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SOCIAL AND PROFESSIONAL PARTICIPATION IN THE CONTEXT OF VISION IMPAIRMENT

DOCTORAL THESIS SUMMARY

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KEY WORDS: disability, inclusion, vision impairment, participation, participation measurement, social and professional participation, specificity, personal factors.

Introduction

With the rise of social model of disability and, implicitly, with the opening of society towards people with disabilities through the philosophy of inclusion, in the scientific world in the field there was a shifting of emphasis from inabilities of individuals towards environmental factors that play central roles in the inclusion of persons with disabilities. Thus, there have been reported problems related to accessibility, policies and legislation, attitudes of other members of the community, equal access to education services and other environmental factors with strong impact on the social inclusion of this group, regarded as minority.

A more complex approach in the dynamic perspective upon disability - officially proposed internationally at the beginning of the Millennium - suggesting that disability is not only a problem of the person caused by a particular health problem (as stipulated in the medical model), nor created mostly socially by an insufficiently adapted medium (according to the social model), but it encompasses both aspects of the individual and its characteristics and also the social context and environment It lays. Thus, the biopsychosocial model was launched, which tries to achieve a synthesis of individual and social perspective, representing a multidimensional approach of disability.

Through this perspective there have been proposed amendments on the terminology related to persons with disabilities by replacing the terms used above (impairment, disability, handicap), the elimination of the term "handicap" and the use of "disability" as a generic term for all three levels - body, individual and society. The term disability thus became a generic term for *impairments, activity limitations* and *participation restrictions,* denoting the negative aspects of the interaction between individual and the contextual factors in which he is found.

If participation restrictions supersede the term handicap from the social model (in which it was referred to as social aspect of a disability), the concept of integration would refer to actions directed towards the reduction of participation restrictions. Participation, however, we consider that it refers to the integration from individual perspective or to the results of integration, whereas it does not concern the external actions aimed at balancing opportunities for participation, but to the actions of individuals, specifically their performance.

The study of participation, in particular in the context of a disability, requires at the moment to manage some significant challenges related to the conceptual difficulties, specific to the new areas of study. The concept of participation is ambiguously defined in the specialty literature, not differentiated clearly or at all by *social participation*, partly confused with activity or even with participation restrictions (expressed more clearly by the concept of *handicap,* according to the social model). In addition, as expected in this context, the proposed instruments to measure participation reflect the corresponding difficulties of operationalization of the construct.

In an effort to overcome these difficulties, the purpose of this paper is to study participation specificity in the context of vision impairment and the analysis of a set of its potential personal factors. In this regard, we propose as collateral objectives an attempt to clarify the meaning of the concept and its operationalization and to propose an instrument for participation measurement, developed in line with our vision on participation, inspired by the current literature.

Intending to analyze the specifics of participation of visually impaired persons and its potential factors, we were in the situation of being unable to identify an instrument for measuring participation, adequate for the special group in focus and for the context of our country, which could be adapted without too much difficulty. In this context, we developed *The Participation Measurement Questionnaire* [PMQ], an instrument that we believe has the potential to be used in both the general population and in special populations, for measuring objective participation of the inhabitants of our country. It contains common elements with other international instruments designed to measure the same construct, further original elements that allow, in our opinion, a greater measurement accuracy.

Thus, the first study that we present in this paper is related to the development of the PMQ and the analysis of its psychometric properties, following in the subsequent ones to analyze and present issues of participation of a group of 80 people with vision impairments and to investigate a set of socio-demographic and psychological factors in relation with socio-professional participation. In order to have a more complete picture of the influence of certain factors on the participation in the context of vision impairment, we also propose to analyze several cases in depth. Except for this last objective, the proposed approach through studies presented in this thesis, remains however of a quantitative, descriptive-exploratory, non-experimental nature, and the addressed theme falls on the border of special education, psychology and sociology.

The paper is divided into two parts, the first containing the theoretical background and the second including the personal contribution in the field of participation measurement and the study of its specificity in the context of vision impairment. The theoretical framework is organized into two sections, the first referring to the three central concepts (deficiency, vision impairment and participation), and the second to the issue of social integration and participation in the context of disability, especially for the visually impaired. The second part of the paper contains five chapters, in the first there are presented common methodological aspects for the personal studies and in the following chapters we present the 4 conducted studies.

Participation of adults with visual impairments is little and ambiguously addressed theme in international studies and even less at the national level, where we failed to identify publications on the subject. Except for official data regarding employment rates, no concrete data is available about other aspects of participation for people with visually impaired or other deficiencies, at least in our country. In the international literature we have identified several studies that analyzed restrictions or difficulties in participation of groups of elderly visually impaired (with age related impairments) and/ or with slighter impairments (visual acuity <0.5, for example), which, however, present very little comparable elements with our data, not refering to the objective participation.

Except for a study on the determinants of participation in a population of elderly with age related vision impairments, so far we have not identified other international or national studies to analyze objective participation in the context of vision impairment. Without claiming that we have exhausted all existing sources, at least in the known international databases, such studies have not been identified using related keywords.

I chose this field of study with initial motivation to try to identify those factors that contribute to the tendency towards isolation of some blind or toward rich social participation of others, assuming that a set of personal factors may considerably explain the variation of participation or isolation level. Overcoming scientific curiosity, I considered important to find out why – or more accurately what are the differences between two blind people who have similar socio-demographic characteristics (same age, the same level of education, a similar financial situation, as healthy or sick and possibly living in the same town) that are situated at two opposite extremes of participation. I assumed they could differ in terms of psychological health, certain personality traits, adaptation to disability, independent living skills, attitudes, interests, concerns and values in life, level of social support received and others as well.

However, taking into account the specific challenges of sampling in special populations, especially the difficulties of identifying cases with low participation, noting that the study field has not been previously treated (or at least we have not found evidences) probably from similar reasons, and that we would have to manage considerable conceptual difficulties regarding participation, we have reduced the amplitude of the initial project, emphasizing basic problems of participation, at least initially.

Under these circumstances, in the current stage of the proposed research, its main limits relate to the small number of participants and the non-probability sampling method chosen, although adaptive - we could say - given the fact that we refer to a very heterogeneous special population in terms of visual experience and the level of residual useful vision. Increased heterogeneity is due to the diversity of visual disorders often present in combination - which implies variable impairment of functional indicators of vision -, but also to the age of the impairment acquisition – which has important repercussions on the level and fidelity of visual representations.

On the other hand, in order to measure participation we use an instrument of our conception, whose psychometric properties are uncertain due to the number of participants and that we consider perfectible.

The importance of participation study derives from its impact on quality of life, both in the presence and in the absence of any disabilities. Participation can be considered a component of quality of life, whereas its subjective evaluation (in relation to the objective according to some authors) makes reference to social and productive wellbeing, two of the five domains of quality of life often mentioned. In disability conditions, participation and therefore quality of life are often affected, context in which participation specificity analysis and identification of its factors present interest not only in constatative purposes, but especially in order to contribute to the development of the scientifically justified objectives of intervention programs that focus on increasing quality of life of the various groups of disabled people.

The study of participation of persons with impaired vision might reveal certain trends or patterns of activity and participation, leading to a better understanding of the psychosocial implications of the deficiency and the possibility to develop support programs targeted on specific issues of the group. Knowledge of the most important factors influencing participation of people with vision deficiencies could provide precious information in the development of effective support models, both at the macro and micro social level, by targeting interventions at the individual level based on scientific evidence.

PART I

This part of the paper contains theoretical framework and is organized into two chapters, the first referring to the three central concepts (deficiency, vision impairment and participation), and the second to issues of integration and social participation in the context of disability, especially of vision.

Chapter 1. Conceptual framework

Impairments- disabilities- handicaps vs. Impairments- activity limitations- participation restrictions

With reference to persons with disabilities in the international literature there are used a variety of terms, especially depending on the perspective from which the disability is tackled. According to the social model of disability, in an approach proposed in 1980 by the World Health Organisation [WHO] through *International Classification of Impairments, Disabilities and Handicaps [ICIDH]* the triad impairment- disability- handicap has been used. WHO proposed a revision of it in 2001, through *International Classification of Functioning, Disability and Health [ICF],* in which the term disability is used as a generic term for all three levels, along with the replacement of the three terms through impairment, activity limitations and participation restrictions. Disability shall be deemed to be the result or effect of the complex relations between the state of health of the individual, personal factors and external factors, which refer to the circumstances of his life, introducing through this approach the bio-psycho-social model of disability. Currently in the literature both approaches are yet used in parallel.

In the paper we present a parallel analysis of the central concepts contained in the two classifications, following a foray into issues related to the evolution of the models in the disability approach.

Vision impairment

The main issues addressed in the paper regarding the vision impairment refer to the definition of the latter, functional indicators of vision, criteria for classification, prevalence, its implications in psychic plan and aspects of spatial orientation and mobility.

The phrase *vision impairment* refers to loss or partial alteration of vision, a variety of more specific terms that express the degree and type of vision impairment being covered under its umbrella. They made tradition in our country two terms that divide, basically, the range of deficiencies in a dichotomy that is intended to distinguish between two levels of severity - namely the terms *blindness* and *amblyopia*. Internationally, there are used in the same sense the terms *blindness* and *low vision* (as correspondent of amblyopia).

While the term *blindness* is widely accepted as referring to the total and almost total loss of sight (total or practical blindness), in regards to amblyopia there is more controversy, as it includes a range of degrees and forms of manifestation of the deficiency.

Vasile Preda (1993, pp. 40-41) draws the attention to the fact that at international level, "the current educational optics fence off the old dichotomy used within visual handicaps -blindness, on one hand, and amblyopia, on the other," imposing some tinting. The author describes three levels of vision functioning in children with visual impairments, expressed in blindness, low vision and partial vision, thus separating into a more operational manner two forms of amblyopia.

In its various degrees and forms, vision impairment involves the deterioration of visual functions, the most important being visual acuity, vision field, contrast sensitivity, color, light, and binocular vision. Directly, depending on the affected indicators, there are consequences for all of the abilities that depend largely on visual functioning (e.g. to read printed texts, visual guided movement.) and determining thereby impaired social functioning and restrictions on participation (through increased effort and/ or decreased independence). In addition, vision impairment also has some indirect effects on the functioning of the individual and on his participation in society, through the relative impact it may have in the psychic plan (sensorial knowledge, higher cognitive processes, the intelligence and personality plan).

Damages to the most simple act of knowledge of the world through the low quality of the visual senzations has a direct impact on the perceptions and representations of the same nature, along with a certain limitation of visual knowledge- leading at an overuse of intact sensory modalities, through the process of compensation.

Assuming the damage of input to be processed at the level of the superior knowledge, vision impairment can involve various difficulties in accessing essential and abstract information, determined mainly by the quality of the input received through the complex process of compensation. Thus, we can speak of a certain specific in the development of thinking, memory, language and imagination, especially in the context of blindness.

Adjustment to a deficiency (as a process of acceptance and psychological adjustment) and functional compensation (as a process of replacing the injured function) is done differently depending on factors such as the type, age of occurrence of the deficiency, socio-educational environment of the individual, his personality, but also- or perhaps especially- his *cerebral plasticity* degree (Preda, 2009), which makes possible the compensation process.

The concept of participation

A modern, multidimensional construct that encompasses, according to the majority of authors, physical well-being, emotional, social, material and productive well-being, is the quality of life concept (Pah & Preda, 2015). Participation can be considered a component of quality of life, whereas its subjective evaluation (in relation to the objective one according to some authors) makes reference to the social and productive well-being.

Nowadays, the concept of participation is considered to be complex and ambiguous, and there's no consensus regarding its meaning to be found in the literature, and even less a universally accepted definition (Albrecht et al., 2006, p. 1210; Dijkers, 2010; Heinemann et al., 2010; Levasseur, Desrosiers & Whiteneck, 2010; Fougeyrollas reliance, 2013 etc.). At an international symposium on the topic of measuring participation in research in the field of rehabilitation, the participants agreed that the existing definitions of participation do not have much success or are poorly elaborated and overlap other constructs (such as quality of life or integration in the community), one of the participants stating that the challenge in defining participation is equivalent to define "a good life"- both of which being equally relative (Heinemann et al. , 2010).

If we relate to the definitions proposed by the two models of disability that try to explain participation and through which the concept has come to be officially introduced (the *Quebec Model of Human Development and Disability Creation Process [QMHD-DCP]* and *The International Classification of Functioning, Disability and Health [ICF]*), it is difficult to overlook the fact that the ambiguity drifts from or maintains in the definitions proposed by them. In the first case, under QMHD-DCP, social participation is defined as the fulfillment of the individual habits of life, while ICF defines participation as referring to involvement in life situations. Firstly, there is no distinction between participation (ICF) and social participation (QMHD-DCP), given the fact that both life habits and life situations refer with the same ambiguity at the meaning of participation, and secondly both classify and include as referring to participation specific human activities, with a focus on life-skills, as well as social activities (involving social interaction specifically).

Following the content analysis of the definitions of (social) participation identified in the literature, in which they separate components of the definitions as a function of who, how, what, where, with whom and when, Levasseur, Richard, and Raymond Gauvin (2010, p. 10) concluded that the definitions focused on *"engagement in activities that imply interactions with other members of society"*. They identified 6 levels of involvement, in a hierarchy of the grade of involvement with others: activities carried out in connection with other people, being together with others, interacting with others without doing a specific task, doing a specific task along with others, help others and contributing to society.

An issue related to the significance of the concept of participation is the lack of a clear distinction between the concepts of participation and social participation, which are frequently used in parallel. Piškur et al. (2014, p. 218) consider that an amendment to the definition of ICF from involvement in life situations towards social roles, would overcome some of its limitations. Societal- level involvement would, thus, be regarded from the perspective of social roles and therefore the distinction between participation and social participation would no longer be required (ibid.). However, if we consider social participation as referring explicitly to interactions with other people, then the distinction would remain a problem.

Whereas the concept of participation is loosely defined in the literature, we considered necessary to formulate a working definition. From the analysis of the existing trends in the conceptualization of participation, we focused on the definition proposed by Whiteneck and Dijkers (2007, apud Bogner et al., 2011, p. 552) by which participation represents *functioning at the societal level and can be defined by the extent to which social roles are met*.

We chose to use an adapted working definition, inspired from the above and other studied definitions, so we refer to participation as the *level of involvement in carrying out the set of social roles the individual owns*.

Considering that following the study of specialty literature with the aim of identifying the main areas and dimensions of participation we could not identify a satisfactory model in order to operationalize the construct, we propose in the thesis a few attempts of classification of activities related to participation, aiming to inventory the most relevant and popular aspects of it. We used as classification criteria the object of participation, level of closeness in relations with others, level of involvement together with others and the roles people participate more frequently.

Chapter 2. Inclusion and participation in the context of disability

This chapter contains a brief foray into literature on social integration of persons with disabilities, followed by the presentation of relevant issues related to participation in the context of the disability, as well as the situation and main factors of employment, ending with the approach of participation in the context of vision impairment, especially in the light of previous studies identified in the literature.

Among the factors mentioned and analyzed as having an influence on the employment of persons with disabilities are the type, severity, age of acquisition of disability, associated health problems, education and vocational training of the person, use of asistive technologies, socio-educational level of the family, receipt of support services, level of psychological functioning, as well as family attitudes toward participation of the individual. Among the specific difficulties concerning employment, lie the poor possibilities in the choice of a suitable profession, waiving certain social allowances for an income that may not be permanent, but above all the reduced opening of employers for diversity in the workplace and for creating the necessary adaptations.

As regards to the impact of deficiency on the functioning and limitations in daily activity, many studies carried out on elderly have shown that low vision diminishes their ability to engage in physical activities of daily living (Bookwala & Lawson, 2011). Reading, writing, watching TV, problems of mobility outside the home, travelling around and the use of means of transport or banking operations were frequently reported as functional problems by the elderly in a study of Gunnel Nordholm, while Travis et al. Also mentioned the selection/ location and identification of items of clothing, kitchen items and money, the use of a telephone, writing a check or medication (apud ibid.). To this list we might add difficulties in organizing and identifying things (especially small ones and those very similar in texture) and documents, consultation of the instructions for use of products and medication prospects, differentiation of the medicines, the use of more sophisticated devices, home cleaning, cleaning the stains from clothing and many other tasks that normally require the use of vision.

In the case of people with visual impairments, the problem of access is particularly important in the context of participation outside the home. While inside and around the house or well-known places they are generally doing better, when they come out on the street, low vision and especially the lack of vision is associated with a real problem of mobility. The irregularities of the road, potholes, kerbs, stairs, obstacles, lack of contrasting visual warnings or auditory ones at the crossings of pedestrians or in bus stations, represents true problems. On the other hand, in public institutions persons with severe visual deficiencies have particular important difficulties to handle without an accompanying person, being forced to turn to foreign people to direct them inside the building, to read a paper or to fill out a form.

Difficulties in carrying out the various activities of daily life, have a direct impact on participation of individuals (the level of involvement in carrying out its own set of social roles) by increasing the amount of time, reducing their performance or impossibility to perform some activities, but also through the psychological impact that the difficulties might have.

The five studies identified regarding participation of visually impaired and its predictors (synthetically presented in the paper) have focused largely on the difficulties or restrictions in participation. The highest participation restrictions were highlighted in areas such as leisure, work and mobility outside the home. Visual acuity (especially at a distance), the physical and mental health (particularly depressive symptomatology) social network size or perceived importance of participation, have been identified as significant predictors of participation. As expected, they found a significantly lower participation of participants with impaired sight compared to those without disabilities.

According to the literature in the field, among the factors that have been identified most often as predictors of employment of visually impaired include the educational level, age, compensatory skills and visual status.

PART II.

This part of the paper contains the personal contribution in respect of the study of participation for persons with impaired sight and its measurement and is organized into five chapters, the first containing methodological issues common for the studies, and in the following chapters we present the four conducted studies.

Chapter 3. Common methodological issues for the subsequent studies

Taking into account the different directions of analysis proposed by the four studies for which we use the same data, in this section we presented common methodological issues, while specific objectives and assumptions for each study in part will be included in the dedicated chapters.

Participants

The sample consists of 80 participants between 21 and 62 years of age and with a visual acuity of less than 0.3, of which 47 were selected using the method known as the "snow ball" and participated to the research solely by telephone interviews in two or three sessions, while the other 33 completed an online form through which the same data were collected in the wake of posting messages on 3 groups of blind persons from Romania. With 29 of them we did the checking and completing of the protocol by phone interviews, thus ensuring reliability of data collection in 95% of cases. The paper contains a detailed presentation of the group of participants in terms of socio-demographic and disability related characteristics, some aspects of personal autonomy and psychological functioning, and a brief analysis of the 12 cases that may be considered refusals to participate in our study.

Instruments

The questionnaire for collecting socio-demographic and disability related data

The questionnaire includes 35 questions related to:

- gender, age, residence, nationality, religion
- level of education, specialization and training, occupation
- marital status, duration of the couple relationship, children, persons living with
- self-perceived or appreciated financial situation
- significant health problems and self-perceived health
- degree of vision impairments, diagnosis, visual acuity, visual field, age of aquisition of impairment and its progressive nature
- distance in centimeters (or meters) of a person recognition and of visually counting fingers
- duration of studies in a specialized school
- used and desired asistive technologies
- extent to which vision can use in everyday life
- level of Braille system and personal computer use
- self-perceived level of independence and of social support.

The Participation Measurement Questionnaire [PMQ]

The Participation Measurement Questionnaire that we developed will be extensively presented and analyzed in terms of psychometric properties in Chapter 4 of this paper. It contains a set of 29 items with numerical answer on scale ratio, which measures participation in various activities of everyday life in the areas productivity, personal relationships, community and out of the house.

The Participation Assessment with Recombined Tools-Objective -17 [PART-O-17], Bogner et al., 2011

PART-O a is an objective measure of participation and has been built on the basis of a bank of items selected from three older instruments that measure participation. The initial validation study results suggest a one dimension construct (Whiteneck et al., 2011). Initially, PART-O one has been validated on a population with moderate and severe traumatic brain injuries. Also, psychometric properties were analyzed for an abbreviated version, consisting of 17 items (PART-O-17, Bogner et al., 2011) on three groups of participants with and without disabilities aged less than 65 years. The authors allow copying and free use of the questionnaire, but not modifying it.

Depression Anxiety Stress Scales [DASS], Lovibond, S.H. & Lovibond, P.F., 1995

DASS (Lovibond, S. H. & Lovibond P.F., 1995) is a set of three self-report scale, built to evaluate the emotional states of depression, anxiety and stress, intended for administration in the general population, for persons aged over 17 years. Romanian version of the questionnaire has 21 items (Perțe, 2013) and received the acronym DASS-21R.

Adaptation and standardization on romanian population has been made by Perțe and Albu (2011) and the romanian- language edition of the manual is marketed by Cognitrom. However, DASS-21R (its items) is in public domain, not covered by copyright laws.

General Self-Efficacy Scale [GSE], Schwarzer & Jerusalem, 1995

The German version of the GSE has been initially developed by Matthias Jerusalem and Ralf Schwarzer in 1979, subsequently adapted to other 32 languages. Romanian version was performed by Băban, Schwarzer and Jerusalem in 1996, available on the website http://userpage.fu-berlin.de. The scale was designed to assess the general feeling of perceived self-efficacy, in order to predict the coping of everyday problems, as well as adaptation to different kinds of stressful life situations. It is intended for adults and adolescents older than 12 years. The authors granted permission for the use of the scale in research, non-commercial purposes, with the amendment to modify it in the light of the context of the research, as well as for use in online research, whether participation is reserved on the basis of the user name and password.

Rosenberg Self-Esteem Scale [RSES], Rosenberg, 1965

Rosenberg self-esteem Scale is one of the most popular instruments for measuring self-esteem. Published for the first time by Morris Rosenberg in 1965, the scale was the subject of numerous studies, having both applications in research and in the practice of psychology (school orientation, clinical diagnosis, psychological counseling etc.). Romanian version of the scale was adapted by Moldovan (2007). RSES can be used without express permission, however the author's family wishes to be informed on its use through the Morris Rosenberg Foundation.

Satisfaction with life scale [SWLS], Diener, Emmons, Larsen & Griffin, 1985

SWLS is a short scale, containing only 5 items and intended to measure overall cognitive judgments related to satisfaction in life. Adaptation and validation of the scale on the Romanian population was carried out initially by Marian (2007) and subsequently by Stevens et al. (2012). The authors allow free use of the scale, for both researchers and practitioners, with the only requirement of proper citation.

Procedură

Data were collected from February to March 2015, through two alternative means: telephone interviews carried out in one or two conversations with each participant (plus the first introductory conversation) and by filling out an online form by the participants, with telephone interview verification and complete of the protocols.

The protocols completed exclusively through telephone interview (47) had a total length of 2753 (49.4 hours) with a minimum duration of one participant interviews of 37 minutes, maximum 110 minutes, media 52,93 and the mode- 55 minutes. Protocols filled out by online form by the participants (33) had a mean duration of completion of 47 minutes with a minimum 26, maximum of 100 minutes, more frequently 60 minutes. In addition, with 29 of the participants we did checking and completion of the protocol through telephone interviews, with a minimum duration of 8 and maximum 35 minutes, with an average of 15 minutes.

The procedure for data collection for each of the two alternative ways is described in detail in the paper and supported by relevant annexes.

For processing and data analysis we used the program IBM SPPS Statistics 20.0.0.

Chapter 4. Study 1: development and validation of the Participation Measurement Questionnaire [PMQ]

Introductory considerations

In this section, we presented the motivation for the PMQ development, its advantages in comparison with other instruments for measuring objective participation and a justification for the difficulty of adapting PART-O-17, stating the changes that we have considered necessary for the adaptation and improvement of the questionnaire. Whereas they would have been numerous, assuming significant changes on items and scales level, we concluded that adapting the instrument was no longer an option, so we developed PMQ as an alternative for the objective measurement of participation, while remaining grateful to PART-O-17 and its authors that provided the general framework and valuable suggestions concerning areas of participation, scoring method, and ideas for the formulation of some questions.

In essence, unlike the instruments identified at the international level, the PMQ is more relevant to the specifics of our country and of the group being investigated, representing at the same time a nationally unique proposal of instrument for measuring the objective participation, also adaptable and usable in other populations.

Presentation of the questionnaire

Beginning with the analysis of the existing definitions of the concept of participation found in the literature and the instruments identified for measuring objective participation, we developed a set of 29 items that measure participation in various activities of everyday life, in the areas of productivity, personal relationships, community and out of the house. In the first version submitted to quantitative analyses, we consider in particular the last two areas as being quite flexible in terms of composition. If participation in productive activities and in personal relations are clearly being distinguished as different areas, participation in the community and outside the home could be addressed as a single domain, with the sensitive difference that the last 6 items do not refer to activities carried out in the community or in conjunction with others so explicitly, which may be undertaken in solitary and/ or relative distant presence others (maybe even more insignificant as serious the deficiency is).

To measure participation in ***productive activities***, we chose a set of 5 items which relate to:

- ❒ number of hours per week spent working for earns
- ❒ number of hours per week spent with study and courses
- ❒ number of hours per week spent on housework
- ❒ number of hours per week spent with study and at courses,
- ❒ number of hours per week spent with caring for other people

Personal relationships are captured by a set of 11 items related to:

- social network size by three different items related to people with ongoing ties:
    - number of close friends,
    - number of close relatives
    - number of other people with ongoing ties.
- frequency of personal meetings per month:
    - with close friends,
    - with close relatives,
    - with others.
- frequency of calls per month:
    - with close friends,
    - with close relatives,
    - with others.
- frequency of attendance at restrained meetings with family or friends, per month
- number of hours spent in activities with the partner, per week.

With regard to ***community participation***, we included 7 items related to:

- frequency of participation in big celebrations like weddings, christening or others similar
- frequency of attendance at meetings with many strangers (e.g. Conferences, symposia, product presentations)
- number of hours per month spent with volunteering activities
- frequency of outgoings in public places to take a meal, dessert, juice, coffee etc., per month
- frequency of participation in religious or spiritual services, per month
- frequency of attendance at meetings in a club or organization (e.g. a political party, blind association or other support group), per year
- frequency of participation in shows, concerts or sporting events, per year.

Participation ***outside the house*** include 6 items, about:

- frequency of outgoings from home, per week
- hours per week spent outside the home
- hours per week spent traveling
- hours per week spent with walks
- frequency of purchase, per month
- number of days is gone on trips, per year.

Conclusions

The dimensionality analysis of PMQ revealed a multidimensional structure thereof in contradiction with what Bogner et al. (2011) showed in the analysis of a similar instrument (PART-O-17), the difference being due to low correlation between items, which render as a multidimensional structure of such a questionnaire to be difficult to highlight. In the case of PMQ the *personal relationships* component has been clearly highlighted as a separate component, while *community* and *outside the house* have had a clearer load in the same component than separately. As regards to the items related to *productivity*, they could not be included in the analysis, whereas the lack of correlation between them (there were only two significant correlations between them) determines such an analysis to be unjustified.

With regard to the reliability of the instrument, it has been analyzed both on components (excluding items related to productivity), as well as for all items together, based on internal consistency index α Cronbach. For the items composing personal relationships, community and outside the house scales, we obtained α Cronbach coefficients between .55- .65 and .69 for the items of the two last common scales (that load in a single component according to the dimensionality analysis). For items that relate specifically to social participation, pertaining to personal relationships and community areas, Cronbach was α. 72, while for all the items (including items pertaining to the four areas) was .74.

Bearing in mind that the specifics of the instruments for measuring objective participation, such as PMQ, is more comparable with inventories of interest or personality rather than with objective tests of knowledge or skills, we do not consider necessary to precautionary approach the scales PMQ- community and outside the house, although it seems more appropriate to consider them as a single scale.

As regards the construct validity, the overall score for participation and the subscale scores have significant correlations (strong or moderate) with the instrument PART-O-17, which leads us to consider the instrument as being valid from the perspective of the construct being measured.

The main limit of the validation study of PMQ is the small number of participants we conducted analyses on, but also the difficulty of comparing data with other instruments. The difficulty arises from the fact that PART-O-17 was considered as being one-dimensional, and items were analyzed using a significantly different method (Rasch analysis), and other identified measures of participation are significantly different from the conceptual point of view, so the comparison with these would be irrelevant.

However, the CMP has proven to have adequate psychometric properties to be used for research purposes, while additional analysis is necessary, with larger samples, for its use for other purposes.

Chapter 5. Study 2: Specifics of participation in visually impaired people and its factors

Through the present study we intended to analyze, in a descriptive-exploratory approach, aspects of participation of a group of 80 people with impaired sight, with visual acuity less than 0.3, with a prevalence of cases with blindness and congenital deficiencies. The group of participants is balanced in terms of gender, age, level of education, marital status, employment status, and the presence of residual vision, which allows us to compare aspects of participation between sub-groups formed according to these characteristics.

Specifically, the objectives of this research are:

- Quantitative analysis of the specifics of participation of persons with vision impairments in the areas of productivity, personal relationships, community, outside the house and leisure
- Comparative analysis of areas and dimensions of participation according to socio-demographic and disability related variables
- Analysis of the relationships between areas and dimensions of participation and socio-demographic, disability related variables and psychological functioning aspects.

Related areas and dimensions of participation on the basis of which we will make the presentation, analysis and interpretation of results are those of the PMQ, presented above. In addition, we will analyze aspects of involvement in leisure activities (mainly solitary).

Whereas we will investigate these issues in a manner focused on description, analysis and exploration, by the present study we have a large number of hypotheses to be tested for exploring purposes, not limited to a set of pre-established hypotheses analyzed exclusively. Under these circumstances, we will point the central assumptions, grouping more analyses included in this study, on the most relevant aspects of the participation of the investigated group:

- There are significant differences regarding areas and dimensions of participation measured according to: gender, level of education, age level, occupational status, marital status, housing status (alone or with others), parental status, level of residual vision.
- The measures of areas and dimensions of participation are significantly associated with aspects of psychological functioning: general self-efficacy, level of depression, anxiety and stress, self-esteem, satisfaction with life.
- The measures of areas and dimensions of participation are significantly associated with disability related issues: the level of residual vision, impairment acquisition age, the use of Braille system, number of years of study in a special school, self-perceived independence.
- The measures of areas and dimensions of participation are significantly associated with: the number of children, number of people living with, self-perceived health, self-perceived financial situation, self-perceived level of social support, the use of a personal computer, satisfaction with involvement in social activities.

Prior to verifying this hypothesis, we presented in the extended paper the data for each dimension of measured participation and the ones related to domain scores. Also, where this was possible we compared these data with some aspects of participation identified with regard to the general population of our country.

The main results of this study will be presented in the *Conclusions* section.

Chapter 6. Study 3. Personal factors of professional participation in the context of vision impairment

We have proposed in this study the analysis of potential factors of professional participation in the case of a batch of 80 participants with impaired sight, through a set of socio-demographic, disability related variables and aspects of psychological functioning.

For this purpose, we set off from the assumptions that there are significant differences according to employment status with regard to: the gender of participants, gender, their age, study level, residual vision level, depression, anxiety, self-esteem, life satisfaction, self-efficacy, self-perceived independence and social support level, satisfaction with involvement in social activities, level of self-perception of being busy, self-perceived health and financial level.

The main results of this study will be presented in the Conclusions section.

Chapter 7. Case analysis

In this section of the paper we presented in-depth analyses of 4 different cases in terms of participation, selected from participants in previous studies presented in this paper. We proposed their study on the basis of qualitative analysis associated with the quantitative, with the aim of exploring additional issues to those from previous studies in relation to professional and social participation.

In this regard, we used both the data collected in previous studies and information collected subsequently by other two telephone interviews conducted in April 2015, the first aiming to collect relevant anamnesis information and to surprise some additional qualitative aspects concerning the socio-professional participation, and in the second the IPIP-50 personality questionnaire was applied, which is presented below.

International Personality Item Pool – 50 [IPIP-50] (Goldberg, 1992)

International Personality Item Pool (IPIP) is a project that aims to develop tools for the assessment of interindividual differences as part of the public domain, emerged as an alternative to the classical instruments of personality assessment protected by copyright laws. IPIP-50 is an instrument developed in this project that assesses five dimensions of personality: Opening, Extraversion, Emotional stability, Consciousness and Agreability, through personality markers described by Goldberg in 1992. IPIP-50 has been adapted on a sample of Romanian students by Rusu, Maricuțoiu, Macsinga, Vîrgă and Sava in 2012, the results reported in their study recommending the use of IPIP-50 in research using romanian samples.

Conclusions

The aim of this thesis was to investigate the particularities of social and professional participation in the context of vision impairment and to analyze a set of personal factors that may contribute to it, including collateral objectives as an attempt to clarify the concept meaning and its operationalization, and also to propose an instrument that measures objective participation, developed according to our view upon participation and inspired from the recent literature.

We will structurally present below the most important findings, followed by several limitations of the research and proposals of potential directions of participation study and its specificity in the context of vision impairment.

From the analysis of the existing trends in the conceptualization of participation, we chose to use an adapted working definition, refering to participation as the *level of involvement in carrying out the set of social roles the individual owns*, attempting to inventory and clasify the most relevant and popular aspects of it.

As we failed to find a proper instrument in assessing objective participation, we developed the Participation Measurement Questionnaire which, as we found, has adequate psychometric properties, indicating that it can be successfully used in research purposes, at least. Further analysis on larger samples is required in order to check whether it could be properly used for other purposes. Although perfectible, this represent an innovative proposal at the national level for assessment of objective participation, having potential to be used in other populations.

Participation in relations with aspects of psychological functioning and other variables

An important result of this research is the confirmation that participation represents an important aspect of quality of life in the context of visual impairment, too, through the significant moderate- intensity association between satisfaction with life and global participation (r=415, p<.01). Among its domains, the strongest association was found between satisfaction with life and community participation (r=328, p<.01), followed by productive participation (r_s=312, p<.01), personal relationships participation (r=304, p<.01) and outdoor (r_s=274, p<.05). The most representative participative indicators to this relation are the frequency of going out of the house per week (r_s=367, p<.01), time spent outdoor (r_s=368, p<.01), communication at distance with closed family members frequency (r_s=307, p<.01), time spend working for money (r_s=264, p<.05), and also the frequency of participation in family or with friends reunions (r_s=257, p<.05).

Furthermore, self-esteem level was positively associated with the overall score of global participation (r_s=275, p<.05), especially in the case of personal relations (r_s=230, p<.05), and community participation (r_s=282, p<.05). People who more often communicate at distance with their family members, more frequently go to public places and participate more often to concerts, spectacles and sports events (r_s=457, p<.001) and to big parties or meetings with many new people, tend to show significantly higher self-esteem levels.

People higher in outdoor participation and global participation tend to show increased general self-efficacy (r_s=328, p<.01, respectively r_s=266, p<.05), especially those who spend more time outdoor (r_s=256, p<.05), go more often to shopping (r_s=239, p<.05) and participate at big parties and meetings with many new persons (r_s=312, p<.01).

Depression levels tend to decrease as global participation and participation in personal relations increases (r_s=-264, p<.05, and r_s=-293, p<.01), those that are higher in depression have less friends (r_s=-234, p<.05), meet and communicate at distance less often with them (r_s=-237, p<.05, and r_s=-237, p<.05) and, interesting, they spend less time taking care of others (r_s=-221, p<.05). On the other hand, those who keep in touch with many people, except close friends and family members, and more often communicate at distance with them, show lower anxiety levels (r_s=-291, p<.01, and r_s=-303, p<.01), and those who spend more time in activities with their partner tend to be higher in anxiety (r_s=289, p<.01). Stress levels tend to decrease in people that participate higher in personal relations (r_s=-259, p<.05), and in those that have more friends and keep in touch with more people except close friends and family members, that tend to meet them more frequently (significant and small correlations).

In male participants, productivity score and especially time spent with household activities, was significantly associated with self-perceived independence (r_s=.329, p<.05, and r_s=.365, p<.05 respectively), the latter could represent both a cause and an effect in relation with productive participation. While male participants in our sample tend to have more severe visual impairments than women, this association suggests further in this relation the importance of independent life abilities.

For the entire sample there was a small significant trend for paid work to increase as self-perceived independence increased (r_s=225, p<.05), while time spent with domestic activities tended to increase as visual impairment indicators increased (e.g. distance for finger counting, r_s=309, p<.01), which is to be expected taking into account the specific difficulties in some of these activities, for which many blind people prefer the help of a seer, considered to be a more efficient.

The personal-relations participation score showed a tendency to decrease as special education programs attendance years increases (rs=-300, p<.01), and also with close friends number (rs=-284, p<.01). Number of people in the personal social network slightly increases as disability development age increases (r_s=232, p<.05), as well as meeting closed family members frequency (r_s=233, p<.05), which may suggest more openness towards diversification of relationships in people who acquired the impairment later in life.

People with lower residual vision slightly tend to communicate more often with friends at distance, while they also show a tendency to less frequently go outdoor, which could be partially explained by lower independence levels in the outdoor settings, particularly for those who are totally blind. Yet, during the interviews we have met some totally blind participants that can independently walk using their cane, which reduce the association's magnitude for the entire sample. On the other hand, many totally blind participants insisted upon their dependence on another person for help when leaving their home, regardless the offset’s goal, which underscores some limitations that they face in participation.

As regards the participation in community, the frequency of attendance of meetings in a club or organization tends to be greater in people with the acquired deficiency later in life (r_s=296, p<.01) and the frequency of participation in concerts, spectacles or sporting events tends to increase with both self-perceived independence (r_s=369, p<.01) and the level at which participants can use Braille system (having more serious impairments, r_s = 261, p <

.05). The frequency of withdrawals at public places tends to be slightly lower in individuals with lower residual vision and, however, slightly increased in more advanced users of the Braille system.

Involvement in leisure activities (mostly solitary) tends to increase as the level of residual vision indicators and self-perceived independence decrease (relations between r_s .406 and .405, $p < .001$). Especially the time spent reading tends to increase with the decrease in the level of residual vision (distance of a person recognition, $r_s = -.425$, $p < .001$, of counting fingers, $r_s = -.389$, $p < .001$ and the level at which he can use vision in everyday life, $r_s = -.342$, $p < .01$) and by default with the increase of the level at which he can use Braille system ($r_s = .309$ $p < .01$). Time spent at the computer tends to be increased especially in the more advanced users of the Braille system ($r_s = .436$, $p < .001$) and in those who have studied more years in a specialized school ($r_s = .319$, $p < .001$). At the telephone spend more time those with lower self-perceived independence ($r_s = -.316$, $p < .01$).

On the other hand, self-perceived financial status slightly increases in people who work more, meet family members and friends more often, communicate more frequently to them at distance and spend more time outdoors. Those that perceive themselves as being healthier, communicate at distance with family members, tend to go to public places and participate to concerts, spectacles and sports events more often.

People higher in computer abilities (self-reported) participate more often at big parties and meetings with many unknown people ($r_s = .324$, $p < .05$), work more ($r_s = .233$, $p < .05$), walk more ($r_s = .308$, $p < .01$), go to public places ($r_s = .355$, $p < .01$) and participate at concerts, spectacles and sports events more often ($r_s = .322$, $p < .01$). Self-perceived social support was slightly lower for people with higher productivity scores and for those who had lower free time activities involvement and higher distant communication frequency with closed family members ($r_s = -.322$, $p < .01$) and for those who exercise more.

Satisfaction with social activities involvement level was moderately higher in people with higher global participation ($r_s = .337$, $p < .01$), particularly in community ($r_s = .357$, $p < .01$) and in personal relationships ($r_s = .245$, $p < .05$).

Specific aspects of participation in the context of vision impairment with respect to its domains and dimensions

According to official statistics, employment participation rate in visually impaired people is among the lowest compared to other disability groups in Romania, about 3% (in 2009 it was lower than 3%, according to ANPH statistics, apud MMFPS, 2009). Less is known about the amount of time spent with paid work in active visual impaired people, our data showing similar rates to the general population (in our sample, more than 1 hour/ week, compared to relevant results extracted from Time Use Survey in Romania, published in 2013).

Less known, however, is the time spent with paid work by persons with impaired sight, and the data reported in our sample suggest that this is very similar to that of the general population (we obtained more than one hour per week, compared with the relevant results extracted from the Time Use Survey in Romania [TUS] published in 2013).

If the rate of participation in household and childcare activities is very similar to the one of general population, we can say that the time spent in such activities is considerably lower in our sample, by our calculations overreaching a reduction of 50%. Some of these differences may be due to underreporting in our sample, more likely than over reporting in the case of TUS (INS, 2013) with whose results we compared data, whereas we requested an estimate of the average time spent with such activities from the participants, while TUS used a considerably more accurate method by completing the daily logs. However, it remains a significant difference, and this might refer to the difficulties encountered in these types of activities especially by the blind (incredibly overcomed by some of them), with preference to cede them in part to other family members or persons paid for this purpose.

As in the general population, there are slight differences by gender in terms of the rate of participation in household, child and others care activities and very large differences between genders in terms of time spent in such activities (Z= -4.309, p<.001, respectively Z= -2.112, p<.05), women spending more than double the time spent by men with such activities both in the general population (average for men being 15 hours per week and for women of 35 hours according to the INS, 2013, p. 98) and in our group (the median for men being of 8 hours per week and for women of 16.5 hours).

Participation in personal relationships is significantly different depending on the gender only with regard to frequency of meetings with friends, in favor of men (using exact tests) and vary according to age category regarding the frequency of meetings with family members (chi-square=9.914 (4), p<.05) and with other persons with whom they keep in touch (chi-square=10.661 (4), p<.05). The young of 21-30 years tend to have more meetings with family members than those between 31-40 years, with a progressive increase after this age, while the frequency of meetings with others conversely differs after 40 years, dropping between 41-50 years and growing again between 51-60 years old. It is possible that this is caused by the increase of free time after 50 years, when children's activities are significantly reduced, or can be determined by increasing openness towards diversification of social relations. We cannot ignore the possibility to have differences in this respect between the generations, but investigating and explaining them exceeds the objectives of this study.

Significant differences were identified by marital status, married people having a richer social network (chi-square=8.095 (2), p<.05), communicating more often at a distance with others except for close friends and family members (chi-square=8.690 (2), p<.05) and, of course, spending more time with activities together with the partner (chi-square=15.523 (2), p<.01). Except for the frequency of distance calls with other people (higher in the case of divorced), in all dimensions of participation in personal relationships, those married have the largest average ranks and those unmarried the smaller ones, except for attending meetings.

Participation in community and in its dimensions is greater for men in our sample (by comparison of the average ranks, even if only in case of some dimensions the differences are significant), with the exception of participation in religious and spiritual services, more frequent in women.

Participation in community score differ significantly depending on education level, purporting to be higher as the studies level increases (chi-square=9.921 (4), p<.05). Specifically, in the same direction differs the frequency of attending meetings with many unknown people (chi-square=12.969 (4), p<.05), frequency of withdrawals at public places (chi-square=13.811 (4), p<.01) and frequency of participation in concerts, spectacles and sporting events (chi-square=17.685 (4), p<.01).

Overall, even though some differences are statistically insignificant (notable, however, by comparison of average ranks), married participants tend to have higher scores for participation in community, and those divorced lower. Participants without children come out significantly more often in public places and participate more frequently at parties, spectacles or sporting events.

Regarding participation outside the house, people with impaired sight from our sample spend significantly less time outside their own dwelling compared to the general population, our estimate approaching a decrease by 40%. However, some of these differences may be due to underreporting and in our sample, more likely than over reporting in case of TUS (INS, 2013) with whose results we compared the data, the motives being explained previously. However, considerable differences remain, that could be explained by the increased challenges in orientation and mobility by the blind participants and their dependence of another person for displacement, additional to the preferences we could consider somewhat adaptive, of spending leisure time. This seems more plausible as totally blind people leave their houses the rarest, with significant differences between them and those with practical blindness, respectively with low vision.

There were significant differences in outdoor participation depending on educational level, both the overall score (chi-square=11.216 (4), p<.05) and the time spent on transport means (chi-square=12.125 (4), p<.05) increased with education degrees. We also identified significant differences by age category, regarding the overall score (chi-square=7.947 (3), p<.05) and home leavings per week (chi-square=8.406 (3), p<.05), both being lower in 41-50 aged participants and higher in the others, particularly in 51-62 age interval.

As regards leisure time activities, overall score significantly differs by residual vision group (it lowers as the residual vision increases, chi-square =11,642 (2), p<.01), but also time spent at the computer (that tops among totally blinded persons, followed by those with low vision, chi-square =8,711 (2), p<.05), time spent reading (which decreases with the increase of residual vision, chi-square =13,177 (2), p<.01), time spent listening to radio (greater in practically blind group, followed by the totally blind, chi-square =7,904 (2), p<.05) and exercise frequency (which drops as residual vision increases, chi-square =6,805 (2), p<.05).

Time spent reading was significantly higher in men (Z=-1.994, p<.05, $\text{median}_{\text{men}}$ =7.5, $\text{median}_{\text{women}}$ = 5 hours/week), as well as time spent at the computer (Z=-2.727, p<.01, $\text{median}_{\text{men}}$=10, $\text{median}_{\text{women}}$=2,5 hours per week, which also happens in the general population, according to INS, 2013). By comparing mean ranks, we observed that men also have higher leisure time activities participation scores, they listen to radio and exercise more, while females spend more time watching TV and talking to the phone.

Of the visually impaired people in our sample, 90% spend more than one hour per week reading, while in general population there are only 26,45% (activity participation rate, according to INS, 2013, p. 185). Even if we compare this data to those that graduated university in the romanian general population (of 38%, the highest depending on the study level), in our sample would still be double. Moreover, if averaged reading time in general population was 1 hour and 17 minutes per week (ibidem, p. 113), our median was 7 hours per week, which determines us to consider that time spent reading in visually impaired people is considerably higher. This is due to increased amount of necessaire time for reading the same content under conditions of low vision, respectively of blindness through audio reading.

The situation regarding computer usage is similar, our sample showing a rate of 82.5%, compared to the one of general population, of only 14.5% (INS, 2013, p. 183). Even if we compare the data to the 22-44 aged students in the general population (with the highest computer-usage rate, of 68,4%, as the same source indicates), there is still a significant difference of 14% favoring our sample. Time spent at the computer differs in a similar manner as time spent reading, which could be determined by the fact that many people in our sample use the computer for audio and classic reading.

Time spent at the computer for entertainment was significantly higher in 21-40 age group as compared to 41-62 and for unmarried persons, compared to the lowest of those that were married.

Large differences were also found regarding radio listening, which rate in the general population is of 7.25 (INS, 2013, p.186), while in our sample is of 78,7%. Mean time spent listening to radio in the general population is less than 20 minutes per week (ibidem, p. 114), while for the visually impaired people the median is 5 hours per week. On the other hand, more that 96% of romanians spent time watching TV (INS, 2013, p. 185), compared to 72,5% in our sample. On average, romanians spend 16 hours and 15 minutes per week watching TV (ibidem, p. 114), while our sample's median was only 5 hours. This was expected, taking into account that the activity is more relevant and rich by stimulating visual processing, not just listening (which is the case for at least 50% of our sample), that could be demotivating for visually impaired people. There are also non-significant trends suggesting that women and divorced persons tend to spend more time watching TV.

On the other hand, visually impaired participants in our sample spend almost fourth as much time at the telephone as compared to general population, this estimation being made by assessing averaged monthly traffic of mobile and fixed-line telephone services (summed) in Romania in 2014 (as ANCOM data indicates). Although differences are not statistically significant, females tend to spend more time speaking at the telephone, while married people spend less.

Professional participation in the context of vision impairment

Participation in paid work activities in our sample was similar for men and women regarding time spent working, with a 14% difference in work participation rate in favour of men. A similar fashion was shown in the general population, with 25-64 aged men indicating a 19.9% higher participation rate that women (INS, 2013, p. 169), gender differences being also identified internationally with other disability groups.

Active men perceive their financial status significantly better than women, similarly their abilities of using Braille system and computer, although they have lower levels of residual vision. Gender differences regarding computer usage were also shown in general population, while higher Braille usage in men could be explained by the more severe impairments.

Differences regarding working hours as a function of educational level in our sample were non-significant, as tested with Kruskal Wallis Test ($p_{\text{Monte Carlo}}$=534). If, however, we analyzed mean ranks of hours spent working depending on the educational level, we could observe considerably reduced rates for vocational and high school graduates as compared to post-secondary school, faculty and post-graduate graduates.

If we relate to occupational status, we can notice that graduates of vocational school and high school are balanced in relation to employment status, instead of post-secondary school graduates are mostly occupied (percentage of those busy being of 70,59%), similar to the faculty graduates (but in a smaller percentage, of 59,26%) and with post-graduate studies (of which 60% are occupied). Thus, although differences as regards the occupational status are statistically insignificant in relation to the level of study, we can say that the rate of employment is considerably increased in graduates of higher levels than high school.

In our sample, 60% of those with total blindness are active, while 50% of those with practical blindness and 61% of those with low vision, with no significant differences regarding occupational status by impairment severity, as well as regarding time spent working. Results of previous studies are contradictory as regards the influence of visual status or residual vision level on work participation. Leonard et al (1999) reported that this factor had a strong impact on income, which is blind people had better chances of occupying higher positions compared to low vision ones. On the other hand, Darensbourg (2013) also found visual impairment severity as a significant predictor of employment outcomes, but in the favor of those with low vision.

There were differences according to the occupational status regarding satisfaction with life (Z=-1.885, p_{exact}<.05), self-esteem (Z=-1.739, p_{exact}<.05) and general self-efficacy (Z=-2.034, p_{exact}<.05), which were higher in active participants. In contrast, the inactive ones had higher anxiety levels (Z=-1.744, p_{exact}<.05).

As expected, we identified significant gender differences with respect to these aspects. Among active participants, women had significantly higher anxiety levels (Z=-2.064, p<.05), while among those inactive, women had significantly higher levels of both anxiety (Z=-2.058, p<.05) and depression (Z=-2.354, p_{exact}<.01).

Previous studies showed that employed, as compared to unemployed people tend to express higher anxiety and depression disorders prevalence, have higher rates of alcohol consumption, and lower self-esteem and quality of life levels (Dutta, Gervey, Chan, Chou & Ditchman apud Chan, Strauser, Gervey & Lee, 2010).

On the other hand, employed participants in our sample spend less time in leisure time activities (mostly solitary), particularly reading besides compulsory study (Z=-2.765, p<.01) and tend to have greater outdoor participation scores (Z=-2.695, p=.055).

Interestingly, our study participants that do not work for money spend considerably less time with domestic activities (mean ranks_{women}=31,47, $_{men}$=17,89 for active ones and $_{women}$=21,58, $_{men}$=12,33, Z=-2.695 for inactive participants, p<.01), perceiving themselves as more dependent (Z=-2.167, p<.05) and less healthy (Z=-1.736, p_{exact}<.05) as compared to active ones, have poorer abilities of computer use (Z=-1.689, p_{exact}<.05), and tend to use assistive technologies less (Z=-1.736, p_{exact}=.054).

We also tested whether there were occupational status and gender differences in participation domains, and found gender differences in personal relations participation for active participants (mean ranks_{women}=18,82, $_{men}$=26,8 Z=-1,986, p<.05), but also regarding leisure time activities participation (mean ranks_{women}=17,32, $_{men}$=27,85, Z=-2,630, p<.01). We assume that these differences may be, at least in part, due to higher amount of time spent by women in household, childcare and others care activities, remaining thus significantly less available time for other types of activities.

Case analysis

Evidence presented in the four conducted case analysis support the idea according to which personal factors as autonomy, personality traits and psychological health are strongly linked to participation related aspects in the context of vision impairment, suggesting both that these variables could considerably explain participation variance, but also the possibility of significant cause-effect relationships.

In all the cases, family over-protection tendency has been highlighted, particularly from parents, representing an important problem highlighted by the participants and an obstacle to the development of independent life skills. In one of the four cases there was no significant improvement of this issue over time, and the participant considered that it had the effect of maintaining her family dependence, with a reduced overall-participation, in contrast to another case which reported that this problem was successfully reduced over time, with a supportive parenting style maintained and the participant is at the present completely autonomous with high participation levels accross all domains.

Likewise, there were emphasized important psychological problems, for example one participant experienced an existential crisis associated with moderate levels of depression symptoms (with history of a suicidal tendency), a very low personal perceived value, dissatisfaction with life and useless feelings, which lead us to the conclusion that professional support is required, on a priority basis from psychological viewpoint. We consider that an intervention focused on depression symptoms reduction and increase of self-esteem and self-efficacy levels would improve their emotional vulnerability and diminish the risk of threatening her life again, while enhancement of her psychological status would have greater chances to also conduct to solving some of the stringent external problems, regarding relations and socio-professional integration overall.

Another case faces isolation in a rural area, has minimal independent life skills, does not see any possibility to improve her quality of life, is discouraged as regards her evolution possibilities and flees in solitary leisure activities, such as reading. We believe she could greatly benefit of a functional rehabilitation programe focused on increasing personal autonomy, especially the autonomy of movement into large spaces would have a strong impact on her quality of life, and in conjunction with formation or improvement of other skills and abilities, this could lead to a significant increase of her social and professional participation.

The analyzed cases confirm the idea that psycho-pedagogical support is required in the context of vision impairment in adulthood too, when psychological and social functioning of individuals may be significantly affected, leading to a variable decrease in quality of life, depending also on their context and life.

Limits of the research and potential directions of study

The main limits of the proposed research refer to a small number of participants and to the non-random sampling method chosed, although this could be considered adaptative taking into account that we refer to a very heterogeneous special population in terms of visual experience and usefull residual vision.

Increased heterogeneity is due to the diversity of visual diseases, often present in combination - which implies variable impairment of vision indicators - but also to the age of impairment aquirement - with significant repercussions upon the level and fidelity of representations. As regards the small number of participants, it imposes certain limits in the possibilities of data analysis and interpretation, but we preferred assuming them in favour of collecting quality data and ensuring its accuracy as much as possible.

Although we consider interviews (by telephone or face-to-face) as the the best option for data collection in similar type of research, allowing a significantly better control of the data quality, this is a costly and presents increased risk to obtain desirable responses even in the context of anonymity. In our research, besides considerable sampling difficulties, scheduling and, in most cases, re-scheduling the interviews came out to be a real challenge until their effective ongoing, assuming a significantly higher time consumtion than expected. Regarding the sampling method, we consider our choice (snow-ball type) as one of the best non-random available method, although we would propose an enhancement of it, eventually by selecting participants who would recommend other participants depending on relevant socio-demographical characteristics, in different sampling stages. Another advantage of the method observed along is a greater openness and accountability of participants due to the recommendation by an acquaintance, with a direct effect on the low rate of refusals of participation.

Online data collection alternative is promising even in the population with vision impairments, if research objectives allow this, but with the condition of considerably smaller sized data sets. In our case, the majority of the protocols were incomplete, implying subsequent efforts to contact the participants on different channels, and interviewing them in order to collect missing data.

In addition, we performed a verification over all the protocols where it was possible, as we considered it as being necessarily given that many participants completed their forms online, using synthetic voices and particularly as we asked for averaged estimations of participative data and wished for confirmation of correctly instruction comprehension in each case (and, if necessarily, recollection of data). We suppose that asuming the responsibility by requesting participant's names in online studies would guarantee a higher validity rate of the protocols, but this could considerably affect response’s honesty. A possible solution might be to use a scale for identification of the tendency for desirable responses, followed by exclusion of those protocols associated with high scores.

On the other hand, we measured participation by using our instrument proposal which has uncertain psychometric properties taking into account our sample size and which we consider perfectible. Nevertheless, PMQ has proven to have adequate psychometric properties at least for its usage in research purposes, further analysis on larger samples being needed in order to use it in other purposes. Additionally, we consider that the study of alternative scoring methods would be needed, founded on the idea of balanced participation between domains, which might be more relevant than the overall participation averaged score with respect to quality of life.

Likewise, investigation of participation in special populations would be more relevant by comparing it to the general population normative data. Given that there is no such data available, a genuine study proposal would consider that aspect. The idea of participation norms was previously challenged in the literature, but on the other hand the importance of participation in well being was well highlighted and we propose aproximation of normative data through relations of different participation areas with representative aspects of well being, in larger samples from general population.

With regard to the importance of participation, a direction of study may be linked to causal relations of it with aspects of psychological functioning. In this respect, we assume that interventions focusing on the reduction of depressive and anxiety symptoms, improvement of self-esteem and self-efficacy, aceptance of disability, but also development of some deficitary social skills (e.g. assertiveness, amability, flexibility, responsibility, persuasion, perseverance, self-control, social confidence s.o.) would lead to a significant increase in the level and satisfaction with participation, thereby enhancing the quality of life. Previously, however, there could be studied psychological factors that differentiate as predictors of global participation and its domains.

In the context of visual impairment, we propose that overall and specific dimensions participation variance could be well explained by independent life abilities development level and other concerns of psychological functioning, and that interventions focused on problematic ameliorable aspects could lead to improvement of important participative components.

In addition, taking into account that the accessible occupations palette available especially for the blind is perceived as being extremely restrained, we propose that an analysis of all the possible and adaptable occupations would be highly useful, with the aim of broadening the horizons of young people who are blind, concurrent to the improvement of access and effectiveness of specialized scholastic and professional orientation services.

BIBLIOGRAFIE SELECTIVĂ

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