

Academic research as human activity: Occupational Therapy contributions for consumer participation

Tatiana Dimov^a, Ellen Cristina Ricci^b

^aDepartamento de Terapia Ocupacional, Universidade Federal de Santa Maria – UFSM, Santa Maria, RS, Brazil.

^bDepartamento de Saúde Coletiva, Universidade Estadual de Campinas – UNICAMP, Campinas, SP, Brazil.

Abstract: The involvement of consumers in research is a recent trend in the world. Involving consumers in researches on health services, therapeutic approaches, effectiveness of support groups, mutual help groups, and even on medication is crucial for obtaining academic results that are representative of the group of consumers, and influence public policies that are effective and functional for consumers. This paper presents an analysis of how consumers can get involved in a research and what can be the role of an occupational therapist in such activity. When governed by the principles of autonomy, empowerment, and recovery, researches with consumer participation promote the principles of equality and recognition, allowing inclusion in the research process, and promoting the recognition of consumer knowledge. As an activity, research can be a motivator, mobilizing wills and desires. It can also be a possibility of leaving stagnation and making decisions. The occupational therapist can help this process. Occupational therapy focus on activities that are significant to the life of individuals. Participation in research becomes a focus for the therapeutic process to the extent that it presents itself as a demand for the client.

Keywords: *Occupational Therapy, Mental Health, Health Service Evaluation, Research Subjects, Consumer Participation.*

A pesquisa acadêmica como atividade humana: participação de usuários da saúde mental e as contribuições da Terapia Ocupacional

Resumo: A participação de usuários em pesquisas é uma tendência recente no mundo. Pesquisas deste tipo enfocam serviços de saúde, abordagens terapêuticas, efetividade de grupos de apoio e ajuda mútua, e medicação. Essas pesquisas são fundamentais para a obtenção de resultados acadêmicos que sejam representativos do grupo de usuários, além de influenciar políticas públicas que sejam efetivas e funcionais para os mesmos. Este artigo apresenta uma análise sobre como pode se dar a participação de usuários de serviços de saúde mental em pesquisas e qual pode ser o papel do(a) terapeuta ocupacional nesta construção. Percebe-se, nestes processos, quando regidos pelos princípios de autonomia, empoderamento e *recovery*, que vão ao encontro dos princípios de igualdade e reconhecimento, na medida em que possibilita não só a inserção no processo de pesquisa, mas também a possibilidade de vivenciar uma relação de igualdade pautada na valorização da experiência e no reconhecimento do saber dos usuários. A atividade de pesquisa pode ser um agente motivador, que mobiliza vontades, desejos, além da possibilidade de o sujeito sair da estagnação e tomar decisões. Dentro desse processo relacional, o(a) terapeuta ocupacional pode co-construir ou reconstruir a ação dos sujeitos no mundo. Entendendo que a terapia ocupacional tem como objeto de trabalho as atividades que são significativas na vida do indivíduo, a participação em pesquisa se transforma em foco para o processo terapêutico, na medida em que isso se apresenta enquanto demanda para e do próprio sujeito em questão.

Palavras-chave: *Terapia Ocupacional, Saúde Mental, Avaliação de Serviços de Saúde, Sujeitos da Pesquisa, Participação Comunitária.*

1 Introduction

Consumer's participation in researches is a recent tendency, not only in Brazil, but in such countries as Australia, Canada, USA, United Kingdom and New Zealand. It is understood that this kind of participation in researches about healthy services, therapeutic approaches, effectiveness of groups of support and mutual help, and even about medication, is fundamental for the acquisition of scientific results that be representative of consumer's groups, besides influencing public politics that be effective and functional for the group of people who are attended.

Dantas and Oda (2014), in an article about studies and publications related to evaluation of services of mental health in Brazil, realized a bibliographic survey through "Banco de Teses da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior" (Capes), and the "Biblioteca Virtual de Saúde" (BVS), and they identified that, in the period between 2004 and 2013, in only 12 (17.6%) of the thesis and dissertations, consumers were the principal and unique source (Scielo, Scopus and Academic Google), and found consumers as single group or together with other informers in 34 articles (33.1%) and, in 16 articles (15.5%), were involved concomitantly mental health workers, direct consumers from the services and consumer's parents.

In Brazilian scenery, we can perceive a lack of works that value the voice of the consumer as a principal informer and service evaluator. In that way, this article intent to present a reflexion about the possibilities and limitations of the role of the occupational therapist together with the consumers of the mental health that participate in academic researches.

2 Civil Society and Knowledge

In dis-centered and pluralists societies, there are many public spheres, those that articulate themselves around common themes, politics circles or functional points of view (HABERMAS, 1997). The public politic sphere is present in diverse domains, extending from free companionship environments to gatherings organized by associations and social movements, showing themselves as

[...] an intermediate structure between the politic system, for one side, and the private sectors and specialized systems of action

in terms of functions, for the other [...]
(HABERMAS, 1997, p. 107).

The debate in those spheres is characterized by dialogicity, by "communicative freedom", conceded by both parts. Among those diverse public spheres, Habermas (1997) considers that the civil society has better capacity for capturing specific problems that affect individuals and groups, once allows the spontaneous speech, out of the conventional/formal politic arena.

Castells (1997) emphasizes the importance of social movements as legitimate way of civil society organization, understanding that the spontaneous character of the speech on those discussion spheres allows the revitalization of practices and democratic institutions. In this way, the civil society contributes for the debate's widening in public sphere, searching for alternative solutions for common problems.

Habermas (1998) presents, in his theory, the breakup with the elitist perspective that the rationality is produced by a determined group, being in that way anchored in public practices of discussion. In that way, the subject is lead to offer the reasons that signify their actions in order to present to others an explanation through a speech, that is publicly shared. For the author, the change in the social order depends on the collective action and, mostly, on competent social actors, with social learning capacity. The public opinion, result of the collective discuss process, subsidize the "taking of decisions" on the formal instances, democratically constituted, of the public system.

Considering this, mental health services consumers are understood here as one of the groups who disputes public space, when they claim their insertion in the society, with certain characteristics and socially sustained representations. The norms that guide social companionship of such groups are related to the collective solidarity norms, as shown in shared social practices (HONNETH, 1999).

While searching for the autonomy's ideal and choice opportunity amplification from those who live the experience of the mental sickness, the Anti-asylum Movement evidences how collective identity finds itself tangled with individual identities. In order for these subjects to have effective conditions of living autonomy, of defining what to do, from economic, professional, medical-hospital interchange, to love relations and friendship, it's necessary that the conditions for individual self-definition be sustained on it's environment, either for the services network that attend him/her, as in the relations that occurs

in diverse social environments, public and private (MÂNGIA; NICÁCIO, 2001).

In this way, mental health consumer's participation on researches, ruled by autonomy principles, empowerment and recovery, appears to meet equality and recognition principles, as far as allow not only the insertion in the research process, but also the possibility of living an equal relationship, ruled in the experience appreciation and in their knowledge recognition. However, the existence of such experience in Brazil is recent and lacks of studies that show indicators related to the effectiveness of social inclusion in this population group.

3 Consumer's Participation in Researches

In international literature, there is a crescent recognition of the importance, the right, and the value of the mental health consumers involvement in researches (ROSE, 2003; GRIFFITHS; JORM; CHRISTENSEN, 2004; HAPPEL; ROPER, 2007; HOPKINS, 2008; NING; WEAVELL; WOODHOUSE, 2010; WOODALL; HOWAR; MORGAN, 2011; HANCOCK et al., 2012). Although the active inclusion importance of those in researches is recognized, appreciating the knowledge that came from the live experience, initiatives that incorporate them in the research team, as researchers and /or collaborators are still rare. Hancock et al. (2012) point to the fact that, although it's crescent the number of publications that valueate this kind of partnership, few are the publications known as scientific, in which consumer's participation happened indeed.

In Brazil, literature about consumer's participation in academic researches is limited, being scarce and recent the experiences of consumer's insertion in researches, reported on scientific literature and mapped by us (FURTADO; CAMPOS, 2008; VASCONCELOS, 2013; PRESOTTO et al., 2013).

Countries such Australia and New Zeland have incorporated Mental Health consumer's participation in researches as a right of those. Happell and Roper (2007) put that their involvement is positive for the own research development, allowing more inclusive approach in terms of design, conduct, and data interpretation; provide more profitable results for the attended population; question's formulation and methodological choices become more adequate from the singular contribution made

by the members of the community; relationship between academic researchers and communitarian¹ allows academic professional development; researches with more horizontal relationships between researchers and consumers result in more credibility for the research among the consumer's group base; it is a valiant opportunity for that communitarian researchers develop new research abilities. In addition, consumer's involvement helps on other partners' adherence for the research, besides decrease abandon risks.

Woodall et al. (2011) studied the reasons that lead consumers to engagement on researches, and the principal reasons presented were: 1) Practical incentives (fulfill on time, opportunity to leave infirmary, remuneration, feeding and transport); 2) Curiosity; 3) Communication (explanations without technical jargon, friendly researchers and professionals, voluntary nature research); 4) Perception of the research as potentially useful (for learning, for obtaining something positive from a negative experience or for talking with other people about own experience); 5) Help others (help researchers or help other consumers); 6) Positive experiences with doctors; 7) Approach's timing, which shall not be very close to internment.

We found, in literature, elements which show up as barriers in this kind of participation. Woodall et al. (2011) point the following factors, those that can hamper this inclusion process: 1) preoccupations related to possible side effects (fear that talking about the subject stops them to carry on, that could have side effects or that could fuddle the recuperation/re-establishment's process in some way); 2) practical barriers, such as lack of time, very large research sessions, not having someone to leave the kids; 3) invitation timing: when the invitation to participate is done soon after the beginning of the treatment; 4) when the participant disagree on conceptual questions about mental illness, as symptoms, for example; 5) Other consumer's influence.

Happell and Roper (2007) point yet to incredulity's problem, from some researchers, who don't value or encourage some members of the community's participation, leading, in some cases, to argue that those are not capable of doing researches solely basing on diagnosis. The lack of academic abilities from the customers, mainly when compared to researchers, is configured as a factor which hampers the insertion of those on the researches, that, without experience and abilities

to the research, take the risk to suffer “criticism” and “tokenism²” (HAPPELL; ROPER, 2007; HANCOCK et al., 2012).

Ning, Weavell and Woodhouse (2010) emphasize that consumers, while participation on researches, tend to propose relevant questions, identify flaws on the research; they are good indicators of the validity of some determined protocols; offer interesting result's interpretations, and track the result's implementation. Besides the importance given to their participation, there are different understandings about how this should come to be (HAPPELL; ROPER, 2007). Rose (2003) propose four levels of customer's involvement in researches³:

1. **Consumer advisory:** is the minimum involvement in research. When customers are invited to represent a group of stakeholders⁴ in groups, as, for example, a committee that follows the research. There's few involvement in the design of the research, in the behavior and in the data analysis. The participation's impact on the research is minimum, due to the fact that they use to be minority on those committees, once it is a habit that they are remunerated for their participation, and researches can't get enough budget to remunerate many consumer's participation.
2. **Consumer consultation:** process by which they are consulted for advising about specific themes on that the research team recognize their living experience. Although the team recognize the existence of a knowledge that come through the experience, participation takes place in specific way, representing a little impact on the research's conduction.
3. **Consumer collaboration:** when there is collaboration between researchers, consumers and non-consumers in all the phases of the research, which includes the formulation of the research's question, methodology's choice, analysis process and the choices referents to the way of publicizing results. If there is no consumer participation in some part of the research, he/she can't be understood as collaborative.
4. **Consumer led involvement:** when all the research's stages are led by consumers. Researchers not consumers can participate eventually in some stages of the research, but

that would take place just under coordination of the consumers who lead the works.

Hopkins (2008) puts that, in the same way that many consumers would like to understand and contribute with their experience for researches, for far beyond participating in an ethic committee, researchers also search for community support to found and legitimate their researches. Happell and Roper (2007) emphasize that this kind of involvement is an empowerment process, which allows users ripening on the construction of their own set of claims, influencing on public politics, health services configuration and attention practices on mental health. However, unappropriated conduction practices of these researches, with minimum consumer's involvement, may lead to the formulation of wrong questions, to inadequate methodological choices and biased interpretation of the facts, and may lead to the formulation of public politics that may not suit to the necessities of this population group.

Griffiths, Jorm and Christensen (2004) put yet that psychiatric diagnosis is not a criterion that determines a determined individual's ability for the development of academic researches and emphasize that, due to the high mental illness incidence on population, it is possible that many of the researchers be also consumers, but don't open this condition as researchers, because of fear of stigma and prejudice.

Ning, Weavell and Woodhouse (2010) emphasize that, although there are problems on consumer's insertion in researches, this is becoming a practice that gives voice to those and to their necessities; however, they emphasize that, in able to the research to be successful, it is necessary correct supports and that academic community make themselves ready to review their practices, so that it's possible to incorporate communitarian researchers.

We place importance in recognizing in the research's participants more their potentialities than their difficulties, that they be encouraged to take decisions about the participation beyond the training focus. Communitarian researchers should have access to appropriated sources, such as guidance, and the ethic committees should value life experience.

4 Occupational Therapy in Action

Benetton (2001, p. 147) places that “occupational therapy has as final purpose social inclusion”, to ensure autonomy and social participation; in this way, occupational therapist works on significant

activities on the living context of each subject (YOUNGSTROM, 2002). The subject is the one who defines what is, for himself, a significant experience, because this understanding finds itself in the scope of their subjective experiences, of their affects and interests, and of their cultural, political and social context.

It is up to the occupational therapist, from what has been identified as significant for each subject of the group, empower their autonomy and social insertion. In that way, in so far that the participation in researches becomes a significant activity for an individual or group, it is the role of this professional to intervene, promoting autonomy and social insertion also on that sphere, because OT is deeply involved with the production of life and ways of being in the world, in that human life constitute itself as a “*continuum of activities*” (QUARENTEI, 2001).

Hancock et al. (2012), understanding that participation in significant activities is a part of the occupational therapy’s work scope, propose that the development of abilities for participation on academic researches could be a focus of the attendances. In this way, the authors realized, with Australian health service consumers, the combined construction of a training guide for abilities enrichment in researches, focusing mainly on the abilities of interviews among them. The obtained results present evidences that consumers can improve their performance in the interviews among them through this kind of initiative.

However, it’s necessary caution while understanding academic space as democratic space and, therefore, catalytic of the consumer’s group inclusion process. Fraser (1995) points to the potential social inequalities reproducer that some spaces understood as democratic have reproduced, in the collective, gender, race and class inequalities. Such observation becomes pertinent inside the spaces joint by consumers, workers, parents, and mental health researchers. On those, many times, the guidelines and speech of the consumers dissolve in the middle of students and researcher’s speeches and guidelines. This tension is present in most part of Brazilian consumer’s association, depends on the mental health’s workers presence for the maintenance of their functioning (VASCONCELOS, 2013) and can be repeated in the relationships between consumers and researchers.

It is in the theory built about the Occupational Therapy role where we find support to think about the acting potential of the occupational therapist in the context that we present here. Although the theme around mental health user’s involvement could cause a first impression showing a set of themes inherent only to the mental health field,

we’d like to empathize that there are some aspects that characterize the population who nowadays define themselves as consumers (that are, in fact, consumers of the Sistema Único de Saúde, SUS), that are far beyond clinic aspects or diagnosis, but tell us about a lived social-cultural reality and about a type of relationship that is established between those who identify themselves as “worker” and “searcher” categories.

Barros, Ghirardi and Lopes (2002) put the necessity of a critical posture in occupational therapy’s performance, stressing the risk that, from the moment that OT’s focus becomes to be to adapt subjects to a norm or pattern, the performance has a potential which is maintainer of the *status quo*. The authors empathize the importance of existing a comprehension, by occupational therapists, of the social reality lived by the attended population. For the authors:

The concept of activity in social occupational therapy is a construct, a mediation of multiples relationships, but still situated on cultural space and time; it’s an unfinished concept and incorporates in itself this incompleteness, consisting by the movement, the communication process in language [...]. Such activities are object that build itself in communication, in experience and in the lived situations according to history, to social practices and cultural values that each person or social group achieve in a particular way (BARROS; GHIRARDI; LOPES, 2002, p. 102).

Barros, Ghirardi and Lopes (2002) highlight yet the necessity that social OT’s action promote decentralization:

1. of the technical knowledge towards the idea of plural knowledge, facing social questions and problems;
2. of the actions from the people (considering ill or deviating body/mind) towards the collective, the culture from which the person cannot be apart;
3. of the action: of the setting towards the daily life spaces;
4. of the concept of activity as an individual process towards insert it in history and culture of a group or a person (BARROS; GHIRARDI; LOPES, 2002, p. 100).

In this way, beyond the “treatment” for the participation on researches proposed by Hancock et al. (2012), mental health consumer’s participation in researches could or not be an intervention object in occupational therapy, as far as there is a comprehension of this demand. What does it mean to the actors of this debate to participate in a research? What’s the meaning of this practice on their lives? In which ways the participation is emancipatory? And in which ways this is a reproduction of social structures of domination that imprison subjects? Questions like these are important before the understanding that politic aspect must be incorporated to the occupational therapist’s daily work, in a way that the professional can be able to, as it is put by Malfitano (2005), establish a dialog between micro-structure and macro-structure, contextualizing individual approaches inside a collective.

Rahman (1986) starts from the premise that science must be mainly *proposing*, with the intention of modify reality, and must unite itself to efforts in this direction, what means that the research must be ideologically targeted. The author criticize the idea that people are not capable of systematize their own knowledge and put that the academic knowledge validation becomes to be one more form of domination. In this way, it’s fundamental to develop a popular way of systematization of the knowledge, in order that a domination structure by the knowledge is not created.

In Pesquisa Ação Participante (PAP) methodology, we found consonance with the principles enumerated by Barros, Ghirardi and Lopes (2002) for social occupational therapy. For Rahman (1986), PAP’s epistemology correspond to the dialectic pragmatism and materialism. The author yet puts that, in PAP, the “researched” group becomes also the researcher, in such a way to form themselves a research collective that will start from some lived problem by the group and so will realize a research that aims at understanding the given problem and searching for solutions to it.

PAP aims at, in the end of the process, there be some kind of transformation of the evolved group, generating in that way the solution for the problem, in accordance with the specific goals of the research. For that reason, during a determined study, it will be able to occur some progressive adjustments in the plannings of the investigation, if it is necessary, “fortifying the theme of the research with action” (FRANCO, 2005, p. 496).

For this kind of research, “the participation of the entangled people is absolutely necessary” (THIOLLENT, 2005, p. 17), thus being “[...] a wide and explicit interaction between researchers and people implicated on the investigated situation” (THIOLLENT, 2005, p. 18). From this interaction, the decisions about the directions to be employed will be taken so that, in the end, the research’s goals can be achieved.

Occupational therapist’s role should not be that to “adequate” consumers to academic knowledge, but to follow, with this consumer, paths where his knowledge, that starts from experience, can dialog with academic knowledge. It is not about overestimating customer’s experience and knowledge, ignoring all the academic knowledge. Freire (2002) puts that it’s the educator role to challenge the student, putting the importance of dialogicity in the process of interchange of knowledge. In that way, we propose, inside a freirian perspective, the possibility of a dialog and the necessity of going through, with the consumer, the path to empowerment, until he/she sees himself/herself on an equal footing to be in that dialog.

The research activity can be a motivator agent that mobilizes wills, desires, allows the subject to go out of stagnation and take decisions. In this relational process, the occupational therapist can co-construct or reconstruct subject’s action in the world, as it is suggested by Malfitano (2005). Besides that, seen as an activity out of setting and inserted in the social context, active insertion of the consumers in researches that propose itself to be participative can transform the local place occupied for these subjects, who move from the consumer place – which carry a suffering history, a diagnosis (or label), a relationship with a service and a society – to the place of “researcher”, enabling other view to this individual social insertion. The activity starts, thus, to serve as a possible way to a co-construction of new ways of living, seen in a context that aims the strengthening of individual networks and that strengths his/her autonomy in the context that he/she is inserted.

5 Conclusion

Understanding that occupational therapy has as objective of work the meaningful activities in individual’s life, participation in researches is transformed in focus for the therapeutic process,

in the way that this is presented as a demand from and for the own subject.

Lopes and Silva (2007, p. 158) call the attention to the fact that

[...] occupational therapy mirrors what their professionals think and produce and the way how they position themselves politically in front to social issues that is shown up in from of them [...].

Understanding that clinic is not neutral, as science, and that researches and therapeutic interventions leave from a vision of the world and a political positioning, we propose here that the occupational therapist role together with consumers who participate in researches in mental health be that of valuing the knowledge that arises from experience, that of facilitator, thinking ways and strategies which enhance the dialog, and that of catalyst in the process of empowerment of the own consumer in the process of valuing his/her knowledge.

Occupational therapy, conceiving activities as existential territories, can enhance the effects of the consumer's, researcher's and researched's meetings, establishing experimentation, appreciation and affirmation of self-construction processes in a new potent action and creator of new ways of relating to the world. Taking care of these meetings, fortify them and amplify consumer's repertory are our works perspective, emancipators of the subject, of the research practices and of the institutions, with those involved, in Brazil.

References

- BARROS, D. D.; GHIRARDI, M. I. G.; LOPES, R. E. Terapia Ocupacional Social. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 13, n. 3, p. 95-103, 2002.
- BENETTON, M. J. Terapia Ocupacional e reabilitação psicossocial: uma relação possível? In: PITTA, A. (Org.). *Reabilitação psicossocial*. São Paulo: Hucitec, 2001. p. 143-149.
- CASTELLS, M. *The power of identity*. Massachusetts: Blackwell, 1997.
- DANTAS, C. R.; ODA, A. M. G. R. Cartografia das pesquisas avaliativas de serviços de saúde mental no Brasil (2004-2013). *Physis: Revista de Saúde Coletiva*, Rio de Janeiro, v. 24, n. 4, p. 1127-1179, 2014.
- FRANCO, M. A. S. Pedagogia da pesquisa-ação. *Revista Educação e Pesquisa*, São Paulo, v. 31, n. 3, p. 483-502, 2005.
- FRASER, N. Rethinking the public sphere – a contribution to the critique of actually existing democracy. In: ROBBINS, B. (Org.). *The Phantom Public Sphere*. Minnesota: University of Minnesota Press, 1995. p. 1-32.
- FREIRE, P. *Pedagogia da Autonomia: saberes necessários à prática educativa*. Rio de Janeiro: Paz e Terra, 2002.
- FURTADO, J. P.; CAMPOS, R. O. Participação, produção de conhecimento e pesquisa avaliativa: a inserção de diferentes atores em uma investigação em saúde mental. *Cadernos de Saúde Pública*, Rio de Janeiro, v. 24, n. 11, p. 2671-2680, 2008.
- GRIFFITHS, K. M.; JORM, A. F.; CHRISTENSEN, H. Academic consumer researchers: a bridge between consumers and researchers. *Australian and New Zealand Journal of Psychiatry*, Asia, v. 38, n. 4, p. 191-196, 2004.
- HABERMAS, J. *Direito e democracia: entre faticidades e validade*. Rio de Janeiro: Tempo Brasileiro, 1997.
- HABERMAS, J. Some Further clarifications on the concept of communicative rationality. In: COOKE, M. *On the pragmatics of communication*. Cambridge: MIT Press, 1998. p. 307-342.
- HANCOCK, N. et al. Participation of Mental health consumers in research: Training addressed and reliability assessed. *Australian Occupational Therapy Journal*, Australia, v. 59, n. 3, p. 218-224, 2012.
- HAPPELL, B.; ROPER, C. Consumer participation in mental health research: articulating a model to guide practice. *Australasian Psychiatry*, Nova Zelândia, v. 15, n. 3, p. 237-241, 2007.
- HONNETH, A. The Social dynamics of disrespect: situating critical theory today. In: DEWS, P. *Habermas: a critical reader*. Oxford: Blackwell, 1999. p. 320-337.
- HOPKINS, H. Consumer participation in research. *Journal of the Consumers Health Forum of Australia*, Australia, v. 1, p. 1-2, 2008.
- LOPES, R. E.; SILVA, C. R. O campo da educação e demandas para a terapia ocupacional no Brasil. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 16, n. 1, p. 1-8, 2007.
- MALFITANO, A. P. S. Campos e núcleos de intervenção na terapia ocupacional social. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 18, n. 3, p. 158-164, 2005.
- MÂNGIA, E. F.; NICÁCIO, F. Terapia Ocupacional em Saúde Mental: Tendências Principais e desafios contemporâneos. In: DE CARLO, M. M. R. P.; BARTALOTTI, C. C. *Terapia ocupacional no Brasil: fundamentos e perspectivas*. São Paulo: Plexus, 2001. p. 63-80.
- NING, L.; WEAVELL, W.; WOODHOUSE, S. Consumer participation in research. *Psychiatric Disability Services of Victoria*, Victoria, 2010. Disponível em: <http://mhco.org.au/attachments/NewParadigm_Autumn2010_Consumer_Research.pdf>. Acesso em: 21 set. 2015.

- PRESOTTO, R. F. et al. Experiências brasileiras sobre participação de usuários e familiares na pesquisa em saúde mental. *Ciência e Saúde Coletiva*, Rio de Janeiro, v. 18, n. 10, p. 2837-2845, 2013.
- QUARENTEI, M. S. Terapia Ocupacional e a produção de vida. In: CONGRESSO BRASILEIRO DE TERAPIA OCUPACIONAL, 7., 2001, Porto Alegre. *Anais...* Porto Alegre: ABRATO, 2001. p. 1-3.
- RAHMAN, M. A. The Theory and practice of participatory action research. In: BORDA, O. F. (Org.). *The challenge of social change*. Washington: Sage Studies in International Sociology, 1986. p. 107-132.
- ROSE, D. Having a diagnosis is a qualification for the job. *British Medical Journal*, Londres, v. 326, n. 7402, p. 1331, 2003. <http://dx.doi.org/10.1136/bmj.326.7402.1331>.
- THIOLLENT, M. *Metodologia da pesquisa-ação*. São Paulo: Cortez, 2005.
- VASCONCELOS, E. M. Empoderamento de usuários e familiares em saúde mental e em pesquisa avaliativa/interventiva: uma breve comparação entre a tradição anglo-saxônica e a experiência brasileira. *Ciência e Saúde Coletiva*, Rio de Janeiro, v. 18, n. 10, p. 2825-2835, 2013.
- WOODALL, A.; HOWAR, L.; MORGAN, C. Barriers to participation in mental health research: Findings from the genetics and psychosis (GAP) study. *International Review of Psychiatry*, Londres, v. 23, n. 1, p. 31-40, 2011.
- YOUNGSTROM, M. J. Occupational Therapy practice framework: the evolution of our professional languages. *American Journal Occupational Therapy*, Washington, v. 56, n. 6, p. 609-639, 2002.

Author's Contributions

Tatiana Dimov contributed on the text's conception, organization and analysis of the sources, essay and text review. Ellen Cristina Ricci organized and analyzed the sources, redacted and revised the text. Both authors approved the final text's version.

Funding Source

The work received financing from CAPES, through one of the author's doctorate scholarship.

Notes

- ¹ In this article, mental health consumers who participate on academic researches will be denominated *communitarian researchers* as well, in view that they develop the researcher role from the appreciation and recognition of their insertion in the community. However, we understand that people who live experiences of mental suffering can be inserted on the academy by diverse ways, including having their role and place as a known "academic researcher", and choosing even to research the more diverse themes.
- ² We didn't find an adequate translation for this term in Portuguese literature. The term is used when researchers get hold of the participant's knowledge, without giving them the appropriated credit.
- ³ In the version of the article in Portuguese we decided to keep the terms set by the author in English in parenthesis, offering a free translation of the same in the title of each item.
- ⁴ Term used for identify support or consultation groups or stakeholders in the evaluation and implementation of projects (both companies and government policies). In the opinion of the authors in Brazil call participation of civil society organizations, or groups of interest in the subject.