



AN ISOLATED TOTALLY BLIND YOUNG WOMAN - CASE ANALYSIS

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Abstract

The paper presents the third in-depth analyze of a series of cases selected from a broader study concerning the issue of participation in the context of vision impairment. The participant with pseudonym Butterfly remarked since she faces isolation in the countryside, 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. I consider she would maximally benefit from a specialized psychological intervention, correlated with following a functional rehabilitation program focused on increasing her personal autonomy, especially regarding spatial orientation and independent movement outside the house.

Keywords: social participation; isolation; blindness; psychological functioning

Introduction

The paper presents the third in-depth analyze of a case selected from the 80 participants in a broader study (briefly presented in Răcășan, 2016 b) concerning the issue of participation in the context of vision impairment. The cases analyzes in the series have been conducted with the aim of exploring additional issues to those from previous studies, in relation to professional and social participation. The other two in-depth analyzed cases have been previously published in papers with a similar structure in Răcășan (2016 a) and Răcășan (2017).

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Method

For the purpose of the present case analysis, we used both the data collected in a previous study (February-March 2015) and information collected subsequently by two other telephone interviews conducted in April 2015, the first aiming to collect relevant anamnesis information and to ascertain additional qualitative data concerning social and professional participation, while in the second phone interview the personality questionnaire was applied.

Instruments

While the instruments have been briefly presented in Răcășan (2016 a, 2016 b) and extensively presented in Răcășan (2015, pp. 42-61), in the present paper we will only enumerate them:

- *The questionnaire for collecting socio-demographic and disability related data* (Răcășan, 2015);
- *The Participation Measurement Questionnaire (PMQ)* (Răcășan, 2015);
- *The Participation Assessment with Recombined Tools-Objective - 17 (PART-O-17)* (Bogner et al., 2011);
- *Depression Anxiety Stress Scales (DASS)* (Lovibond & Lovibond, 1995; Perțe, 2013);
- *General Self-Efficacy Scale (GSE)* (Schwarzer & Jerusalem, 1995; Băban, Schwarzer, & Jerusalem, 1996);
- *Rosenberg Self-Esteem Scale (RSES)* (Rosenberg, 1965; Moldovan, 2007);
- *Satisfaction With Life Scale (SWLS)* (Diener, Emmons, Larsen, & Griffin, 1985; Marian, 2007; Stevens et al., 2012);
- *International Personality Item Pool – 50 (IPIP-50)* (Goldberg, 1992; Rusu, Maricuțoiu, Macsinga, Vîrgă, & Sava, 2012).

Presentation of the case

General information

Pseudonym: Butterfly, gender: female, nationality: Romanian, religion: Orthodox

At the date of the interviews, Butterfly was 26 years old, single, with no children and lived in a village in Romania together with her father, his concubine and his mother. She has a twin sister that lives in another country

and two other sisters, one also established in another country and the other one living in a close city.

Her family history includes the movement from the south of the country to the west, the twins living a few years with the grandparents, the divorce of the parents, Butterfly living with her distant mother and the move at the countryside, to live with her father and her grandmother.

She studied for 2 years in a regular school and 12 years in specialized schools for the blind, with good results. She graduated high school with *Environment protection* specialization, after post high school studies obtaining a *Balneo- physio- kinesitherapy* diploma.

Butterfly has total blindness, innate; she underwent 14 surgical interventions with the only effect of temporary color perception, lost afterwards and remaining with the perception of light. She doesn't have any other significant health problems, with her overall health appreciated as being good (8, on a scale from 1-10). In terms of assistive technologies, she only uses an adapted computer and an adapted mobile phone.

She declares that she is an advanced user of the Braille system (10, on a 1 to 10 scale) and a medium computer user (6, on the same scale), she rates her actual level of independence at level 4 and the level of self-perceived social support as being 9, on the same scale.

Relevant anamnestic aspects and family context

Regarding parent's studies and occupation, her father graduated high school and is unemployed, while her mother also has post high school studies and higher education, being in pension. She has very close relations with her both sisters, good relations with her father and with grandmother, while with the mother she has a distant relation, both emotionally and physically. Regarding her mother, butterfly tells that they only meet twice a year and that she did not benefit from her emotional and practical support, and considers her mother as being a rather distant, difficult and selfish person.

During studies, parent's expectations were not very high regarding her school results, but occasionally her mother pressured her to study. Likewise, as Butterfly says *"They encouraged my dependency ever since I was a kid and my grandparents did the same. Only one grandmother let me to do some things. I always felt their over-protection and it always bothered me. I saw other parents different and of the former colleagues, many are on their own. I think this is*

also related”[...]. “I only started to wash dishes in high school. I do not know how to go through the village alone. Nor would anyone leave me. I always go with someone”.

Some aspects of psychological functioning

Butterfly had a medium self-esteem level, as measured with the *Rosenberg scale* (score = 32), and a low level of self-efficacy (*General Self-Efficacy Scale* score = 15), as compared to the other 79 visually impaired participants in the larger study. According to the sub-scores obtained in *Depression, Anxiety and Stress Scale* (6 for depression, 3 for anxiety and 4 to stress) she seems to have mild symptoms of depression, and is unsatisfied with her life (score = 14 at *Satisfaction With Life Scale*) compared to the general population ranges, and also to the other 79 visually impaired participants.

According to the results obtained at the IPIP-50 personality questionnaire, as compared with a sample of 747 Romanian students, Butterfly has a very low level of openness, is an introverted person, with medium levels of agreeableness, emotional stability and conscientiousness (scores of 22, 15, 39, 26 and 34 in dimensions openness, extraversion, agreeableness, emotional stability and conscientiousness).

Issues regarding social and professional participation

Compared to the other 79 participants with visual impairments, Butterfly had low and very low levels of participation in productive activities, in personal relationships, outside the home and in the community. Instead, she was heavily involved in leisure activities such as reading, TV and computer. She had a small number of people in her social network (she declared to have 2 close friends, keep in touch with 3 family members and only 10 other people) and not being involved in a love relationship. Overall, she had a low level of global participation and was unsatisfied with her involvement in social activities (she places herself at level 2 on a scale from 1 to 10).

The choice of specialization for college and accessibility issues during studies

Butterfly chose the specialization for post high school studies on the basis that it is suitable for the blind, even if her father did not agree with the choice, motivating that she is too frail for massage. She wanted to study *Sociology*, but sustains that her mother did not support her. During the studies

she did not encounter any difficulties related to accessibility, as studying mostly in specialized schools.

Professional inclusion

Butterfly would like to have a job, but she considers her options as being very limited and is also irresolute. Moreover, her father discourages her and the mother's support is absent. As expected, she hesitatingly finds some answers when asked about what she would like to work and what she could work. At the time of the interview, she had never been or tried to be employed.

Social integration and perceived attitudes

When asked about how she perceives people's attitudes towards her, Butterfly answers *"People look at you as if you would be worthless... until they get to know you. Some people in the village even think that somebody else feeds me. A blind person has to fight to show others that he can do different things"*.

She also mentions that it frequently happened to feel pity from the others (answering to *"Did you ever felt like being regarded with pity?"*) and considers that especially in the villages this is a usual reaction. She also exemplifies her felt discriminated: *"when a doctor talked only with my father, ignoring me as if I wouldn't be capable to understand [...]"*.

Question: *"When you went to school, did you felt easily accepted by others or on the contrary, you have been viewed with skepticism? Did you felt rather dismissed or admired?"*

Butterfly: *"At the regular school my colleagues laughed at me, sometimes tripped me and others alike"*.

Case summary and conclusions

At her 26 years old, Butterfly is a young woman that apparently prefers to avoid looking to the future, the outlooks being almost absent. She never had a job, being discouraged by her father who thinks that massage isn't suitable for her, and even if she would find a job in the city there would be nobody to help her with the transport, in addition to the low profitability of the activity. Butterfly agrees, considering that she would be completely dependent by an attendant and that her only option would be to work from home, eventually on the computer.

In the family they did not try to develop her independent life abilities, on the contrary. She mentions that she started to wash the dishes only in high school and that she is actually completely dependent in going out of the house. She says that she never went alone in the village and that her family wouldn't even allow her to. Butterfly notices that her dependency had been highly encouraged, and considers that this has negatively influenced the development of her skills, as compared to the performance of other blind colleagues who have been treated differently at home.

She seems to have mild symptoms of depression, a low self-efficacy level and is unsatisfied with her life compared to the general population ranges, and also to the other 79 visually impaired participants. She has a very low level of openness, is an introverted person, with medium levels of agreeableness, emotional stability and conscientiousness. Overall, she has a low level of global participation and is unsatisfied with her involvement in social activities.

Butterfly is isolated in the countryside, has minimum independent life abilities and does not see possibilities to increase her quality of life. I deduced that she would want a change in her life especially by increasing her personal and financial autonomy. However, she doesn't see the means to do so considering her actual life context, feels discouraged by her possibilities of development and flees in solitary leisure activities, such as reading. I consider she would maximally benefit from a specialized investigation and intervention for her psychological issues, correlated with a functional rehabilitation program focused on increasing her personal autonomy, especially regarding spatial orientation and independent movement outside the house. Additionally, with the formation of other practical skills and improvement of some social skills could lead to a significant increase in her social and professional participation and, implicitly have a strong impact on her quality of life.

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