHAM, J. GAMBLE, J. PALLANT & J. FENWICK (2017) 'Prevalence of Burnout, Depression, Anxiety and Stress in Australian Midwives: A Cross-Sectional Survey', *BMC Pregnancy and Childbirth* 17, 13 (<https://doi.org/10.1186/s12884-016-1212-5>).
- CRESWELL, J.W. & C.N. POTH (2018) *Qualitative Inquiry & Research Design: Choosing among Five Approaches* (4th ed., Thousand Oaks: Sage).
- DREISON, K.C., L. LUTHER, K.A. BONFILS, M.T. SLITER, J.H. MCGREW & M.P. SALYERS (2018) 'Job Burnout in Mental Health Providers: A Meta-Analysis of 35 Years of Intervention Research', *Journal of Occupational Health Psychology* 23(1), 18–30 (<https://doi.org/10.1037/ocp0000047>).
- FREUDENBERGER, H.J. (1974) 'Staff Burn-Out', *Journal of Social Issues* 30(1), 159–65 (<https://doi.org/10.1111/j.1540-4560.1974.tb00706.x>).
- FRISCH, N.C. & D. RABINOWITSCH (2019) 'What's in a Definition? Holistic Nursing, Integrative Health Care, and Integrative Nursing: Report of an Integrated Literature Review', *Journal of Holistic Nursing* 37(3), 260–72 (<https://doi.org/10.1177/0898010119860685>).
- GARROSA, E., B. MORENO-JIMÉNEZ, A. RODRÍGUEZ-MUÑOZ & R. RODRÍGUEZ-CARVAJAL (2011) 'Role Stress and Personal Resources in Nursing: A Cross-Sectional Study of Burnout and

- Engagement', *International Journal of Nursing Studies* 48(4), 479–89 (<https://doi.org/10.1016/j.ijnurstu.2010.08.004>).
- GRANEHEIM, U.H. & B. LUNDMAN (2004) 'Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness', *Nurse Education Today* 24(2), 105–12 (<https://doi.org/10.1016/j.nedt.2003.10.001>).
- GÜL, A., H. GÜL, U.C. ÖZKAL, Z. KINCIR, G. GÜLTEKIN & H.M. EMUL (2017) 'The Relationship Between Sluggish Cognitive Tempo and Burnout Symptoms in Psychiatrists with Different Therapeutic Approaches', *Psychiatry Research* 252, 284–88 (<https://doi.org/10.1016/j.psychres.2017.03.015>).
- HÅKANSSON, C. & G. AHLBORG (2017) 'Occupations, Perceived Stress, and Stress-Related Disorders among Women and Men in the Public Sector in Sweden', *Scandinavian Journal of Occupational Therapy* 24(1), 10–17 (<https://doi.org/10.3109/11038128.2016.1170196>).
- HANSSON, A.-S., B.B. ARNETZ & I. ANDERZÉN (2006) 'Risk-Factors for Stress-Related Absence among Health Care Employees: A Bio-Psychosocial Perspective. Associations between Self-Rated Health, Working Conditions and Biological Stress Hormones', *Italian Journal of Public Health* 3(3–4), 53–61.
- HOLMGREN, E. (2015) *Våga vara rädd: en bok om utmattningssyndrom* [Dare to be afraid: A book about burnout syndrome] (2nd ed., Falun: Parus)
- HOLMGREN, K., S. DAHLIN-IVANOFF, C. BJÖRKELUND & G. HENSING (2009) 'The Prevalence of Work-Related Stress, and its Association with Self-Perceived Health and Sick-Leave, in a Population of Employed Swedish Women', *BMC Public Health* 9, 73 (<https://doi.org/10.1186/1471-2458-9-73>).
- HRICOVÁ, M. (2020) 'The Mediating Role of Self-Care Activities in the Stress-Burnout Relationship', *Health Psychology Report* 8(1), 1–9 (<https://doi.org/10.5114/hpr.2019.89988>).
- JÄRVIKOSKI, A., M. MARTIN, I. AUTTI-RÄMÖ & K. HÄRKÄPÄÄ (2013) 'Shared Agency and Collaboration Between the Family and Professionals in Medical Rehabilitation of Children with Severe Disabilities', *International Journal of Rehabilitation Research* 36(1), 30–37 (<https://doi.org/10.1097/MRR.0b013e32835692d3>).
- JIN, M. U., S.H. JEONG, E.K. KIM, Y.H. CHOI & K.B. SONG (2015) 'Burnout and its Related Factors in Korean Dentists', *International Dental Journal* 65(1), 22–31 (<https://doi.org/10.1111/idj.12142>).
- Kavalieratos, D., D.E. Siconolfi, K.E. Steinhäuser, J. Bull, R.M. Arnold, K.M. Swetz & A.H. Kamal (2017) '“It Is Like Heart Failure. It Is Chronic ... and It Will Kill You”': A Qualitative Analysis of Burnout Among Hospice and Palliative Care Clinicians', *Journal of Pain and Symptom Management* 53(5), 901–10 (<https://doi.org/10.1016/j.jpainsymman.2016.12.337>).
- KOITHAN, M. S., M.J. KREITZER & J. WATSON (2017) 'Linking the Unitary Paradigm to Policy through a Synthesis of Caring Science and Integrative Nursing', *Nursing Science Quarterly* 30(3), 262–68 (<https://doi.org/10.1177/0894318417708415>).
- LIDSTRÖM, C. & E. DAHLGREN (2018) *Hjälp jag är utmattad* [Help, I'm burned out] (Stockholm: Nordstedts).
- LINDEBERG, S.I., M. ROSVALL, B. CHOI, C. CANIVET, S.O. ISACSSON, R. KARASEK & P.O. ÖSTERGREN (2011) 'Psychosocial Working Conditions and Exhaustion in a Working Population Sample of Swedish Middle-Aged Men and Women', *European Journal of Public Health* 21(2), 190–96 (<https://doi.org/10.1093/eurpub/ckq039>).
- LOUW, J. M., T.S. MARCUS & J.F.M. HUGO (2017) 'Patient- or Person-Centred Practice in Medicine? - A Review of Concepts', *African Journal of Primary Health Care & Family Medicine* 9(1), 1–7 (<https://doi.org/10.4102/phcfm.v9i1.1455>).

- MAGNUSSON HANSON, L., T. THEORELL, G. OXENSTIERNA, H. WESTERLUND & M. HYDE (2008) 'Demand, Control and Social Climate as Predictors of Emotional Exhaustion Symptoms in Working Swedish Men and Women', *Scandinavian Journal of Public Health* 36(7), 737–43 (<https://doi.org/10.1177/1403494808090164>).
- Marine, A., J. Ruotsalainen, C. Serra & J. Verbeek (2006). 'Preventing Occupational Stress in Healthcare Workers', *Cochrane Database of Systematic Reviews* 4, CD002892 (<https://doi.org/10.1002/14651858.CD002892.pub2>).
- MASLACH, C., W.B. SCHAUFELI & M.P. LEITER (2001) 'Job Burnout', *Annual Review of Psychology* 52(1), 397–422 (<https://doi.org/10.1146/annurev.psych.52.1.397>).
- MCCORMACK, B. & T.V. MCCANCE (2006) 'Development of a Framework for Person-Centred Nursing', *Journal of Advanced Nursing* 56(5), 472–79 (<https://doi.org/10.1111/j.1365-2648.2006.04042.x>).
- MEEUSSEN, L., & C. VAN LAAR (2018) 'Feeling Pressure to Be a Perfect Mother Relates to Parental Burnout and Career Ambitions', *Frontiers in Psychology* 9, 2113 (<https://doi.org/10.3389/fpsyg.2018.02113>).
- NYGREN, N. (2017) *Ett slut: en början - en psykiatrikers funderingar kring sitt utmattningssyndrom* [An end, a beginning: A psychiatrist's thoughts about his own burnout syndrome] (Falun: Parus).
- OSHIO, T., A. INOUE & A. TSUTSUMI (2017) 'Does Work-to-Family Conflict Really Matter for Health? Cross-Sectional, Prospective Cohort and Fixed-Effects Analyses', *Social Science and Medicine* 175, 36–42 (<https://doi.org/10.1016/j.socscimed.2016.12.039>).
- PAVLAKIS, A., V. RAFTOPOULOS & M. THEODOROU (2010) 'Burnout Syndrome in Cypriot Physiotherapists: A National Survey', *BMC Health Services Research* 10, 63 (<https://doi.org/10.1186/1472-6963-10-63>).
- PETERSON, U., G. BERGSTRÖM, M. SAMUELSSON, M. ÅSBERG & Å. NYGREN (2008) 'Reflecting Peer-Support Groups in the Prevention of Stress and Burnout: Randomized Controlled Trial', *Journal of Advanced Nursing* 63(5), 506–16 (<https://doi.org/10.1111/j.1365-2648.2008.04743.x>).
- PIKÓ, B.F. & M. MIHÁLKA (2017) 'A Study of Work Satisfaction, Burnout and Other Work-Related Variables Among Hungarian Educators', *European Journal of Mental Health* 12(2), 152–64 (<https://doi.org/10.5708/EJMH.12.2017.2.2>).
- ROTENSTEIN, L.S., M. TORRE, M.A. RAMOS, R.C. ROSALES, C. GUILLE, S. SEN & D.A. MATA (2018) 'Prevalence of Burnout among Physicians: A Systematic Review', *JAMA – Journal of the American Medical Association* 320(11), 1131–50 (<https://doi.org/10.1001/jama.2018.12777>).
- SALMINEN, S., A. MÄKIKANGAS, M. HÄTINEN, U. KINNUNEN & M. PEKKONEN (2015) 'My Well-Being in My Own Hands: Experiences of Beneficial Recovery During Burnout Rehabilitation', *Journal of Occupational Rehabilitation* 25(4), 733–41 (<https://doi.org/10.1007/s10926-015-9581-6>).
- SCANLAN, J.N. & M. STILL (2019) 'Relationships Between Burnout, Turnover Intention, Job Satisfaction, Job Demands and Job Resources for Mental Health Personnel in an Australian Mental Health Service', *BMC Health Services Research* 19, 62 (<https://doi.org/10.1186/s12913-018-3841-z>).
- SCHAUFELI, W.B. (2018) *Burnout In Europe: Relations with National Economy, Governance and Culture* (Leuven: KU) retrieved 2 May 2021 from <https://www.wilmarschaufeli.nl/publications/Schaufeli/500.pdf>.
- SCHAUFELI, W.B., M.P. LEITER & C. MASLACH (2009) 'Burnout: 35 Years Of Research and Practice', *Career Development International*, 14(3), 204–20 (<https://doi.org/10.1108/13620430910966406>).

- SEIDLER, A., M. THINSCHMIDT, S. DECKERT, F. THEN, J. HEGEWALD, K. NIEUWENHUIJSEN & S.G. RIEDEL-HELLER (2014) 'The Role of Psychosocial Working Conditions On Burnout and its Core Component Emotional Exhaustion – A Systematic Review', *Journal of Occupational Medicine and Toxicology* 9, 10 (<https://doi.org/10.1186/1745-6673-9-10>).
- SHANAFELT, T.D., O. HASAN, L.N. DYRBYE, C. SINSKY, D. SATELE, J. SLOAN & C.P. WEST (2015) 'Changes in Burnout and Satisfaction with Work – Life Balance in Physicians and the General US Working Population between 2011 and 2014', *Mayo Clinic Proceedings* 90(12), 1600–13 (<https://doi.org/10.1016/j.mayocp.2015.08.023>).
- SHAPIRO, J. (2011) 'Illness Narratives: Reliability, Authenticity and the Empathic Witness', *Medical Humanities* 37(2), 68–72 (<https://doi.org/10.1136/jmh.2011.007328>).
- SLADE, M. (2009) *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals* (Cambridge: Cambridge UP).
- STREIFFERT, M. (2015) *Utbrändheten: och vägen tillbaka som människa och idrottare* [Burnout: The way back as a person and an athlete] (Lerum: Visto).
- SVÄRD, E. (2017) *Med mitt mod genom utmattningssyndrom* [With my bravery: Getting through burnout syndrome] (Stockholm: Fresh Eye).
- WESTERMANN, C., A. KOZAK, M. HARLING & A. NIENHAUS (2014) 'Burnout Intervention Studies for Inpatient Elderly Care Nursing Staff: Systematic Literature Review', *International Journal of Nursing Studies* 5(1), 63–71 (<https://doi.org/10.1016/j.ijnurstu.2012.12.001>).

ERIKA KISS* & EMESE PAJOR

POPULATION FEATURES
OF VISUALLY IMPAIRED CHILDREN
AND THEIR PARENTS LIVING IN HUNGARY**

(Received: 4 March 2021; accepted: 13 May 2021)

This exploratory research (2014–2019) was conducted among visually impaired children aged 0–14 years and their parents. The paper focuses on the crucial features of the healthcare and pedagogical services provided for visually impaired children and analyses the situation of parents raising them. In order to explore the population characteristics of visually impaired children in Hungary, we relied on two major data sources: the census data of the Hungarian Central Statistical Office between 1990–2016, and the examination documents of the Corps of Pedagogical Services of Visually Impaired Children between 2009–2013. The research included data of 1,432 visually impaired children. In order to survey the situation of these children’s parents, we conducted semi-structured, individual interviews. We investigated the retrospective narratives of 39 mothers and 29 fathers through narrative categorical content analysis and performed the situation analysis of the parents, using the model of game theory between humans and environment, whilst we also took into consideration the Hungarian and international methodological context for researching parents raising visually impaired children. Results suggest that the population of visually impaired children is under transformation: visually impaired groups based on the classical interpretation of visual performance are being replaced by new groups governed by needs. What the parents of such children seem to lack the most in the Hungarian care system are the opportunities for physical and mental relief. It would be vital to improve the situation of the parents concerned by more flexible special education and social services that could support both single parents and couples to overcome their difficulties.

Keywords: visually impaired children; age-related prevalence of VI children in Hungary; parents raising VI children; protective and risk factors; narrative categorical content analysis

* Corresponding author: Erika Kiss, Semmelweis University Doctoral School of Mental Health Sciences Budapest, Balassa u. 6., 1083 Hungary; Early Intervention Centre Budapest, Bártfai u. 34/a, 1115 Hungary; Eötvös Loránd University Bárczi Gusztáv Faculty of Special Needs Education, Budapest, Ecseri út 3., 1097 Hungary; kiss.erika@barczy.elte.hu.

** Ethical approval: Permit was obtained separately from each interviewee.

Disclosure statement: The authors have stated explicitly that there are no conflicts of interest in connection with this article.

1. Introduction

Within the research focusing on the situation of families raising visually impaired children (GARAI & KOVÁCS 2014; MÁNDOKI 2018), no study about the situation and the quality of life of families raising visually impaired children has been published in the past few decades in Hungary. Also, we could not find any Hungarian researches which would inform us about the life circumstances and population features of the parents raising visually impaired children, and how they adapt to their children's visual impairment. Our information about the visually impaired children's parents mostly comes from practising experts' experience and assumptions, and in most cases the information is limited to describing a phenomenon or providing experience.

Studies exclude the relationship between the family system and the pedagogical, medical care system. Certain aspects of the population features appear as fragmented or incomplete: the qualitative features of visually impaired children are very often linked with an educational institute, a group of visually impaired children, or illnesses (PARASZKAY 2007). The quality of life features applicable in the context of visually impaired children and their parents (demographic, family structure data, household features) appear only for institutes with smaller numbers of children or in groups linked only to one county (KOTROCZÓ 2018). Furthermore, the age group prevalence of visually impaired children is not identified in Hungary, which hinders comparison with international data.

As practising special education teachers and as a former employee of the national special pedagogical diagnostical center (The Center of Pedagogical Services – Board for Special Education, Early Intervention of Visually Impaired Children, in short: The Center VI), we learned that the Center has been collecting the *qualitative and quantitative features of the visually impaired children and their parents* for several decades, and this documentary collection contains these otherwise incompletely accessible, but – from a pedagogical, medical and social care perspective – relevant and very sensitive data for a very high number of children. These data that refers to more than a thousand cases was not processed before our study.

2. Aim

In one of the foci of the examination are the visually impaired children, who from a pedagogical perspective qualify as children with *sensory special educational needs* (*sensory SEN*) or visually impaired if they have an impairment of visual functioning even after treatment and/or standard refractive correction, and have a visual acuity of 0–0.33 (0–33%), or a visual field of less than 10 degrees from the point of fixation in either direction, that is 20 degrees altogether (The Educational Authority 2020). Whether or not a child has a visual impairment in the pedagogical sense (Sensory special educational needs) is determined by the Center of Pedagogical Services that provides pedagogical diagnosis and rehabilitation services for children. From a (special) pedagogical perspective, not all children with an ophthalmologic diagnosis are

visually impaired, but all children who are categorized as visually impaired from a pedagogical perspective have an ophthalmologic or neurological diagnosis stating that their vision is modified to the extent that an optical aid may not prevent them from a considerable limitation in gaining knowledge and having proper orientation (KISS & PAJOR 2020).

In the second focus of the research stand the features of parents raising impaired and visually impaired children. In the life of families, thinking about and taking care of impaired children posits a permanent stress to family members (ROBERTSON & BROWN 1992), which throws the family off balance for a longer or shorter period of time (SELIGMAN & DARLING 2007). As KOPP (2001) states, the most important factors assuring the balance between person and environment and lessening the probability for the loss of control are: (1) adaptive coping strategy, conflict managing strategies (FOLKMAN & LAZARUS 1980); (2) adaptive attitudes; (3) social support, social net. The coping strategies may be categorized *on the axis of adaptive – non-adaptive* (KOPP & PRÉKOPA 2011). DANIS and KALMÁR (2011) list three main forms of coping abilities: forms aiming at *problem-solving, emotional coping, and seeking supportive people*. Coping with the fact of disability, the birth, and the existence of a disabled child has been described variously (SELIGMAN & DARLING 2007). Certain authors (KÜBLER-ROSS 1969; KÁLMÁN 1994) describe this coping process as one corresponding to the stages of grief processing, while others (LIVNEH & ANTONAK 1997; LIVNEH 2001) define it as a recurring, cyclically repetitive, spiral form. The latter theory also divides coping with difficulties into various stages, but they regularly return into one's life. During the process, characteristics of the adaptive and non-adaptive approaches appear in a mixed form in the life of a family or a parent, and during this process, a high number of moderating factors, that is, protective and risk factors (DANIS & KALMÁR 2011) are identifiable. This research examines the coping factors of parents raising visually impaired children in this interpretative framework.

Several authors have pointed out that the quantitative and qualitative analyses examining the family or individual functioning of the parents raising children with disabilities mostly refer to white parents living in a partnership and belonging to the middle class (DAVIS 1993; O'CONNOR & RUTTER 1996; TUNALI & POWER 2002; GRAY 2006); therefore, the conclusions of these studies cannot be applied to the whole population of parents raising children with a visual impairment without limitations. Thus, the cited research reports emphasize the importance of including parents with low socio-economic status. Such an objective is reachable with qualitative methods and the examination of individual walks of life and parental narratives (GARAI 2005; BOGNÁR 2012).

MAYO and colleagues (2018) have found that a significant relationship exists between the family environment in which children with visual impairment are managed and disability coping. It has important implications for the intervention, as it was found that a family environment with cohesion, organization, an intellectual-cultural, active-recreational and moral-religious family attitude is positively related to the use of adaptive coping strategies. As LUPÓN and colleagues (2018) claim, some

parents express feelings of helplessness, frustration, lack of attachment or guilt for not understanding their children's behavior. Parents raising children with a visual impairment are mainly worried about their children's future and their school performance; they also express concern about psychosocial issues and family organization aspects. Some examples of the coping strategies parents commonly use and define as empowering are as follows: a conscious attitude of acceptance, an active search for help, a feeling of responsibility towards the child, gaining knowledge about the VI, mutual respect and support within the family, talking about the situation, gaining a positive perspective of the situation, finding time for leisure or respite, helping children develop their skills and encourage the child's independence, amongst others. In addition, within the family context, better results and better adjustment of all family members (including the person with VI) are possible if the family is flexible, adaptable, cohesive, supportive, and well-functioning (BAMBARA et al. 2009).

3. Objectives

Based on the surveyed publications and our experience as practicing experts, we defined the objectives of our fact-finding research as follows: (1) Determining the quantitative features (*sample size, rate, prevalence*) of visually impaired children aged between 0 and 14 in an organizing manner. (2) The exploratory examination of the coping factors applied by parents raising visually impaired children in a representative parental sample (*including low SES, single parents*).

The research aims at answering research questions that are of an exploratory nature. During this process, we do not apply an examination suitable for testing a hypothesis; therefore, we pose the following research questions, which relate to the exploratory examination of the population features of visually impaired children and their parents:

What is the age-related prevalence of visual impairment in Hungary like compared to the international data?

What repetitive characteristics do mothers and fathers raising visually impaired children articulate in their retrospective narratives?

4. Methods

The methodology of the research relies on three pillars, as it applies two comprehensive quantitative methods and a qualitative analytical method.

4.1. Quantitative analytical method I.

This quantitative analytical method involves filtering and analysing the data from The Hungarian Central Statistical Office: Census 1990; 2001; 2011; Microcensus 2016 (KSH [HCSO] 1993; 2018; CSORDÁS 2014) that refers to visually impaired children aged between 0 and 14.

4.2. Quantitative analytical method II.

This quantitative analytical method involves large sample, complex data collecting with document analysis about the demographic, medical, and pedagogical features of children with sensory special educational needs (and their parents) based on the examination documents from 2009–2013 of the Center VI archives. The *analytical sample* contains only data of children aged between 0 and 14 in the cases of whom the medical and pedagogical diagnostic process unambiguously confirmed the fact of vision impairment (sensory SEN). The sample size of the analytical sample is 1,432 persons, which means that the so-called examination files (on paper) of 1,432 visually impaired children aged between 0 and 14 were analysed. During data collection, we managed to gather categorical data from the anamnesis reports, medical reports, birth discharge summaries and the recapitulatory pedagogical-psychological discharge summaries; then by further analysing these data, we determined the occurrence frequencies. Due to a limited access to these data, researchers could only prepare handwritten notes based on the paper documents, which could not include personal data that could have made identification possible. (At the moment, there is no clear principle or administrative/public educational protocol regulating the research on the continuously growing amount of documents stored in the various institutes dealing with the pedagogical diagnostics of the national or county pedagogical special services. Giving out and sharing these very sensitive data falls under the full responsibility of the head of the institute or the head of the educational district.) Despite its large sample size, the analytical sample may not be considered representative of the whole population, because not all children who may be suspected to have visual impairment get in touch with the Center VI. However, no other institute or database exists that would possess reliable data concerning children with *sensory special educational needs* that has such a large sample size. The study discusses in detail the background of the visually impaired children who stay outside the pedagogical diagnostic system.

4.3. Qualitative analytical method

In the course of our research, we contacted parents raising a visually impaired child who was at least 5 years old but not older than 16. The interviewees came from the past clientele of *the Center VI* and the *Early Intervention Centre Budapest*, who have used the special pedagogical services of these institutes between 2000 and 2014. Basing our research completely on voluntary participation and assuring complete anonymity, we contacted the parents via email or telephone. We could contact 136 possible interviewees, and with 68 of these parents we could do interviews resulting in processable narratives. Half-structured interviews were made with mothers (39 persons) and fathers (29 persons) raising visually impaired children. The demographic and family structure features correspond to the rates in the large sample of Corps VI. Beside the socio-demographic data, we asked about the status

of partnership, the duration of partnership, the number of children, the degree of their subjective feeling of satisfaction with their financial situation, the data concerning medical, pedagogical and institutional care, and the specifics of keeping contact with people in similar situation. A narrative categorical content analysis method was applied (LÁSZLÓ et al. 2013) to analyse the texts of the individual interviews with the use of Webnarrcat text analytical software (EHMANN et al. 2014). When one analyses with NarrCat, there is a data reduction of a specific thematic: the software transforms determined units (sentences/parts of sentences) of the individual and group narratives into categories that later may serve as the basis for a narrative psychological analysis (EHMANN et al. 2014). The core of the system is the narrative categorical, that is, psycho-thematic modules. The four most robust of these are emotion, evaluation, agency and cognition (EHMANN et al. 2014, 139).

5. Results

5.1. Results I.

Based on the data tables of The Hungarian Central Statistical Office (HCSO) (Census 1990; 2001; 2011; Microcensus 2016) we determined and summarized in table format (*Table 1*) the occurrence rates of visually impaired children aged 0 to 14 within the whole population and in their age group. In the entire population, the prevalence of the VI group increases in every ten years. The prevalence of the VI group was 0.050% in 1990, but 0.063% in 2001 and 0.083% in 2011. Interestingly within the population aged between 0 and 14, the prevalence of the VI group decreases in every ten years. The prevalence of the ‘youth’ VI group was 0.04% in 1990, but 0.03% in 2001 and 0.026% in 2011.

A more accurate methodological and conceptual establishment of principles (KSH [HCSO] 2018) is connected to the samples of the *2011 Census and the 2016 Microcensus*; therefore, the prevalence values were determined more emphatically in these two samples. Based on the aggregated data, the prevalence of childhood visual impairment was 0.026% in 2011 and 0.022% in 2016 in the entire population. *This means that in every ten thousand people 2.6 adults and 2.1 children were visually impaired.* The age group prevalence is 0.18% in 2011 and 0.15% in 2016; that is, *out of ten thousand children of the same age group (aged between 0 and 14), 18 were visually impaired in 2011 and 15 were visually impaired in 2016.*

Table 1
The number of disabled people, visually impaired people,
and visually impaired people below the age of 14, and their rate within the entire population
and within the population aged between 0 and 14
(Census data)

	Population	Entire population		In the population aged 0 to 14		
		Disabled	VI	Number	Disabled	VI
<i>Census 1990</i>	10,374,823	368,270 3.55%*	51,400 0.50%*	2,130,549 20.5%*	33,485 1.57%***, 0.32%*	4,135 0.19%***, 0.040%*
<i>Census 2001</i>	10,198,315	577,006 5.66%*	64,558 0.63%*	1,694,936 16.6%*	28,803 1.70%***, 0.28%*	3,065 0.18%***, 0.030%*
<i>Census 2011</i>	9,937,628	490,578 4.94%*	82,484 0.83%*	1,447,659 14.6%*	23,190 1.60%***, 0.23%*	2,591 0.18%***, 0.026%*
<i>Microcensus 2016</i>	9,803,837	408,021 4.16%*	69,747 0.71%*	1,421,937 14.5%*	22,857 1.61%***, 0.23%*	2,137 0.15%***, 0.022%*

* rate in the entire population, ** rate in the population aged between 0 and 14.

The collected data of the visually impaired population aged between 0 and 14 were further categorized and recorded in all four surveyed periods into *low vision* and *blind categories* (Table 2), and we completed them with individual visual impairment categories that vary according to the surveys (*blind in one eye, deafblind*). According to the Census 1,990, in the visually impaired population aged between 0 and 14, there were 4,135 children. The number of children with a visual impairment has declined over the next two decades. In 2001, there were 3,065 children with VI and in 2011, there were 2,591 children with VI.

Table 2
Categories of visually impaired children aged between 0 and 14 based on Census data

	<i>Blind</i>	<i>Low vision</i>	<i>All VI</i>	<i>Blind in one eye</i>	<i>Deafblind</i>
<i>Census 1990</i>	1,020	3,115	4,135	635	no data
<i>Census 2001</i>	334	2,731	3,065	438	no data
<i>Census 2011</i>	247	2,344	2,591	no data	124
<i>Microcensus 2016</i>	335	1,802	2,137	no data	75

Due to the evident signs of condition for blindness, international literature (GILBERT & ELLWEIN 2008) determines a prevalence value only for the blind population,

so using the 2011 Hungarian age-group population number (1,447,659), the age-group prevalence value for blindness was 0.17‰. Using the 2016 data, the age-group prevalence value for blindness was 0.23 ‰. Thus in 2011, out of 10,000 children below the age of 14, 1.7 persons were found blind; in 2016, this value is 2.3 persons.

5.2. Results II.

In the group of children with visual impairment (n = 1,432) there are 559 girls (39%) and 873 boys (61%). 56 percent (n = 809) of the sample were children with low vision and 36 percent (n = 509) were children with blindness. According to the statistical analysis, 8 percent (114 persons) of the sample is made up of babies and toddlers below the age of 18 months who may not be categorized with certainty as blind or low-vision, but need early intervention due to their condition signs and/or their ophthalmologic or neurological diagnosis. The data about family features of the visually impaired children are summarized in Table 3. In most cases (82.6%), the children have two parents or caregivers. Most children live with their biological parents (48.5%), but a significant number live in families where one of the parents is not the biological parent (26.5%). The rate of adopted children with impaired vision is 3.9% in the sample.

Table 3
Family structure of children with impaired vision

FAMILY STRUCTURE n = 1,156 (no data = 276)	Blind	Low vision	Below 18 mo.	Total
Two parents (biological)	206	292	63	561 (48.5%)
Two parents (biological + foster)	131	161	14	306 (26.5%)
Two parents (foster)	14	29	5	48 (4.2%)
Two adoptive parents	9	23	7	39 (3.4%)
One parent (biological)	29	61	22	112 (9.7%)
One parent (foster)	14	9	0	23 (1.9%)
One adoptive parent	4	2	0	6 (0.5%)
Orphanage	31	27	3	61 (5.3%)

58% of the parents living in relationships were married and 29% lived in cohabitation when they first registered at Corps VI. There were 141 parents (13%) who claimed to raise their children alone as single caregivers (some of these parents had divorced or their partner had died). Most visually impaired children had one sibling (49.75%), 17.9% of them had no siblings. 5.3% of the children with visual impairment live in orphanages.

5.3. Results III.

In the parents' sample, the interviews and narratives of 39 mothers (age range: 26–47; deviation: 6.57) and 29 fathers (age range: 26–49 years; deviation: 6.35) were analysed. In order to encode and thematize the texts, the *Webnarrcat* text-analysing software was used with the help of two independent encoding specialists. Based on the *Webnarrcat* scores, we could separate the highest scoring text parts which contained the most frequent parental responses, *emotional and cognitive relations* and *factors for seeking social support*. For methodological considerations, these factors were listed as *adaptive and non-adaptive features*. It is important to note that parents featured coping strategies, responses and relations from both categories, often at the same time. Within the adaptive and non-adaptive categories, the motifs are listed in order of frequency. *Figure 1* shows the summary of the explored coping factors of the parents.

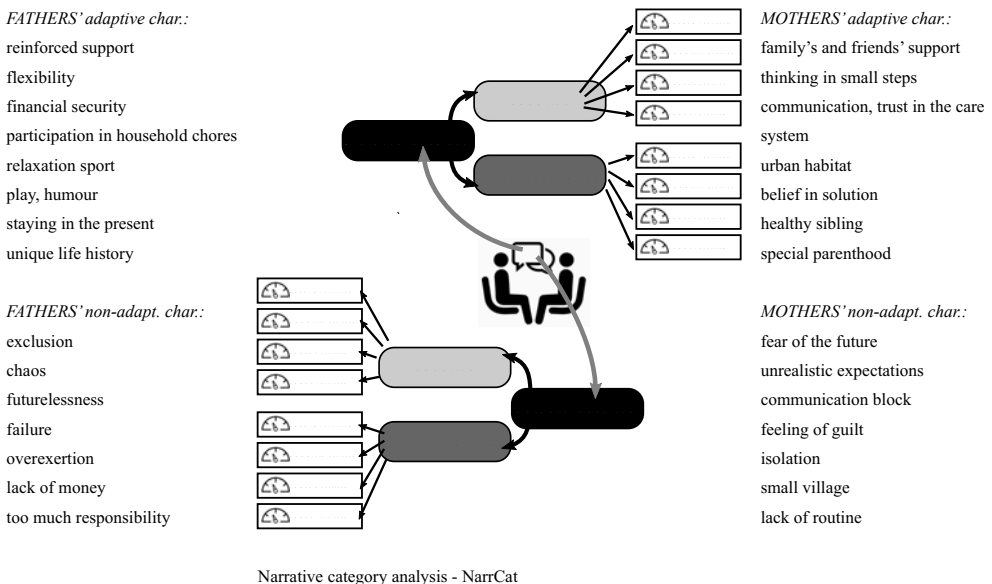


Figure 1.
 Frequency of Characteristics of the Adaptive and Non-Adaptive Approaches via the narrative category analysis

The parents' narratives reveal a number of protective and risk factors: (1) it appears that social support is an important protective factor regarding quality of life: parents who live together and the presence of siblings, grandparents, supportive friends and neighbours all have a positive impact on the quality of life. (2) If

the parents have more professional support, more information, and they have more trust in experts and institutions, they can assess their situation significantly better. (3) If the child has moderate visual impairment, the parents are more often confronted with dilemmas: diagnoses show a progression of the condition, it takes longer for the children to be registered in the care system, and the actors in majority education, basic children healthcare, and state administration, have little if any knowledge about the criteria of low vision. (4) It considerably restricts access to the care system should the adequate institutions or services be located far from the families' place of residence. (5) Most of the parents claimed that sooner or later they could acquire the basic information necessary to develop and take care of their children; however, they found no possibilities for receiving relief, either physical or mental, in the state-supported care system.

6. Discussion

The age-related prevalence of visual impairment in Hungary, compared to the international data GILBERT and ELLWEIN (2008), suggests that the occurrence of childhood visual impairment may be estimated based on the level of social and economic development and the mortality below the age of 5. Accordingly, in countries with low income and a high mortality rate below the age of 5, the average blindness rate for 1,000 children is 1.5. This rate *in developed countries is only 0.3*. The research by PHILIP and DUTTON (2014) points out that in developing countries, the rate of visually impaired children below the age of 16 is 40 children/10,000 live-births, whereas *in developed countries, this rate is only 10–22 children/10,000 live-births*. Based on the above, WHO estimates that all around the world there are about 1.4 million blind children, two-thirds of whom live in the poorest regions of Africa and Asia. The number of children with moderate or severe visual impairment is estimated to be 18 million (GILBERT & ELLWEIN 2008). In Hungary, the 2011 census (carried out by HCSO) registers *altogether 2,591 persons as visually impaired children aged between 0 and 14*, out of whom 247 children were categorized as blind and 2,344 children were categorized as children with moderate visual impairment. *This is 0.026% of the total population, and 0.18% of the population within the same age group.*

Based on the 2011 census' data (considered representative) and the 2016 micro-census (both conducted by HCSO), the age group prevalence of the Hungarian visually impaired children aged between 0 and 14 years does not exceed the values estimated for developed countries.

We interviewed mothers and fathers raising visually impaired children to ask their opinions about their own life situations. By using a narrative content analysis of the parents' answers to our questions in the interview, we managed to identify the most frequently occurring adaptive and non-adaptive coping mechanisms in the groups of mothers and fathers. We aimed at using an examination sample of the parents that is representative of the whole population, but due to the actual number we could work with, the relations and the results may not be generally applied to the

whole population of parents raising visually impaired children. Instead, we emphasize the possible extension and the applicability of the research results to groups of parents raising children with other disabilities. In their adaptive mechanisms, fathers most frequently apply a problem-focused and social support strategy, and they mobilize their psychic immune systems so that they may be able to act in a strengthened social support role and to react to the various challenges in an effective manner. In the dimension of adaptive coping mechanisms, mothers tend to apply an emotion-focused coping mechanism, but a visible growth of cognitive and social factors is detectable. In the course of adaptive coping, we identified a new strategy: that of organising effectively the scope of the duties around the child, which is one of the keys to long-term adapting. Furthermore, in the cases of adaptive coping, we could detect a growing frequency of reinterpreting parenting roles ('special parenthood', 'unique walk of life', 'less is often more') (BOGNÁR 2012; GARAI & KOVÁCS 2014; BERSZÁN 2015; KISS 2020).

The parental mechanisms may not be divided into clear adaptive and non-adaptive groups. *Considering the narrative tones of the parental self-confessions and their temporal spheres, we may differentiate between periods during which the parents behave according to one of the dimensions alternately.* The events that may trigger a change in the parent's attitude from a generally stable position to a more positive or more negative tone are critical situations, such as the cyclically repeated birthday of the child, or changes of institutes, medical or pedagogical check-up examinations or bigger social events. This observation stands in harmony with the theory (LIVNEH 2001; DAVIS 1993; LIVNEH & ANTONAK 1997) stating that coping with the difficulties of having a child with disability is a recurring, cyclically repeated process. In the adaptive dimension of the parents' narratives, social support features (*personal and professional support, family resources*) frequently emerge. Especially, mothers gave a high proportion (81–100%) of answers with a social support thematic, but the answers provided by fathers also had a 61–70% frequency category for *family and professional support*. For parents, professional support means the activity and the communication by people who got into contact with their children and belong to the medical, pedagogical, or social care branches.

7. Limitations

This study has some limitations. The biggest problem is that in Hungary, no official protocol and/or directive for the methodology of investigating the documents and data of SEN children exists. The Principal or the Director of the Institute is in charge of these sensitive and important data. The documents are forbidden to be copied, so researchers must take notes by hand. That is the reason that this research, in which we processed 1,432 documents, took two years. The second limitation comes from the fact that the 2016 microcensus was conducted with a sampling fraction of 10% of the population, so we must take this into consideration when using its data. Therefore, the data are to be regarded as highly reliable estimates, but in the case of

smaller populations, such as the group of visually impaired children, the reliability may somewhat decrease. When using these data, it is important to emphasize that they are based on estimation and accordingly, the statistical power of the possible conclusion is limited. The third limitation of the study, as was mentioned previously, is that despite the large sample size, the analytical sample may not be considered representative of the whole population, because not all children who may be suspected to have visual impairment get in touch with the Corps VI. However, the research could use only one institute because there are no more institutes or databases that would have reliable data concerning children with *sensory special educational needs* with such a large sample size.

8. Conclusion

It is of utmost importance to create for the parents concerned mental hygienic and support services, as well as information systems that take into account individual differences. It is also a priority to provide visual impairment specific training and continued professional support for the experts working in early intervention and inclusive education. All fields – social, medical and pedagogic – that are in connection with visually impaired children and their families, need more publications, brochures, or webpages about client pathways or VI children pathways.

What parents raising children with visual impairment seek most but do not find in the care system is support for their physical and mental relief. It would be important to improve the situation of parents raising a child with visual impairment with more flexible special education and social services in which both single and cohabiting parents receive support to solve their life situation difficulties. There would be a particular need to set up a system of mental health support and home help services that are available to the parents concerned, taking into account differences in individual family structures.

Families need more projects, workshops, and lectures for parents of VI children under and in school age to learn more about childhood development and parenting visually impaired children, to broaden their knowledge of the care system, and develop appropriate parental competences. A project or a brochure is better if it is made by not only professionals but parents having practical, everyday knowledge as experts by experience. An interactive website would help parents, families, and professionals find guidance on care paths, and would help families contact, as soon as possible, with the right care provider corresponding to their needs.

References

- BAMBARA, J.K., V. WADLEY, C. OWSLEY, R.C. MARTIN, C. PORTER & L.E. DREER (2009) 'Family Functioning and Low Vision: A Systematic Review', *Journal of Visual Impairment & Blindness* 103(3), 137–49 (<https://doi.org/10.1177/0145482X0910300303>)
- BERSZÁN, L. (2015) 'Megküzdés és reziliencia? Amikor a kevesebb több' [Coping and resilience? When less is more], *ET Social Science Journal* 13(1), 9–19 (<https://doi.org/10.17177/77171.1>)
- BOGNÁR, V. (2012) *A szülőség átértelmezése: Autizmussal élő személyek támogatása a családban* [Reinterpretation of parenthood: Supporting people who have autism in the family] (PhD diss., ELTE TÁTK, Budapest).
- CSORDÁS, G. (2014) 'Módszertani megjegyzések, fogalmak' [Methodological notes, concepts] in G. CSORDÁS, ed., *2011 évi népszámlálás, 11. Fogyatékosággal élők* [2011 Census, 11. People with Disabilities.] (Budapest: KSH) 89–96, retrieved 12 May 2021 from www.ksh.hu/docs/hun/xftp/idoszaki/nepsz2011/nepsz_11_2011.pdf.
- DANIS, I. & M. KALMÁR (2011) 'A fejlődés természete és modelljei' [The nature and models of development] in I. DANIS, M. FARKAS, M. HERCZOG & L. SZILVÁSI, eds., *Biztos Kezdet Kötetek 1. A génektől a társadalomig: a kora gyermekkori fejlődés szinterei* [Safe Start Volumes 1. From Genes to Society: Arenas of Early Childhood Development] (Budapest: Nemzeti Család- és Szociálpolitikai Intézet) 76–121, retrieved 5 May 2021 from <https://mek.oszk.hu/14800/14803/14803.pdf>.
- DAVIS, H. (1993) *Parents of Children with Chronic Illness or Disability – Communication and Counselling* (Baltimore: Brookes).
- EHMANN, B., I. CSERTŐ, R. FERENCZHALMY, É. FÜLÖP, R. HARGITAI, P. KÖVÁGÓ, T. PÓLYA, K. SZALAI, O. VINCZE & J. LÁSZLÓ (2014) 'Narratív kategoriális tartalomelemzés: a NARRCAT' [Narrative categorical content analysis: NARRCAT] in A. TANÁCS, V. VARGA & V. VINCZE, eds., *X. Magyar Számítógépes Nyelvészeti Konferencia* (Szeged: Szegedi Tudományegyetem) [X. Hungarian Computer Linguistics Conference (University of Szeged)] 136–47, retrieved 10 May 2021 from http://real.mtak.hu/20127/7/jav_MSZNY2014_press_b5.pdf.
- FOLKMAN, S. & R.S. LAZARUS (1980) 'An Analysis of Coping in Middle-Aged Community Sample', *Journal of Health and Social Behaviour* 21(3), 219–39 (<https://doi.org/10.2307/2136617>)
- GARAI, D. (2005) *Az identitásalakulás fordulópontjai és a megküzdés sajátosságai veleszületetten és trauma következtében sérült mozgáskorlátozott személyek narratívumaiban* [Turning points in identity development and peculiarities of coping in the narratives of people having reduced mobility] (PhD diss., Debrecen: Debreceni Egyetem BTK).
- GARAI, D. & L. KOVÁCS (2014) 'Másképpen működnek-e a fogyatékos gyermekeket nevelő családok? A családi működés sajátosságai sérült gyermekek családjában' [Do families raising children with disabilities function in a different way? Characteristics of family functioning in families raising children with disabilities], *Magyar Pszichológiai Szemle* [Hungarian Journal of Psychology] 69(1), 235–62 (<http://dx.doi.org/10.1556/MPSzle.69.2014.1.12>).
- GILBERT, C.E. & L.B. ELLWEIN (2008) 'Prevalence and Causes of Functional Low Vision in School-Age Children: Results from Standardized Population Surveys in Asia, Africa, and Latin America', *Investigative Ophthalmology & Visual Science* 49(3), 877–81 (<https://doi.org/10.1167/iovs.07-0973>).
- GRAY, D.E. (2006) 'Coping over Time: The Parents of Children with Autism', *Journal of Intellectual Disability Research* 50(12), 970–76 (<https://doi.org/10.1111/j.1365-2788.2006.00933.x>).
- KÁLMÁN, ZS. (1994) *Bánatkő: Sérült gyermek a családban* ['Sorrow stone': Disabled child in the family] (Budapest: Bliss Alapítvány: Keraban).

- KISS, E. (2020) 'Adaptív és nem adaptív megbirkózási stratégiák jellemzői látássérült gyermekeket nevelő szülők körében' [Characteristics of the adaptive and problem-oriented approaches among parents raising visually impaired children], *Gyógypedagógiai Szemle* [Hungarian Special Education Review] 48(1-2), 23–42.
- KISS, E. & E. PAJOR (2020) 'A 0–14 év közötti látássérült gyermekek populációjának egészségügyi és pedagógiai jellemzői Magyarországon' [The Medical and pedagogical features of the population of visually impaired children aged between 0 and 14 in Hungary], *Ophthalmologia Hungarica* 157(3), 294–302, retrieved 12 May 2021 from <http://szemrovostarsasag.hu/szemeszet>.
- KOPP, M. (2001) 'Magatartástudományi ember-környezeti rendszerelméleti modell' [Behavioral human-environment system theory model] in B. BUDA, M. KOPP & E. NAGY, eds., *Magatartástudományok* [Behavioral Sciences] (Budapest: Medicina) 23–46.
- KOPP, M. & A. PRÉKOPA (2011) 'Ember-környezeti játékelméleti modell' [Model of Game Theory Between Humans and Environment], *Magyar Tudomány* [Hungarian Science] 172(6), 665–77, retrieved 12 May 2021 from <http://www.matud.iif.hu/2011/06/05.htm>
- KOTROCZÓ, B. (2018) *Látássérült gyermeket nevelő szülők hazai helyzete Nógrád megyében* [Parents raising a visually impaired child in Nógrád county] (MSc thesis, ELTE BGGYK, Budapest).
- Központi Statisztikai Hivatal [Hungarian Central Statistical Office] (1993) 'Demográfiai adatok' [Demographics] in O. NAGY, ed., *1990 évi Népszámlálás, 27. Demográfiai adatok, I. kötet* [1990 Census, 27th Demographics, Volume I] (Budapest: KSH).
- Központi Statisztikai Hivatal [Hungarian Central Statistical Office] (2018) *Mikrocenzus 2016: A fogyatékos és az egészségi ok miatt korlátozott népesség jellemzői* [Microcensus 2016: Characteristics of the population with disabilities and health-related impairments] (Budapest: KSH) retrieved 12 May 2021 from www.ksh.hu/docs/hun/xftp/idoszaki/mikrocenzus2016/mikrocenzus_2016_8.pdf.
- KÜBLER-ROSS, E. (1969) *On Death and Dying* (New York: The Macmillan).
- LÁSZLÓ, J., I. CSERTŐ, R. FERENCZHALMY, É. FÜLÖP, R. HARGITAI, B. PÉLEY, T. PÓLYA, K. SZALAI, O. VINCZE & B. EHMANN (2013) 'Narrative Language as Expression of Individual and Group Identity: The Narrative Categorical Content Analysis', *SAGE Open* 3(2), 1–12 (<https://doi.org/10.1177/2158244013492084>)
- LIVNEH, H. (2001) 'Psychosocial Adaptation to Chronic Illness and Disability: A Conceptual Framework', *Rehabilitation Counseling Bulletin* 44(3), 151–60 (<https://doi.org/10.1177/003435520104400305>)
- LIVNEH, H. & R.F. ANTONAK (1997) *Psychosocial Adaptation to Chronic Illness and Disability* (Gaithersburg: Aspen).
- LUPÓN, M., M. ARMAYONES & G. CARDONA (2018) 'Quality of Life among Parents of Children with Visual Impairment: A Literature Review', *Research in Developmental Disabilities* 83, 120–31 (<https://doi.org/10.1016/j.ridd.2018.08.013>).
- MÁNDOKI, N. (2018) 'A fogyatékossgal élő gyermek nevelése: anya-gyermek interakciók, anyai nevelési viselkedés és szubjektíven megélt megterheltség eltérő fejlődésmenet esetén' [Education of children with special needs], *Gyermeknevelés* [Journal of Early Years Education] 6(3), 1–18, retrieved 12 May 2021 from https://epa.oszk.hu/02400/02411/00015/pdf/EPA02411_gyermek_neveles_2018_03_001-018.pdf.
- MAYO, M.E., E.M. TABOADA, P.M. IGLESIAS, J.E. REAL & A. DOSIL (2018) 'Family Environment and Coping Strategies for Families Dealing with Children that are Blind or Visually Impaired', *Current Perspective in Depression and Anxiety* CPDA–101 (DOI: 10.29011/CPDA-101.100001).

- O'CONNOR, T.G. & M. RUTTER (1996) 'Risk Mechanisms in Development: Some Conceptual and Methodological Considerations', *Developmental Psychology* 32(4), 787–95 (<https://doi.org/10.1037/0012-1649.32.4.787>).
- Oktatási Hivatal [The Educational Authority] (2020) 'A látási fogyatékos tanulók iskolai nevelésének – oktatásának irányelvei' [Guidelines for the school education of students having visual impairment] in *A sajátos nevelési igényű tanulók iskolai oktatásának irányelvei* [Guidelines for the school education of students having special educational needs] 7–33, retrieved 13 May 2021 from https://www.oktatas.hu/koznevelo/kerettantervek/2020_nat/iranyelvek_alapprogramok.
- PARASZKAY, S. (2007) *Közelről nézve: A gyengénlátó gyermek* [Watching closely: The low-vision child] (Budapest: Gyengénlátók Általános Iskolája, EGYMI és Diákotthona).
- PHILIP, S.S. & G.N. DUTTON (2014) 'Identifying and Characterising Cerebral Visual Impairment in Children: A Review', *Clinical & Experimental Optometry* 97(3), 196–208 (<https://doi.org/10.1111/cxo.12155>).
- ROBERTSON, S.E. & R.I. BROWN, eds. (1992) *Rehabilitation Counselling: Approaches in the Field of Disability* (San Diego: Chapman and Hall).
- SELIGMAN, M. & R.B. DARLING (2007) *Ordinary Families, Special Children: A Systems Approach to Childhood Disability* (3rd ed.; London & New York: Guilford).
- TUNALI, B. & T.G. POWER (2002) 'Coping by Redefinition: Cognitive Appraisals in Mothers of Children with Autism and without Autism', *Journal of Autism and Developmental Disorders* 32(1), 25–34 (<https://doi.org/10.1023/A:1017999906420>).

NIKOLAY GRIGORIEVICH NEZANOV*, LEV SAVVICH KRUGLOV,
VLADIMIR YURYEVICH SERPOV, ISMAYIL HIKMAT ATAYEV,
INNA VALENTINOVNA KISELEVA & ALEKSEY ALEKSANDROVICH CHESNOKOV

MENTAL DISORDERS IN PATIENTS AT GERIATRICIAN ATTENDANCE

Basic Variants and Influence on Social Functioning (The Experience in Russia)**

(Received: 18 June 2020; accepted: 30 October 2020)

Introduction: Data exists showing a significant prevalence of mental disorders in the growing elderly population, but indices have a fairly wide range. This study's aim was to analyze the frequency and variants of such disorders of the elderly in geriatrician attendance and their influence on social functioning.

Material and methods: Of newly-admitted geriatrician patients, 37.2% were found to have deviations at the time of screening (Geriatric Depression Scale, Zung anxiety scale, MMSE and the clock drawing test). Of these 32 patients (24 women) were 69.5 ± 4.4 years old and had somatic illnesses, mainly cardiovascular diseases and diabetes. The detailed assessment included the Neuropsychiatric Inventory Questionnaire, the Clinical Global Assessment, and the Global Assessment of Functioning scales. Statistics were based on Student's criterion (taking into account the normal distribution of the sample data).

Results and their discussion: Fully 93.7% of the disorders met the International Classification of Diseases (10th edition) criteria for adaptation disorder, organic anxiety disorder, recurrent depressive disorder with a moderate depressive episode. Two patients had dementia with confusion (delirium). The significant ranking of the anxiety-depressive disorders can be explained by their prevalence in the elderly population as a whole, the close relationship of such disorders with somatic pathology, and in dementia and psychotic cases, more frequent visits to psychiatrists. About a third of the patients manifested signs of impaired functioning, dependent on the presence of family ($t = 2.9$; $p < 0.05$) and their relationships within the family (the complex ones excluded indices above 70 points of GAF).

* Corresponding author: Prof. Nikolay Grigorievich Neznanov, National Medical Research Center for Psychiatry and Neurology named after V.M.Bekhterev, Bekhterev str. 3, St.Petersburg, Russia; spbinstb@bekhterev.ru.

** Acknowledgments: All colleagues from the department and co-authors of this paper would like to express their gratitude to Professor L.S. Kruglov, who started this work and was unable to complete it due to his sudden death, and to honor his memory.

Conclusions: More than a third of newly-admitted geriatric patients have mental disorders, mostly those on the anxiety-depressive depressive spectrum. Biological factors and psychosocial influences are both present represented as their reasons. Social functioning may suffer and highly depends on microsocial environments.

Keywords: elderly age; mental disorders; social functioning; anxiety; depression; geriatrician attendance

1. Introduction

1.1. Context

1.1.1. Background

Currently, the share of elderly people in the populations of most the world's countries has significantly increased. According to WHO data (World Health Organization 2015), in 2000 there were 600 million people at 60 years of age and older, which is almost three times more than this group numbered in 1950 (205 million). In subsequent years, this tendency continued: in 2009, the above-mentioned age class exceeded 737 million people, and according to forecasts, by 2050 that figure will exceed two billion. This trend also concerns Russia, wherein the population's share of the elderly, as in industrialized countries, stands at about 20% (YARYGINA & MELENTIEVA 2010).

Thus, the current world situation as a whole is characterized by a permanently increasing rate of the elderly population, and in this context, programs, such as the increasing adaptation of the elderly population, are widely discussed, including those related to the presence of different diseases (BUFFEL et al. 2014).

All of this makes a wide range of issues relevant for ensuring in old age a life worth living. Meanwhile, this period of life as a rule is characterized by a well-known deterioration in health, including in the fields of mental activity.

1.1.2. Mental disorders in the elderly

Since the middle of the 21st century's first decade, epidemiological studies have established a tendency of increasing prevalence regarding mental disorders among people of the elder age groups. Initially, it mainly affected the primary disease incidence rate and, possibly, was the result of improving methods for identifying this pathology (BEZDOS & MAKSIMOVA 2006; CHURKIN & TVOROGOVA 2012). Moreover, in particular, this pathology was related to determining cognitive impairments as a result of extensive examination programs for the elderly and the aged senile (ZAKHAROV 2006).

Nowadays, an increase in not only the primary disease incidence, but also the general prevalence rate of mental disorders among elderly population groups, has been established (DEMICHEVA et al. 2017). In general, in Russia the prevalence of mental disorders among the elderly stands at approximately 27.4%, which is consistent

with global indicators (29.8%) (Ministry of Health of the Russian Federation 2015; KRASNOV et al. 2013).

A significant frequency of mental disorders in old age determines the relevance of their systematic research. In this connection, not only studies that are carried out in outpatient and inpatient psychiatric institutions, but also data obtained as a result of the patients' examinations by the geriatrician service, are of considerable interest.

1.1.3. The present state of the problem

Meanwhile, the analysis of how the different types of mental disorders rank in an unorganized population (united only by the territory of residence and age composition) is still insufficiently presented in the literature. A significant scatter of indices characterizes the latest information. So, the frequency of depressive disorders ranges from 10% to 20%, while anxious neurotic disorders – from 5 to 15%, and cognitive decline, including dementia – range from 30 to 60% (MIKHAILOVA 1996; SLUCHEVSKAYA 2008).

The same data should become the basis for fashioning solutions containing the best options for monitoring elderly patients affected by mental disorders. And we can also assume that a significant segment of such patients does not need permanent psychiatric monitoring due to the non-psychotic nature of their disorders (NEZANANOV & KRUGLOV 2015).

It should be noted that the assessment of the elderly patients' mental status can be difficult, since the appearance of any mental deviation may be considered by the patients themselves and their relatives as simple age-related changes. In particular, it is possible to classify the manifestations of the anxiety-depressive spectrum and a significant deterioration in memory as allegedly 'the usual signs of oldness'. As a result, the correct diagnosis is very often carried out late (BALDWIN et al 2002; DUBENKO 2008). Accordingly, treatment and rehabilitation measures therefore also begin unreasonably late.

1.2. Aim

The aim of this study was to analyze the mental disorders' rate (according to the experience in Russia) that are detected during geriatrician examinations by using clinical scales and level of social functioning of these patients' assessment.

2. Methods and general characteristics of the studied patients

In the Geriatric Medical and Social Center of St. Petersburg, there was a group of newly admitted geriatric patients that had been previously identified by means of a continuous method during a two-month period of 2020. Patients who signed written informed consents were offered screening tests conducted by a psychiatrist researcher, and then (in case of mental disorder signs) their condition was assessed using more detailed psychometric assessment methods, as well as an examination of

disease data history. Screening techniques included the Geriatric Depression Scale, the Zung anxiety scale, MMSE screening, and the clock drawing test. A further assessment of psychometric indicators was carried out via the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Clinical Global Impression (CGI), and the Global Assessment of Functioning (GAF) scales. The statistical processing of the obtained data included the determination of absolute values and relative values, and the Student criterion was used to compare these values (taking into account normal distribution).

At this stage of the study, 32 patients (37.2%) out of 86 newly-admitted by the geriatrician service were found to have some degree of mental decline and were included in the clinical and statistical development. Of these, 24 (75%) were women, and their average age stood at 69.5 ± 4.4 years.

Until the moment of visiting the geriatrician, none of the patients had been observed by a psychiatrist or psychotherapist; they did not receive systematic treatment with psychotropic medications. At the same time, most of them – 81.3% – took anxiolytics and antidepressants (selective serotonin reuptake inhibitor), prescribed by neurologists or therapists (mainly in connection with complaints of sleep disturbances and increased anxiety), for a short time and with an unstable effect. The patients' somatic confounding factors, as one would expect, were primarily based on the influence of the vascular factor. Thus, in 78.1% of patients, essential hypertension was diagnosed, and 62.5% of the total number of examined patients had data indicating acute cerebrovascular conditions (transitory ischemic attacks and strokes). More than half of the patients (53.1%) showed clinical (confirmed by cardiologists' examinations) manifestations of coronary heart disease. In 50% of the cases, Type 2 diabetes was noted. Finally, indices of a significant decrease in hearing and vision stood rather high (84.4% and 68.8%, respectively).

3. Results

A diagnostic assessment of the revealed psychopathological symptoms was carried out according to the criteria of the International Classification of Diseases (ICD-10). In 13 cases (40.6%), adjustment disorder (F43.2 rubric of ICD-10) was found. The criteria of such a state include subjective distress and emotional disturbance, usually interfering with social functioning and performance, and arising in the period of adaptation to a significant life change or a stressful life event. The most common cause of this in the studied patients was the death of a loved one (usually one of the spouses), which was found in nine cases. The patients experienced the feeling of loss and the inability to adapt to the situation of absence of the closest and beloved person. In four other cases, the adjustment disorder was connected with moving to another residence, where the elderly could not find new companions and had to learn to function in an all new environment.

In two patients (6.3%), a recurrent depressive disorder with a current episode of moderate severity (F33.1 rubric of ICD-10) was found. Stable mood deterioration,

and anxiety characterized such cases, as well as the loss of opportunity for receiving positive emotion from hobbies and usually pleasant former occupations.

Fifteen other patients (46.9%) suffered from organic anxiety disorder (F06.4 rubric of ICD-10) (mainly vascular), as well as vascular-dysmetabolic (due to Type 2 diabetes and cerebrovascular disease) etiology. Such a disorder is characterized by the manifestation of anxiety as the major symptom and is not restricted to any particular environmental situation. Depressive and obsessional symptoms, and even some elements of phobic anxiety, may also be present, provided that they are clearly secondary or less severe. The arising symptoms are the consequence of an organic etiological factor.

In general, these three groups (with adjustment disorder, recurrent depressive disorder, and organic anxiety disorder) formed 93.8% (N = 30) of the total number of patients (N = 32), and the symptoms of the anxiety-depressive depressive spectrum of disorders predominated in the general description of their mental state.

The correctness of the distinction among the indicated diagnostic groups was found, in particular, to be confirmed by the results of their comparison in the average indices of depression and anxiety by the NPI-Q score. The highest rate of depression level (7.5 ± 1.1) was found in recurrent depressive disorder, while in organic anxiety disorder, it was statistically significantly lower (4.7 ± 0.2 ; $p < 0.05$); the intermediate position between them was occupied by an adjustment disorder with a depression rate of 5.8 ± 0.3 and the same level of anxiety. The latter, in turn, had the highest value in organic anxiety disorder (6.7 ± 0.3) and the lowest in recurrent depression (3.5 ± 1.2 ; $p < 0.05$).

In connection with the extremely rare group of recurrent depressive disorder among the studied patients, it should be noted that in both its cases a depressive episode was observed for the current period; however, a similar condition was already noted in their history, and it was then developed due to a traumatic situation connected with the loss of a loved one. Moreover, in both cases there had been in fact no visit to a doctor on this occasion, and the degree of the condition itself reduced without special treatment.

Severe cognitive impairment, reaching the level of dementia and complicated by phenomena of mental confusion (delirium), was observed in two patients (6.3% of the total number). These patients' clinical picture revealed signs of motor anxiety and fragmentary visual hallucinations, especially during night time. In this regard, for further examination and observation, these patients were referred to a psychiatrist in the clinical department.

The average value of the disease severity index on a CGI scale was 3.6 ± 0.2 , while all patients according to this index were in the range of three to five points.

Among patients exhibiting a predominance of anxiety-depressive depressive spectrum disorders with non-psychotic etiology, an analysis of social functioning was made using the GAF scale. It was found that most of these patients (70%), despite their clinical conditions, had a fairly high level of this index. They retained the ability to exhibit a fairly high activity (of course adjusted for age and especially in the

community-acquired area), but with the safety of their hobbies they showed life satisfaction, found solutions for daily questions, and only in rare cases experienced difficulties, and so, the overall impairment of functioning remained mild. Only a fifth of the patients indicated at least some signs of its deterioration, and only 10% had obvious signs of such a phenomenon.

The comparison of the average GAF scores among patients with different variants of established disorders within the anxiety-depressive depressive spectrum showed the absence of statistically significant differences: This was 77.1 ± 3.2 among the patients with adaptation disorder, 78.7 ± 2.6 with recurrent depressive disorder, and 75.9 ± 2.4 for organic anxiety disorder ($p > 0.05$).

When analyzing the influence of different factors regarding the elderly patients' functioning level at this stage of the study, primary attention in this aspect was paid to the possible influence of the individual's social network. For objective reasons related to the specifics of life in old age, this influence – namely having a family, relatives, or other individual social network – has always been regarded as very significant. The present study's data confirms the corresponding connection. The level of social functioning was characterized by an index above 70 points in GAF scale; i.e. a very satisfactory value, among most (17 of 21) patients having a family or receiving constant support from relatives (*Table 1*; $t = 2.9$; $p < 0.05$).

Table 1
The influence of the family presence factor on indicators of the patients' functioning
(N – number of patients)

<i>GAF score</i>	<i>Single (N)</i>	<i>In a family or with a constant support of relatives (N)</i>	<i>Total (N)</i>
<i>51–70</i>	5	4	9
<i>71–90</i>	4	17	21
<i>Total (N)</i>	9	21	30

At the same time, the psychological connotation of an individual's social network relationships was also significant in this regard. *Table 2* presents an analysis of this issue. It shows that a satisfactory penumbra of relationships with family members, in fact, excluded such a decrease level of functioning (70 points and below), which would at least become noticeable to others.

Table 2

The influence of the nature of relationships between family members on indicators of functioning (N – number of patients)

<i>GAF score</i>	<i>Family relations assessment (N)</i>		
	<i>Distressing</i>	<i>Satisfying</i>	<i>Total (N)</i>
<i>51–70</i>	9	–	9
<i>71–90</i>	9	12	21
<i>Total</i>	18	12	30

4. Discussion

The fact that in an overwhelming majority of cases (93.7%) during geriatrician visits, only moderate (non-psychotic) mental disorders are found seems to be explained by the probability that deeper deviations in mental activity prompt, if not the patient himself, then his relatives, to look for help from psychiatrists, or – with a pronounced lack of readiness for such treatments due to common mental characteristics – from neurologists.

Given the possibility of such non-compliance, one would expect higher values in the frequency of calls to the geriatrician for psychotic phenomena, which in the completed analysis manifested as one of their most frequent options – mental confusion in patients with dementia.

Non-psychotic disorders established among this study’s patients can be conditionally combined inside the concept of anxiety-depressive spectrum disorders, although anxiety neurotic disorders – traditionally referred to this group of disorders, along with two others represented in the studied patient population – in this case are ‘substituted’ by an ‘anxiety disorder of organic nature’, according to the formulation of ICD-10. This fact probably reflects objective trends regarding the elderly in whom cerebrovascular disease, as well as its combination with diabetes, occurs more often than in younger patients, and is manifested by the formation of a variety of neurosis-like (rather than neurotic) manifestations, while signs of moderate cognitive decline exist. The legitimacy for the inclusion of such manifestations – which could be more briefly named as organic anxiety disorder – into the group of disturbances on the anxiety-depressive spectrum, can be justified according to the ICD-10 criteria for this rubricate by the fact of their full coincidence with the one presented in the neurotic section (manifestations of which are constantly included into the anxiety-depressive disorders). In this regard, we can take into account the common feature of such an umbra effect for a variety of psychopathological symptoms that occur in this age. It is also reasonable to assume that a significant proportion of these patients (in the total number of patients who applied for geriatrician service), largely reflects the widespread prevalence of cognitive impairment among the elderly, which, however, does

not become a reason for visiting a doctor. Only when the combination of cognitive and affective features appears, although moderately expressed, but creating a certain mental deviation phenomenon, does such an occasion directly arise for patients and their relatives.

Depressive disorder is known as one of the most common types of mental deviations found among elderly people. In this regard, the rarity of identifying such disorders among patients included in this study requires a meaningful explanation. It should be assumed that, at least in part, the specific situation of visiting a geriatrician determines this rarity when, apparently, mental disorders in themselves do not stand as the leading cause of the visit, and are not entirely clear to either the patient or his relatives as a mental disorder and are otherwise combined with a complex of phenomena related to old age's somatic pathology and adverse psychosocial aspects. In this regard, it is indicative that in both cases of the examined patients, the diagnosis of recurrent depressive disorder was ascertained precisely by a psychiatrist who carried out the investigation, when taking into account anamnestic information about an already existing similar state in these patients. Geriatricians had diagnosed a 'depressive mood' but the previous similar state was only assessed in context of a need for a psychiatrist's consultation. Moreover, obtained data about similar episodes in the past did not establish their diagnosis of the disorder as a 'recurrent' type.

In this regard, it should also be noted that in all those patients examined with disorders of the anxiety-depressive spectrum at the stage of the geriatric examination, 'senile asthenia' ('senile fragility') was stated. This assessment is widely used in the practice of specialists of this profile; however, it can be assumed from the materials of this work that from a psychiatric point of view, the determination of the anxious component of the patient's condition is affected marginally, since the majority of those included in the study had a pronounced component of such manifestations.

The uniformity of the mental state's influence on the functioning of patients in the established diagnostic groups is most likely due to their similarity: that is, belonging to the same degree of psychopathological phenomena severity. Besides, the features of the GAF scale also play a prominent role in this regard. This scale, as well as a number of other tools for assessing the social functioning of the mentally ill, along with the prevailing characteristics of this particular aspect in the instructions for determining the desired data, also has a brief indication of the severity of psychopathological symptoms and its possible visibility to others. At the same time, it should be noted that in many aspects, this combination of partially clinically severe symptoms, and mainly the social characteristics of patients' ability to function, is inevitable and reflects the close relationship these aspects retain in the assessment of the mentally ill in general.

The data about positive impact on patients' functioning by the factor of living in the family or with the constant support of relatives appear to be expected. In this regard, it's known that loneliness remains among the common and, as a rule, adverse factors of late age. First of all, it seems necessary to consider these data in the general context of the psychological and emotional aspects of elderly people's life. In this

case, objective trends contribute to the well-known limitation of the circle of communication, and the subject of experiences associated with this circumstance largely dominates the patients' thoughts (WOODS 1999; ZOZULYA 2000). Moreover, such thoughts, in fact, affect various aspects regarding the formation of a situation of loneliness, which in relation to older people should be considered in a broader sense. This is not only a specific absence of relatives or even a situation of separation from young family members. More significant is the conscious loneliness in connection with misunderstanding microsocial relationships or being in openly conflicting ones. It is these unfavorable conditions that violate the adaptation to the natural contact restriction that comes with age. It is quite understandable that in cases when affective manifestations are present in the mental state – including within the framework of the options established in this work – the factor under consideration has a direct effect on the possibilities of compensation, which are manifested especially in patients' functioning levels. Therefore, it is no coincidence that the nature of microsocial relationships is significant, which is reflected in higher functioning indices with their favorable character. At the same time, among some patients living in a family exhibiting a warm attitude towards them, a tendency existed to seek excessive help from relatives in performing everyday functions, although at least partially this was explained by periods of decompensated concomitant somatic pathology. All this stresses that not only the timely appointment of medicines, but a psychotherapeutic correction of these conditions, as well, is needed.

5. Conclusions

More than a third of patients newly-admitted by geriatricians have mental disorders, mostly those of the anxiety-depressive spectrum. Among the reasons of these phenomena, biological factors (the formation of organic changes in the brain due to age and somatogenic influences) and psychosocial influences, are both represented. The relatively satisfactory level of social functioning of such patients can still suffer, however, and is at the same time significantly dependent on the presence of a positively tuned individual's social network.

This data stresses the need of a systematic and complex – pharmacological and, especially, psychotherapeutic – approach to prolonged socio-medical activities, carried out for the study's discussed elderly patients.

In the context of an interdisciplinary approach to the problem, the need for the systematic sustainment of a primary psychiatric training of geriatricians is clear, as is the use of simple, but informative, psychometric assessment instruments in their practical work.

References

- BALDWIN, R.C., E. CHIU, N. GRAHAM & C. KATONA (2002) *Guidelines on Depression in Older People: Practicing the Evidence Guidelines on Depression in Older People: Practicing the Evidence* (London: Martin Dunitz).
- BEZDOS, S.A. & N.E. MAKSIMOVA (2006) ‘Dolgosrochny prognoz chisla psichicheski bolnyh pozhilogo I starchyego vozrasta’ [Long-term prognosis of the number of mentally ill elderly and senile in the Russian Federation], *Rossiiskiy psichiatricheskii zhurnal* [Russian Psychiatric Journal] 5, 21–25.
- BUFFEL, T., P. MCGARRY, C. PHILIPSON, L. DE DONDER, S. DURY, N. DE WITTE, A. SMETCOREN & D. VERTÉ (2014) ‘Developing Age-Friendly Cities: Case Studies from Brussels and Manchester and Implication for Policy and Practice’, *Journal of Aging & Social Policy* 26, 52–72 (<https://doi.org/10.1080/08959420.2014.855043>).
- CHURKIN, A.A. & N.A. TVOROGOVA (2012) ‘Chastota psichicheskikh rassroystv v Rossijskoi Federacii v 2010’ [The prevalence of mental disorders in the Russian Federation in 2010], *Bulleten Nevrologii Psichiatrii I Neurochirurgii* [Bulletin of Neurology, Psychiatry and Neuro-surgery] 2, 3–7.
- DEMICHEVA, N.K., Z.I. KEKELIDZE, B.A. KAZAKOVTSSEV & E.V. MAKUSHKIN (2017) ‘Dinamika obshei I pervichnoy zabolevaemosti’ [Dynamics of the general and primary incidence of mental disorders of the population of the Russian Federation aged 60 years and older in 2000–2016], *Rossiiskiy Psichiatricheskii zhurnal* [Russian Psychiatric Journal] 4, 4–11.
- DUBENKO, A.E. (2008) ‘Cognitivnye rassnoistva I depressiya u pozhilyh – differentsialnyy diagnoz I comorbidnost’ [Cognitive disorders and depression in the elderly – differential diagnosis and comorbidity], *Zhurnal Zdorovya Ukrainy* [Journal of Health of Ukraine] 12, 30–33.
- KRASNOV, V.N., T.V. DOVZHENKO, A.E. BOBROV & E.G. STAROSTINA (2013) ‘Psichiatrya v pervichnom zvene zdavoohraneniya’ [Psychiatry in the primary health care: a new solution to the old problem], *Sotsialnaya I klinicheskaya psichiatrya* [Social and Clinical Psychiatry] 4, 5–13.
- MIKHAILOVA, N.M. (1996) *Psichicheskies rasstroistva v gerontopsichiatricheskom cabinete obshesomatiicheskoy kliniki* [Mental disorders in patients of the gerontopsychiatric office of the general somatic clinic: Clinical-statistical and medical-organizational aspects] (PhD diss., Moscow: med. sciences).
- Ministry of Health of the Russian Federation (2015) *Obshaya chastota naseleniya pensionnogo vozrasta v Rossii v 2014 (Moskva: statisticheskii materialy Ministerstva zdavoohraneniya Rossiiskoy Federacii* [The total incidence of the population over working age in Russia in 2014] (Moscow: Statistical materials of the Ministry of Health of the Russian Federation) retrieved 14 Oct 2020 from <https://www.ros-minzdrav.ru>.
- NEZNANOV, N.G. & L.S. KRUGLOV (2015) ‘Predposylki biopsichosotsialnoy determinirovannosti psichopatologicheskoy simptomatiki v pozdnen vozraste’ [Background biopsychosocial determination of psychopathological symptoms in patients of late age], *Obozrenie psichiatrii I medicinskoj psichologii* im. V.M. Bekhtereva [Review of Psychiatry and Medical Psychology. V.M. Bekhtereva Psychology] 4, 3–8.
- SLUCHEVSKAYA, S.F. (2008) *Clinicheskies I epidemologicheskies charakteristiki pozhilyh psichicheskii bolnyh v Sankt-Peterburge* [Clinical and epidemiological characteristics and the organization of medical and social care for the mentally ill elderly in St. Petersburg] (PhD diss., Moscow: med. sciences).
- WOODS, R.T. (1999) *Psychological Problems of Aging* (Chichester: Wiley).

- World Health Organization (2015) *World Report on Aging and Health*, © WHO, retrieved 14 Oct 2020 from https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1.
- YARYGINA, V.N. & A.S. MELENTIEVA (2010) *Rukovodstvo po gerontologii I geria trii* [Guide to Gerontology and Geriatrics] (Moscow: GEOTAR-Media).
- ZAKHAROV, V.V. (2006) ‘Vserossiyskaya programma issledovaniya epidemiologii I terapii kognitivnyh rasstroystv („Promety”)’ [The All-Russian Program for the Study of Epidemiology and Therapy of Cognitive Disorders in the Elderly (“Prometheus”)], *Nevrologicheskiy zhurnal* [Neurological Journal] 2, 27–32.
- ZOZULYA, T.V. (2000) ‘K probleme preotvrasheniya psichicheskyyh rassroistv u pozhilyh’ [On the problem of prevention of mental disorders of the elderly], *Psychologia zrelosti I srarenia* Psychology of Maturity and Aging 2, 113–23.

DAVID DIAS NETO*, INÊS ROCHA, MARIA JOÃO FIGUEIRAS
& ANA NUNES DA SILVA

MEASURING MENTAL HEALTH LITERACY

Adaptation and Validation of the Portuguese Version of the Mental Health Literacy Scale (MHLS)

(Received: 19 September 2020; accepted: 20 April 2021)

Understanding mental health literacy is essential for promoting empowerment and proactivity in patients, reducing stigma, and increasing population awareness. The constitutive dimensions of mental health literacy are still being researched, and instruments' research can shed light on the involved processes. The Mental Health Literacy Scale (MHLS) is a self-report measure of mental health literacy. This study aimed to adapt the MHLS to Portuguese and evaluate mental health literacy in a broad sample. A broad sample of 337 individuals participated in the adaptation. Besides filling out the MHLS, the participants were invited to fill out a general lifestyle measure. The global results reveal a good internal consistency of the MHLS. A three-factor structure (i.e., attitudes towards mental illness, knowledge about mental illness, and the ability to recognize symptoms) explained 35% of the total variance. Despite not finding an association with the general lifestyle measure, the MHLS scored higher in women and individuals with higher schooling, as expected. The results reinforce the role of MHLS as a useful measure of mental health literacy. The identified structure is discussed in light of the current understanding and implications of this essential process.

Key Words: mental health literacy; MHLS; stigma; mental disorders

1. Introduction

There has been a significant evolution in public health concerning the targets and kinds of medical treatments. An aging population means that particular conditions gain prominence. The advances in medicine have reduced infectious diseases and increased the number of treatments for chronic non-communicable diseases. Symptom management and illness prevention interventions play a more significant role.

* Corresponding author: Ass. Prof. David Dias Neto, ISPA - Instituto Universitário APPsyCI - Applied Psychology Research Center Capabilities & Inclusion, Lisboa, Portugal (ORCID ID 0000-0002-3129-262X) Rua Jardim do Tabaco 42, 1100-081; d.neto@campus.ul.pt.

Furthermore, the long duration of treatments implies that they have to become self-managed and typically imply a greater complexity and diversity in healthcare. These characteristics mean that citizens need to have an increased and accessible knowledge and they benefit from a proactive attitude toward seeking and managing treatments. Due to this evolution, international organizations such as the World Health Organization (WHO 2013) have been calling for research, intervention, and policy developments in the field of health literacy.

One of the critical domains in health literacy research is mental health. Mental health is not only an issue because of the high prevalence of mental health disorders and their impacts (NETO & SILVA 2008; WHO 2018). In Portugal, 22.9% of adults have met the diagnostic criteria for a mental disorder in the previous year, and these results are similar to other western countries (ALMEIDA & XAVIER 2013). Another reason for the relevance of addressing mental health is the high rates of stigma (NETO et al. 2017; STUART & ARBOLEDA-FLÓREZ 2012). The generalization of negative attitudes towards mental illness means that communities will not discuss or convey information on mental health issues. Stigma can, therefore, reduce individual awareness and health-seeking behaviors (GULLIVER et al. 2010).

Despite the existing literature on health literacy in general, research in mental health literacy, in particular, is still in its infancy. There is evidence that programs to increase mental health literacy improve knowledge, awareness, and health-seeking attitudes (GULLIVER et al. 2012; PALAZZO et al. 2017). Some doubts remain as to which conditions higher health literacy translates into changing behavior. These doubts also remain for other areas of health literacy, such as diabetes (AL SAYAH et al. 2013). This means that future research needs to be conducted to determine which aspects of health literacy and specifically mental health literacy are relevant for behavior change. This increased understanding is essential to promote social inclusion and to empower citizens who have mental health problems.

In mental health literacy, research has also been affected by the lack of researched instruments. Research is frequently conducted with mental health-related instruments or instruments that measure a specific aspect of mental health literacy. In a review of mental health literacy and related measures, WEI and colleagues (2015) found: 69 knowledge measures (14 validated), 111 stigma measures (65 validated), and 35 help-seeking related measures (10 validated). This lack of research as detected in the international literature is higher in Portuguese-speaking countries. To our knowledge, there are no validated instruments in Portuguese. LOUREIRO and colleagues have adapted the 'Survey of Mental Health Literacy in Young People – Interview' (LOUREIRO 2015) for Portuguese, but it is a measure developed for a research survey, and it is specific to adolescents.

The lack of validated instruments also exists in health literacy in general. Two of the reasons for this shortage may be the lack of consensus in the definition of health literacy and the lack of consideration for some of its dimensions in developed measures (HAUN et al. 2014; JORDAN et al. 2011). For example, if health literacy implies reasoning aspects, self-reported measures may be insufficient. These limitations have

two implications for the present research: Firstly, different instruments may be derived from different understandings of health literacy. Secondly, those who develop instruments must pay great attention to issues of definition and construct.

2. The Mental Health Literacy Scale

The concept of mental health literacy assessed in the MHLS (O'CONNOR & CASEY 2015) was initially designed to measure six attributes grouped into three processes: recognition, knowledge, and attitudes. The six attributes were: 1) Recognition of disorders, 2) Knowledge of how to seek mental health information, 3) Knowledge of risk factors and causes, 4) Knowledge of self-treatments, 5) Knowledge of professional help available, and 6) Attitudes that promote recognition and appropriate self-seeking. An expert panel developed iteratively the items that sought to identify the six dimensions of mental health literacy. After conducting a systematic review of the literature (O'CONNOR et al. 2014), these six attributes were identified. This formulation corresponds to the definition of mental health literacy as considered in the present study.

The authors found a four-factor structure for the final scale, but given the low communalities and mean factor loadings, they concluded that a unifactorial structure was the most meaningful interpretation. The MHLS was found to have good test-retest reliability and a Cronbach alpha of .873 (O'CONNOR & CASEY 2015). The scale also showed promising results when compared with a General Help-seeking Questionnaire, thus showing construct validity. Expanded versions of the scale have been adapted for Mandarin Chinese (CHAO et al. 2020) and Iranian (NEJATIAN et al. 2021).

The scale has been used with UK university students (GORCZYNSKI et al. 2017). The authors found that mental health literacy was higher in women and postgraduate students. Participants with a history of mental problems had lower mental health literacy levels, and the total score was associated with help-seeking behavior. Also, in the UK, the MHLS was used in a large sample of medical students (MARWOOD & HEARN 2019). The results were similar in showing higher mental health literacy levels in females and students in later years of study. Furthermore, it was higher in participants with a close friend or family member with mental illness.

The present study aims at adapting the MHLS to Portuguese. Considering the lack of measures in Portuguese, this will allow the development of further research on the topic. Also, this measure is one of the most complete measures in assessing this multi-factorial construct. Besides providing a tool for measuring this important concept, improving mental health literacy assessment can increase our understanding of this concept. This understanding is crucial for developing policies or interventions to reduce stigma and empower users. To achieve this goal, we will translate and adapt this scale. The scale's psychometric properties will be analyzed, and a concurrent validity analysis will be conducted with a lifestyle measure. It is assumed that people with high mental health literacy have better lifestyles. The current study aims at tackling the lack of mental health literacy instruments in Portugal.

3. Methods

3.1. Participants

Portuguese citizens over 16 years of age were invited to participate in this study. 337 individuals accepted the invitation. 266 (79 %) were female having an average age of 29.2 years (SD = 10.02; range 17–72). This convenience sample was gathered via a paid ad on social networks. There was an effort to include participants from different regions of the country. The frequencies by district are as follows: Aveiro 4 (1.2 %), Beja 3 (0.9 %), Braga 14 (4.2 %), Coimbra 7 (2.1 %), Évora 4 (1.2 %), Faro 7 (2.1 %), Guarda 2 (0.6 %), Leiria 4 (1.2 %), Portalegre 3 (0.9 %), Porto 21 (6.2 %), Santarém 8 (2.4 %), Lisboa 124 (36.8 %), Setúbal 131 (38.9 %), Vila Real 2 (0.6 %), Viseu 3 (0.9 %). *Table 1* presents the sample's remaining demographic characteristics.

Table 1
Socio-demographic characteristics of the sample

<i>Variable</i>	<i>Option</i>	<i>Freq.</i>	<i>Percent.</i>
<i>Marital status</i>	Married or cohabiting	101	30
	Divorced or separated	18	5.3
	Widow	1	0.3
	Single	217	64.4
<i>Professional status</i>	Full-time	149	44.2
	Part-time	26	7.7
	Unemployed	35	10.4
	Student	124	36.8
	Retired	3	0.9
<i>Schooling</i>	4 years	1	0.3
	6 years	3	0.9
	9 years	13	3.9
	12 years (secondary schooling)	121	35.9
	Bachelor degree or higher	199	59.1

3.2. Instruments

Mental Health Literacy Scale (MHLS). The MHLS is a 35-item measure with six different sections. The first section, having eight multiple-choice questions, focuses on the recognition of the most common mental health disorders. The second section, with two multiple-choice questions, explores the knowledge of risk factors and mental illness causes. The third section, possessing two multiple-choice questions, refers to the knowledge of self-treatments; namely, common strategies recommended for

mental health and wellbeing. The fourth section includes three multiple-choice questions to inquire about the knowledge of available professional help. The fifth section contains four items in a four-point Likert scale to assess knowledge on how to seek mental health information. The final section includes 16 items, in a five-point Likert scale, to measure attitudes that promote recognition and appropriate help-seeking. Twelve items have a reverse scoring. The final score is obtained by summing all the items. The scale results range from 35 to 160.

'My lifestyle' questionnaire (MLQ). 'My lifestyle' questionnaire (RIBEIRO 2004) comprises 28 items that measure healthy lifestyles in the following dimensions: physical exercise, nutrition, self-care, safety, and drug use. The items are scored on a five-point Likert scale ranging from almost always to hardly ever. In the original adaptation, the scale reached a Cronbach alpha of .76 and showed concurrent validity with a general health questionnaire (RIBEIRO 2004). In the current application, this questionnaire reached an alpha of .86.

3.3. Procedure and analysis

The Instituto Piaget review board approved the study. Three Portuguese native speakers independently translated the scale's 35 items. The three translations were discussed and harmonized considering the face and content validity of the items; small cultural adjustments were implemented to make the items understandable to a Portuguese reader. For example, the term 'mental illness' was translated as 'mental disorder' to respect Portuguese usage. A professional translator, not included previously, back-translated all the items into English to ensure that no significant deviations had been made. The original authors were contacted to assist with some of these translation issues.

The following step was the application to a broad community sample. The sample was gathered via social networks, and it was a convenience sample. An initial snowball procedure was complemented with paid Facebook ads to increase the dissemination of the study. A written informed consent was requested to access the questionnaire, and the researcher contacts were provided. Given the size of the application protocol, the participants were invited to fill in the 'My lifestyle' questionnaire a week after filling in the socio-demographic questionnaire and the MHLS. This choice led to a 19% attrition rate. Both applications were conducted online using google forms.

We conducted an exploratory factor analysis using principal component analysis (PCA) to extract factors to reduce the data into a smaller number of components, calculated as a linear combination of the original variables, to explain as much variance as possible. An oblimin rotation was used (allowing the factors to be correlated), and the selection criteria were eigenvalues greater than 1.1 and factor loadings higher than .5. The analysis was conducted using the Software Statistical Package for the Social Sciences (SPSS – version 25).

4. Results

4.1. Factor structure of the MHLS

The original scale's internal consistency of the 35 items was analyzed, and the Cronbach alpha for a single dimension was .853. The average score for the whole sample was 129.1 (SD = 12.4), range 35–160. One of the present study's goals was to investigate the factor structure of the MHLS and determine which of the items best represent each of the dimensions. This analysis included all of the 35 items of the scale and was conducted on the data collected from the 337 individuals. The factor solution produced seven factors with eigenvalues greater than 1.1, but only one factor explained more than 10% of the variance.

The original authors of the MHLS had developed the measure to assess a three-dimension formulation of mental health literacy (O'CONNOR et al. 2014). Considering this formulation, the scales' 35 items were entered into the PCA using a forced factor extraction of 3 factors, in which eigenvalues greater than 1.1 and factor loadings equal or higher than .5 were interpreted to represent a particular factor. This analysis produced a solution that together accounted for 35% of the variance.

Considering the dimensions proposed in the literature, these factors were labelled: (1) Attitudes towards mental illness (items: 29, 30, 31, 32, 33, 34, 35); (2) Knowledge about mental illness (items: 16, 17, 18, 19, 20, 21, 24, 28); and (3) Ability to recognize symptoms (items: 1, 4, 5, 6, 8). All the subscales demonstrated fairly good internal reliability, ranging from 0.66 to 0.89, and the content of these loadings is shown in *Table 2*.

Table 2
Pattern matrix of the MHLS (n = 337)

	<i>F1</i>	<i>F2</i>	<i>F3</i>
	<i>Alpha: α=.89</i>	<i>α=.66</i>	<i>α=.68</i>
	<i>Explained variance: 18%</i>	<i>9%</i>	<i>8%</i>
31. How willing would you be to make friends with someone with a mental illness?	.796		
30. How willing would you be to spend an evening socializing with someone with a mental illness?	.782		
33. How willing would you be to have someone with a mental illness marrying into your family?	.773		
32. How willing would you be to have someone with a mental illness start working closely with you on a job?	.766		
35. How willing would you be to employ someone if you knew they had a mental illness?	.738		
29. How willing would you be to move next door to someone with a mental illness?	.724		
34. How willing would you be to vote for a politician if you knew they had suffered a mental illness?	.621		
6. Knowledge on agoraphobia		.616	
1. Knowledge on social phobia		.586	
5. Knowledge on dysthymia		.578	

	<i>F1</i>	<i>F2</i>	<i>F3</i>
	<i>Alpha: α=.89</i>	<i>α=.66</i>	<i>α=.68</i>
	<i>Explained variance: 18%</i>	<i>9%</i>	<i>8%</i>
4. Knowledge on generalized personality disorder			-.556
8. Knowledge on substance abuse			.542
17. I am confident using the computer or telephone to seek information about mental illness			.555
21(-). Mental illness is a sign of personal weakness			-.545
24(-). It is best to avoid people with mental illness so that you don't develop this problem			-.544
19. I am confident I have access to resources (e.g., GP, internet, friends) that I can use to seek information about mental illness			.537
18. I am confident attending face to face appointments to seek information about mental illness (e.g., seeing the GP)			.537
28(-). I believe treatment for a mental illness, provided by a mental health professional, would not be effective			-.511
20 (-) Mentally ill people could be better if they wanted to			-.511
16. I am confident that I know where to seek information about mental illness			.503

F1 – Attitudes towards mental illness; F2 – Ability to recognize symptoms; F3 – Knowledge about mental illness. Items that scored below the threshold (< .5) for the three factors are omitted from this table.

As presented in *Table 3*, these factors significantly correlate with each other and the total score. A moderate correlation was found between ‘Attitudes towards MH’ and ‘Knowledge about MH’. ‘Symptom recognition’ weakly correlates with a ‘Knowledge about MH’ and very weakly with ‘Attitudes towards MH’.

Table 3
Pearson correlations between factors and the total score (N = 337)

	<i>Attitudes towards MH</i>	<i>Knowledge about MH</i>	<i>Symptom recognition</i>
<i>Attitudes towards MH</i>	1		
<i>Knowledge about MH</i>	.40**	1	
<i>Symptom recognition</i>	.12*	.29**	1
<i>Total Score</i>	.73**	.77**	.53**

* $p < .05$ (two tailed) ** $p < .001$ (two tailed).

4.2. Descriptive and validity analysis

The validity of the test was assessed by contrasting it with an existing lifestyle questionnaire and conducting a comparative analysis using the sample's main demographic characteristics. The global score of the MHLS was compared against the ‘My

Lifestyle' questionnaire (MLQ) results. No correlation was found between the two measures, $r(273) = .06$, $p = .364$.

A comparative analysis was carried out for the proposed factors and total score of the MHLS, according to sex, level of education, and age group (See *Table 4*). A *t*-test analysis indicated a significant difference between males and females, with females having higher total scores ($t(335) = 5.3$; $p = .000$) and concerning 'Attitudes towards MH' ($t(335) = 5.1$; $p = .000$) and 'Knowledge about MH' ($t(335) = 3.6$; $p = .000$). Age was recoded in three levels: 17–30, 31–44, and 45–72. There were no significant differences by age group concerning the proposed factors and the total score of the MHLS.

Education level was recoded into two groups: from primary to secondary level and university graduation. Significant differences existed between these two levels of education (See *Table 4*). Participants with higher levels of education have higher scores on MHLS ($t(335) = -5.23$; $p = .000$). This was also observed for the three factors: 'Attitudes towards MH' ($t(335) = -2.33$; $p = .020$); 'Knowledge about MH' ($t(335) = -4.45$; $p = .000$); and 'Symptom recognition' ($t(335) = -4.47$; $p = .000$).

Table 4
Descriptive statistics and demographic characterization of MHLS's three factors

	<i>Attitudes towards MH</i> (Min 1; Max 5)	<i>Knowledge about MH</i> (Min 2.6; Max 5)	<i>Symptom Recognition</i> (Min 1; Max 4)	<i>Total score</i> (Min 93; Max 155)
<i>Total</i>	M = 3.88 (SD = .76)	M = 4.14 (SD = .55)	M = 3.20 (SD = .49)	M = 129.11 (SD = 12.44)
<i>Sex</i>				
Male	M = 3.48 (SD = .88)	M = 3.93 (SD = .58)	M = 3.14 (SD = .47)	M = 122.4 (SD = 13.1)
Female	M = 3.98 (SD = .69)	M = 4.19 (SD = .52)	M = 3.21 (SD = .49)	M = 130.9 (SD = 11.6)
<i>Education</i>				
Prim. - sec.	M = 3.76 (SD = .80)	M = 3.98 (SD = .51)	M = 3.06 (SD = .46)	M = 125.0 (SD = 11.6)
University	M = 3.95 (SD = .72)	M = 4.25 (SD = .54)	M = 3.29 (SD = .48)	M = 131.9 (SD = 12.2)
<i>Age groups</i>				
17-30	M = 3.88 (SD = .71)	M = 4.08 (SD = .53)	M = 3.17 (SD = .47)	M = 128.6 (SD = 11.9)
31-44	M = 3.94 (SD = .80)	M = 4.30 (SD = .56)	M = 3.25 (SD = .50)	M = 131.4 (SD = 13.0)
+45	M = 3.58 (SD = .89)	M = 4.07 (SD = .50)	M = 3.21 (SD = .52)	M = 125.4 (SD = 13.4)

5. Discussion

The present study sought to develop the Portuguese version of the Mental Health Literacy Scale (MHLS). This adaptation was conducted to respond to a lack of validated instruments for mental health literacy, in general, and in Portuguese-speaking countries in particular. The overall results suggest that the Portuguese version of the

MHLS has good psychometric properties. The scale has good internal consistency showing that the items reliably represent the same construct.

As the original authors stated, no reliable factor structure was found in the preliminary unrestrained exploratory factor analysis in the present study. The original authors found that a unifactorial structure, for mental health literacy, explained their application of the MHLS. Unlike the original study, we obtained a valid structure when forced for three factors. The reason for this option was the theoretical consideration of three broad constitutive elements for mental health: relevant knowledge about mental health, attitudes towards mental illness, and recognition competencies. It is important to notice that this factorial structure merely explains 35% and that the alphas for the 'Symptom recognition' and 'Knowledge about MH' factors only approximately reach the acceptable values. Nevertheless, the results give strength to thinking about mental health literacy as the conjugation of the knowledge that individuals have about mental health and the attitudinal dimension of this knowledge as well as the application to processes such as self-recognition of signs and symptoms of distress. It is important to keep in mind that in self-reported health literacy measures, other processes or reasoning dimensions may be more difficult to assess.

The results of our population's characterizations are similar to those found in the literature. Women and individuals with higher schooling show greater health literacy. Concerning the contrast with a lifestyle questionnaire, no significant association was found with our measure. This may have happened for several reasons. Firstly, the chosen instrument was not specific to mental health. It may be that mental health literacy does not relate as well with general lifestyle measures. Secondly, the fact that not all participants filled out the lifestyle questionnaire may have skewed the results. The original study had found significant associations with a General Help-seeking Questionnaire but not with a psychological distress measurement (O'CONNOR & CASEY 2015). So, research is needed to evaluate which variables are functionally related to mental health literacy.

This study has several limitations. The size of the sample is small given the number of items of the scale (participant to item ratio is 9.6). The fact that the data was gathered online means that participants may be more literate than the general population. Furthermore, the sample was imbalanced with respect to gender (79% female). This may have affected the scale's overall results with a higher prevalence of health literacy scores. Our concurrent validity results suggest that future research needs to assess the correlation between this scale and other outcomes. Finally, there may be elements on the original scale that, despite our concern for cultural adaptation, may have a different meaning than in its original context. For example, CBT is much less familiar with Portuguese-speaking individuals than in countries from the Anglo-Saxon world. Items that involve understanding such elements may be interpreted differently in different cultures. We chose a conservative stance and kept the scale as close to the original as possible. Future research should further investigate the cultural differences in this or other instruments.

Researching mental health literacy is essential for several reasons. The understanding of mental health literacy may help to reduce societal stigma and its impact on help-seeking behavior. This understanding is also paramount in developing individual and public health interventions to improve mental health literacy. Mental-health literate individuals will be able to recognize and act upon signs of distress. This proactivity is essential in addressing the significant impacts of mental health problems and providing care, as well as promoting the inclusion of these individuals.

References

- AL SAYAH, F., S.R. MAJUMDAR, B. WILLIAMS, S. ROBERTSON & J.A. JOHNSON (2013) 'Health Literacy and Health Outcomes in Diabetes: A Systematic Review', *Journal of General Internal Medicine* 28(3), 444–52 (<https://doi.org/10.1007/s11606-012-2241-z>).
- ALMEIDA, J. & M. XAVIER (2013) *Estudo epidemiológico nacional de saúde mental: 1º relatório* (Lisboa: Nova Medical School) retrieved 4 May 2021 from http://www.fcm.unl.pt/main/alldoc/galeria_imagens/Relatorio_Estudo_Saude-Mental_2.pdf.
- CHAO, H.J., Y.J. LIEN, Y.C. KAO, I.C. TASI, H.S. LIN & Y.Y. LIEN (2020) 'Mental Health Literacy in Healthcare Students: An Expansion of the Mental Health Literacy Scale', *International Journal of Environmental Research and Public Health* 17(3), 948 (<https://doi.org/10.3390/ijerph17030948>).
- GORCZYNSKI, P., W. SIMS-SCHOUTEN, D. HILL & J.C. WILSON (2017) 'Examining Mental Health Literacy, Help Seeking Behaviours, and Mental Health Outcomes In UK University Students', *The Journal of Mental Health Training, Education and Practice* 12(2), 111–20 (<https://doi.org/10.1108/JMHTEP-05-2016-0027>).
- GULLIVER, A., K.M. GRIFFITHS & H. CHRISTENSEN (2010) 'Perceived Barriers and Facilitators to Mental Health Help-Seeking in Young People: A Systematic Review', *BioMed Central Psychiatry* 10, 113 (<https://doi.org/10.1186/1471-244X-10-113>).
- GULLIVER, A., K.M. GRIFFITHS, H. CHRISTENSEN & J.L. BREWER (2012) 'A Systematic Review of Help-Seeking Interventions for Depression, Anxiety and General Psychological Distress', *BMC Psychiatry* 12, 81 (<https://doi.org/10.1186/1471-244X-12-81>).
- HAUN, J.N., M.A. VALERIO, L.A. MCCORMACK, K. SØRENSEN & M.K. PAASCHE-ORLOW (2014) 'Health Literacy Measurement: An Inventory and Descriptive Summary of 51 Instruments', *Journal of Health Communication* 19(2), 302–33. (<https://doi.org/10.1080/10810730.2014.936571>).
- JORDAN, J.E., R.H. OSBORNE & R. BUCHBINDER (2011) 'Critical Appraisal of Health Literacy Indices Revealed Variable Underlying Constructs, Narrow Content and Psychometric Weaknesses', *Journal of Clinical Epidemiology* 64(4), 366–79 (<https://doi.org/10.1016/j.jclinepi.2010.04.005>).
- LOUREIRO, L.M.J. (2015) 'Questionnaire for Assessment of Mental Health Literacy – QuALiS-Mental: Study of Psychometric Properties', *Revista de Enfermagem Referencia*, 4(4), 79–88 (<https://dx.doi.org/10.12707/RIV14031>).
- MARWOOD, M.R. & J.H. HEARN (2019) 'Evaluating Mental Health Literacy in Medical Students in the United Kingdom', *The Journal of Mental Health Training, Education and Practice* 14(5), 339–47 (<https://doi.org/10.1108/JMHTEP-01-2019-0001>).
- NEJATIAN, M., H. TEHRANI, V. MOMENIYAN & A. JAFARI (2021) 'A Modified Version of the Mental Health Literacy Scale (MHLS) in Iranian People', *BMC Psychiatry* 21, 53 (<https://doi.org/10.1186/s12888-021-03050-3>).

- NETO, D.D. & A.N. SILVA (2008) 'Characterization of Readmissions at a Portuguese Psychiatric Hospital: An Analysis Over a 21 Month Period', *The European Journal of Psychiatry* 22(2), 69–76 (<https://doi.org/10.4321/s0213-61632008000200002>).
- NETO, D.D., M.J. FIGUEIRAS, S. CAMPOS & P. TAVARES (2017) 'Impact of Economic Crisis on the Social Representation of Mental Health: Analysis of a Decade of Newspaper Coverage', *International Journal of Social Psychiatry* 63(8), 736–43 (<https://doi.org/10.1177/0020764017737102>).
- O'CONNOR, M. & L. CASEY (2015) 'The Mental Health Literacy Scale (MHLS): A New Scale-Based Measure of Mental Health Literacy', *Psychiatry Research* 229(1–2), 511–16 (<https://doi.org/10.1016/j.psychres.2015.05.064>).
- O'CONNOR, M., L. CASEY & B. CLOUGH (2014) 'Measuring Mental Health Literacy - A Review of Scale-Based Measures', *Journal of Mental Health*, 23(4), 197–204 (<https://doi.org/10.3109/09638237.2014.910646>).
- PALAZZO, M.C., B. DELL'OSSO, A.C. ALTAMURA, D.J. STEIN & D.S. BALDWIN (2014) 'Health Literacy and the Pharmacological Treatment of Anxiety Disorders: A Systematic Review', *Human Psychopharmacology* 29(3), 211–15 (<https://doi.org/10.1002/hup.2397>).
- RIBEIRO, J.L.P. (2004) 'Avaliação das intenções comportamentais relacionadas com a promoção e protecção da saúde e com a prevenção das doenças', *Análise Psicológica* 2(22), 387–97.
- STUART, H. & J. ARBOLEDA-FLÓREZ (2012) 'A Public Health Perspective on the Stigmatization of Mental Illnesses', *Public Health Reviews* 34, 12 (<https://doi.org/10.1007/BF03391680>).
- WEI, Y., P.J. MCGRATH, J. HAYDEN & S. KUTCHER (2015) 'Mental Health Literacy Measures Evaluating Knowledge, Attitudes and Help-Seeking: A Scoping Review', *BMC Psychiatry* 15, 291 (<https://doi.org/10.1186/s12888-015-0681-9>).
- WORLD HEALTH ORGANIZATION (2013) *Health Literacy: The Solid Facts*, retrieved 1 May 2021 from <https://apps.who.int/iris/bitstream/handle/10665/128703/e96854.pdf>.
- WORLD HEALTH ORGANIZATION (2018) *Mental Health Atlas – 2017*, retrieved 1 May 2021 from <http://apps.who.int/iris/bitstream/handle/10665/272735/9789241514019-eng.pdf?ua=1>.

APPENDIX

MHLS – Item translation

Recognition of disorders

- 01) Se alguém ficou extremamente nervoso ou ansioso em uma ou mais situações com outras pessoas (ex. numa festa) ou em situações de desempenho (ex. falar numa reunião) em que pessoas como esta tinham medo de ser avaliados por outros e que agiriam de forma que era humilhante ou sentindo-se embaraçados, então em que medida considera provável que pessoas como esta tenham Fobia Social.
- 02) Se alguém ficou muito preocupado com um determinado número de eventos ou atividades onde este nível de preocupação despropositada, teve dificuldade em controlar esta preocupação e teve sintomas físicos, como tensão muscular e fadiga, então em que medida considera provável acha que pessoas como esta têm Perturbação de Ansiedade Generalizada.
- 03) Se alguém experienciou um humor negativo por duas ou mais semanas, teve perda de prazer ou interesse nas suas actividades normais e experimentou mudanças no seu apetite e sono, então em que medida considera provável que pessoas como esta têm uma Perturbação Depressiva Major.
- 04) Em que medida considera provável que Perturbações da Personalidade é uma categoria de perturbação mental
- 05) Em que medida considera provável que Distímia é uma perturbação mental.
- 06) Em que medida considera provável que o diagnóstico de Agorafobia inclua ansiedade sobre situações em que a fuga possa ser difícil ou embaraçosa
- 07) Em que medida considera provável que o diagnóstico de Perturbação Bipolar inclua períodos de humor elevado (ou seja, em alta) e períodos de humor deprimido (ou seja, em baixo).
- 08) Em que medida considera provável que o diagnóstico de Dependência de Substâncias inclua tolerância física e psicológica (ou seja, que é preciso maior quantidade de droga para ter o mesmo efeito).

Knowledge of risk factors and causes

- 09) Em que medida considera provável que no geral, em Portugal, as mulheres têm MAIOR probabilidade de experienciar uma perturbação de qualquer tipo quando comparadas com os homens.
- 10) Em que medida considera provável que, no geral, em Portugal, os homens têm MAIOR probabilidade de experienciar uma perturbação da ansiedade quando comparados com as mulheres

Knowledge of self-treatments

- 11) Em que medida considera que seria útil para alguém melhorar a qualidade do sono, havendo dificuldades em gerir as suas emoções (ex., ficando muito ansiosos ou deprimidos)
- 12) Em que medida considera que seria útil para alguém evitar todas as actividades ou situações que fazem sentir ansiedade, em caso de existirem dificuldades em gerir as emoções.

Knowledge of available professional help

- 13) Em que medida considera que é provável que a Terapia Cognitivo-Comportamental (TCC) é uma terapia que se baseia em desafiar os pensamentos negativos e a aumentar os comportamentos positivos.
- 14) Os profissionais de saúde mental estão sujeitos à confidencialidade, no entanto, existem certas condições nas quais isto não se aplica. Em que medida é que considera provável que a seguinte circunstância permitiria que um profissional de saúde mental quebrasse a confidencialidade:

Se você está em risco eminente de magoar-se a si ou aos outros

- 15) Os profissionais de saúde mental estão sujeitos à confidencialidade; no entanto, existem certas circunstâncias nas quais isto não se aplica. Em que medida é que considera provável que a seguinte circunstância permitiria que um profissional de saúde mental quebrasse a confidencialidade: Se o seu problema não ameaça a sua vida e os profissionais querem ajudar outros a apoiarem-no.

Knowledge of how to seek mental health information

- 16) Estou confiante de que sei onde procurar informações sobre perturbação mental
- 17) Estou confiante de que sei usar o computador ou telefone para procurar informação sobre perturbação mental.
- 18) Estou confiante de consigo fazer contactos pessoais para procurar informação sobre perturbação mental (ex., com o médico de família)
- 19) Estou confiante de tenho acesso a recursos (ex., médico de família, internet, amigos) para procurar informação sobre perturbação mental

Attitudes that promote recognition and appropriate self-seeking

- 20) Pessoas com perturbação mental poderiam “dar a voltar por cima” se quisessem
- 21) A perturbação mental é um sinal de fraqueza pessoal
- 22) Perturbação mental não é uma doença médica real
- 23) Pessoas com perturbação mental são perigosas

- 24) É melhor evitar pessoas com perturbação mental de forma a não desenvolver este problema
- 25) Se eu tivesse uma perturbação mental, não contaria a ninguém
- 26) Consultar um profissional de saúde mental significa que não se é forte o suficiente para gerir as próprias dificuldades
- 27) Se eu tivesse uma perturbação mental, não procurava ajuda de um profissional de saúde mental
- 28) Eu acredito que o tratamento para a perturbação mental, prestado por um profissional de saúde mental, não seria eficaz
- 29) Estaria disponível para mudar para a casa ao lado de alguém com perturbação mental?
- 30) Estaria disponível para passar uma tarde a socializar com alguém com uma perturbação mental?
- 31) Estaria disponível para ser amigo de alguém com uma perturbação mental?
- 32) Estaria disponível para ter alguém com perturbação mental a trabalhar junto de si?
- 33) Estaria disponível para ter alguém com perturbação mental casada com um familiar seu?
- 34) Estaria disponível para votar num político que soubesse que tinha sofrido de uma perturbação mental?
- 35) Estaria disponível para empregar alguém se soubesse que tinha tido uma perturbação mental?