Everyday life, schizophrenia and narratives of illness experience¹

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Abstract: Introduction: This paper presents a narrative review of the literature on the everyday life of people diagnosed with the schizophrenia spectrum, from their narratives about the illness experience, published as articles in indexed journals. The narrative reviews start from broad issues with data sources and selection of articles that may contain some bias, seeking to develop a contextual and theoretical theme. Objective: The main objective is to indicate how narrative studies on the everyday life and experience of schizophrenia are presented in the national and international scenario; the most relevant authors; how the everyday life concept is described; type of studies performed and the possible contributions to the health/disease/care in mental health care process. Method: We sought the breadth of the researched material, appropriation, and organization of it. We reported the findings in quantitative terms on the subject to then present an overview of the selected papers. We aimed to know those who present the everyday life experienced by people diagnosed with schizophrenia. Results: Considering the seven databases used during this review, we selected 281 papers, 90% of them were international and just under one-third (82 papers) report/describe and value their narrative in the first person about the illness experience. Conclusão: We discuss the relevance and responsibility of mental health research centered on the experience, the current sciences scenario, and the dialogues with singularities, and regarding the different experiences of illness in the Brazilian sociocultural context

Keywords: Everyday Life, Narratives, Schizophrenia, Review Literature as Topic.

Cotidiano, esquizofrenia e narrativas da experiência de adoecimento

Resumo: Introdução: Apresenta-se uma revisão bibliográfica narrativa de estudos sobre o cotidiano de pessoas com diagnóstico do espectro esquizofrênico a partir das suas narrativas sobre a experiência do adoecimento, publicados na forma de artigos em revistas indexadas. As revisões narrativas partem de questões amplas, com fontes de dados e seleção de artigos que podem conter algum viés, buscando o desenvolvimento de um tema de forma contextual e teórica. Objetivo: O objetivo foi indicar como os estudos de narrativas sobre o cotidiano e experiências de adoecimento em esquizofrenia apresentam-se no cenário nacional e internacional, os autores mais relevantes, como conceituam cotidiano, tipos de estudos realizados e as possíveis contribuições para processo saúde/doença/cuidado na assistência em saúde mental. Método: Buscou-se a amplitude do material pesquisado, a apropriação e o fichamento deste. Relatamos o que foi encontrado, em termos quantitativos sobre o tema, para em seguida apresentar a análise geral dos artigos selecionados. Neste trabalho nos interessou conhecer aqueles que apresentam como o cotidiano é experimentado por pessoas com o diagnóstico de esquizofrenia. Resultados: Considerando as sete bases de dados utilizadas durante esta revisão, selecionamos 281 artigos, 90% destes de origem internacional e pouco menos de um terço (82 artigos) relatam/descrevem e valorizam as narrativas em primeira pessoa sobre a experiência de adoecimento. Conclusão: Discute-se a pertinência e responsabilidade das pesquisas em saúde mental centradas no vivido, no cenário contemporâneo das ciências, e o diálogo com as singularidades e respeito às diferentes experiências de adoecimento no contexto sociocultural brasileiro.

Palavras-chave: Cotidiano, Narrativas, Esquizofrenia, Literatura de Revisão como Assunto.

1 Introduction

This article presents the narrative bibliographical review conducted to support the main discussion of the master's project: "Everyday life and Schizophrenia: user's reports of Psychosocial Care Centers (CAPS) from the illness experience", which had the main objective to meet users everyday with diagnosis of schizophrenic spectrum inserted in CAPS from their illness experiences.

The narrative reviews start from broad issues with data sources and selection of articles that may contain some bias, but its primary focus is to seek the "state of art" or the development of a theme of contextual and theoretical form through critical analysis (ROTHER, 2007).

The steps of this review followed what Minayo (2012) proposes in the amplitude of the studied material, and appropriation and report. We report what was found in quantitative terms on the subject; then we presented an overview of the selected articles. The purpose was to indicate how the narratives of studies on everyday life and illness experiences in schizophrenia are presented in the national and international scene, the most relevant authors, how they conceptualize the everyday life, types of studies and possible contributions to the health/disease/care in mental health care.

Studies of schizophrenia are many. In this work, we are interested in knowing those who present how people diagnosed with schizophrenia experience the everyday life.

Studies published as articles in the index journals, using the everyday life concept even in the field of occupational therapy, in which the concept is central to the practice are scarce. Salles and Matsukura (2013) found 12 articles from 2003 to 2012, although they observe growth in the production of everyday life concept studies. Dantas and Oda (2014), in a literature review of evaluation studies on mental health services offered to the population, say the minority of these values or foregrounds the voice of users on their attention.

This article indicates that in the scientific field, understood as the state of the balance of power between the protagonists in the fight, agents or institutions and unequal distribution (BOURDIEU, 1983), the struggle appears unevenly between studies (guided by studies in the biomedical model and narrative studies guided by the illness experience and everyday life). Since the quantitative results miniature of narrative studies focusing on

the experience of people still fewer that studies are evaluating the everyday perspective of the outside observer, not who experience. It presents the following narrative review of studies on the narratives of illness experience and the everyday life of people with a diagnosis of the schizophrenic spectrum.

2 Method

The review took place between January and April 2014 in Bireme Platform (BVS), chosen for its relevance in the national academic. This platform adds 12 health databases: LILACS, MEDLINE, ADOLEC, BBO, BDNENF, HISA, LEYES, MEDCARIB, REPIDISCA, PAHO, WHOLIS and DESASTRES.

The coverage includes publications in Brazil, USA, Spain, among other countries with emphasis on medical and biomedical, health sciences, public health, dentistry, nursing, basic legislation on health, basic engineering and environment.

The following keywords were used: cotidiano, saúde mental, esquizofrenia, doença mental, psicose, vida diária, atividades cotidianas, daily life, everyday life, mental illness, schizophrenia, experience e narratives. There were 16 combinations built from them: Cotidiano and Saúde Mental; Cotidiano and Doença Mental; Cotidiano and Psicose; Cotidiano and Esquizofrenia; Vida Diária and Saúde Mental; Vida Diária and Doença Mental; Vida Diária and Psicose; Vida Diária and Esquizofrenia; Atividades Cotidianas and Saúde Mental; Atividades Cotidianas and Psicose; Atividades Cotidianas and Esquizofrenia; Daily Life² and Mental Illness and Narratives; Daily Life and Schizophrenia and Narratives; Daily Life and Mental Illness and Experience; Everyday Life³ and Mental Illness; Everyday Life and Schizophrenia.

The first access to BVS occurred from the keywords mentioned above. By the titles of the articles found, it was identified which keywords and combinations revealed relevant work to the master's project object, about the relationship between schizophrenia, everyday life, and experience of the illness.

Articles that contain at least one of the keywords in the title, and later, by reading the abstracts, sought to find those who had, at least, two projects thematic (schizophrenia, mental health, everyday life, stories, the experience of the illness, community health services).

The following combinations were highlighted in Table 1 below with the publications found.

Among the first 144 selected abstracts, only 15 articles were read and analyzed by presenting interviews or narratives of people with schizophrenia reporting their perceptions of their illness experience and their everyday lives. Then, the Table 2 shows the references of articles read in full.

From this small number of studies found, it was considered to expand the search to new bases of research and information. The hypothesis was that other fields such as sociology and anthropology, producing narratives research on the illness experience from other assumptions. Therefore, this production would be indexed to other platforms and bases of international data, multidisciplinary and Social Sciences.

Six bases were selected: Academic One File (Multidisciplinary database - 1980, Academic Search Premier (Multidisciplinary Database - 1920-2014); ProQuest Central (Multidisciplinary Platform - 1950-2014); Francis (Social Sciences Base - 1972-2014); Jstor (Social Sciences Data Base - 2000-2014); Web of Science (Multidisciplinary database - 1945-2014). The selection criteria for these bases were Capes and/or Unicamp signature; a collection with different periods of coverage and different nationalities, a website accessible in English and bilingual descriptors support.

Table 3 below shows the selected databases, and the number of publications found using the same criteria for search selection of BVS.

Among the 137 selected abstracts and described in the table above, 67 articles presented interviews or narratives of people with schizophrenia reporting the own perceptions about the illness experience, making more significant number than the found in BVS (15).

The reading and analysis of 82 articles were performed (BVS + 6 bases) and the following discussion of the findings in the theme of this article was present.

3. Results and Discussion

The first article on the subject researched dated in 1959, although studies on schizophrenia and daily life continue scarce until the decade of 1990. From that date, an increase of publications accelerates the first years of the decade of 2000. The word "everyday life" remained as a synonym for a set of daily life activities (DLAs) in international productions. Considering the seven databases listed in Tables 1 and 3, 281 articles were selected, 90% of international origin and just under a third (82 articles) reported/described and value the narrative in the first person about the illness experience.

The above data shows that in the field of scientific knowledge (BOURDIEU, 1983), most of the studies that consider mental disorders from variables such as etiology, diagnosis, prognosis, acuteness, chronicity and course of the disease are still a majority (COELHO; ALMEIDA FILHO, 2002). Studies of historical-cultural and environmental context in which the person is inserted, their way of being in the world, to relate to others and to live and understand their own experience of illness, remain scarce, although it is known that social and political phenomena directly affect the health condition of the people (SARACENO, 2001; SERPA JUNIOR et al., 2011).

Table 1. Keywords and quantity of publications found.

Combinations of keywords N° of Publications	Found	Nº Publications	Nº of Publications
		Selected Filter by title Título	Selected Filter by abstract
Cotidiano and Saúde Mental	634	172	56
Cotidiano and Esquizofrenia	16	8	3
Atividades Cotidianas and Esquizofrenia	561	83	37
Daily Life and Mental Illness and Narratives	34	4	3
Daily Life and Schizophrenia and Narratives	5	4	4
Everyday Life and Schizophrenia	145	65	27
Everyday Life and Mental Illness and	172	23	14
Experience			
Total	1567	359	144

Source: Portal Regional da BVS (2014).

- **Table 2.** Articles that show interviews or narratives of people with schizophrenia reporting their perceptions of their illness experience and their everyday lives.
- BORG, M.; DAVIDSON, L. The nature of recovery as lived in everyday experience. *Journal of Mental Health*, Londres, v. 17, n. 2, p. 129-140, 2008. Available on: http://informahealthcare.com/doi/abs/10.1080/09638230701498382?journalCode=jmh. Access on: 20 nov. 2014.
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- MOLL, M. F.; SAEKI, T. A vida social de pessoas com diagnóstico de esquizofrenia usuárias de um Centro de Atenção Psicossocial. *Revista Latino-Americana de Enfermagem*, Ribeirão Preto, v. 17, n. 6, p. 995-1000, 2009. Available on: http://www.scielo.br/scielo.php?pid=S010411692009000600011&script=sci_arttext. Access on: 28 nov. 2014.
- NASI, C.; SCHNEIDER, J. F. O Centro de Atenção Psicossocial no cotidiano dos seus usuários. *Revista da Escola de Enfermagem da USP*, São Paulo, v. 45, n. 5, p. 1157-1163, 2011. Available on: http://www.scielo.br/pdf/reeusp/v45n5/v45n5a18.pdf. Access on: 28 nov. 2014.
- Utiliza o conceito de cotidiano de Alfred Schutz (1979).
- SALLES, M. M.; BARROS, S. Reinternação em hospital psiquiátrico: a compreensão do processo saúde/ doença na vivência do cotidiano. *Revista da Escola de Enfermagem da USP*, São Paulo, v. 41, n. 1, p. 73-81, 2007. Available on: http://pesquisa.bvsalud.org/portal/resource/pt/lil-450461>. Access on: 20 nov. 2014. Utiliza o conceito de cotidiano de Agnes Heller (1994).
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Table 3. Platform and Database/number of publications found.

Platforms and Database	Nº of Publications Found	N° of Publications Selected Filter of Title	N° of Publications Selected Filter of abstract
1. Academic One File (Multidisciplinar	112	36	15
Database– 1980 to 2014)			
2. Academic Search Premier	281	98	58
(Multidisciplinary Database – 1920 to 2014)			
3. Proquest Central (Multidisciplinar	2,197	130	23
Platform– 1950 a 2014)			
4. Francis (Social Sciences Database – 1972 to 2014)	5,661	44	11
5. Jstor (Social Sciences Database – 2000 to	1,020	31	13
2014)			
6. Web of Science (Multidisciplinary	256	36	17
Database- 1945 to 2014)			
Total	7,527	375	137

Source: Sistema de Bibliotecas da Unicamp (2015).

Since 1970, most research on schizophrenia and daily life emphasize the need to understand the everyday life of people from their stories and experiences (DAVIDSON, 2002; BATES, 2004).

Some aspects seem to determine this growth:

- The appearance of longitudinal studies of schizophrenia, dating back to the 1960s, conducted in various countries, showing that there is a broad outcome spectrum of schizophrenia, even when it manifests in a severe and persistent way, linked to the socio-cultural context;
- The consolidation of struggles and movements against the asylums, with proposals for new models of care, as well as the guarantee of social rights for its graduates. It was recommended in countries of Anglo-Saxon, Italian-Iberian culture, with strengthening care projects in mental health as deinstitutionalization and psychosocial rehabilitation (BARROS, 1994);
- The emergence of new ways to investigate the health/disease/care, strengthening research in which the person evaluates his life, tells what he considers important for him since there are new treatment alternatives in freedom, centered on psychosocial rehabilitation and territorial services (MOLL; SAEKI, 2009).

This is not restricted to mental health. In the 1980s, there were ethnographic studies examining medicine and its procedures as a cultural system, with special attention to doctor-patient relationships, the

medicalization of disease and the bureaucratization of care. Production in the scientific field, however, remains restricted to the embodied experience and their reports in narrative forms. In literature, it became apparent, because the amount of non-selected articles from the first filter (title) and the second filter (abstract) revealed the strong investment in quantitative research related to neuroscience, effects of drugs and evaluative scales behavioral standards expected after different treatments in mental health that do not consider the experience of the ill person.

Most of the articles found and selected by the abstract in this review also reduced the everyday life of daily activities and taking as a health professional role to fit them to a healthier life. They indicated activities morally accepted in certain cultures, but did not question how these people are living, sometimes in alternative spaces, sometimes already well embedded in other social and institutional boundaries established, as families, religions, alternative treatments. Thus, the everyday life reduced to the ADL is still used indiscriminately and decontextualized historically, neglecting the cultural and social diversity (GALHEIGO, 2003).

Borg and Davidson (2008) state that the recovery of serious mental illness is often seen as an individual process that occurs in treatment contexts little linked to culture and social relationships of people. However, recent research is beginning to explore the recovery as a social process that develops in everyday life, both in its simplicity and in the complexity of everyday experiences.

Lysaker and Lysaker (2010) also agree that studies of schizophrenia tend to examine the lives of people by biological and social impacts of individual files and described by health professionals. However, they state that research is not considering the dimensions in the first person about the disease may be incomplete. They maintain longitudinal research exploring the possible implications for the treatment and valuing the scale of the illness in the first person to achieve a complete descriptions of this experience and forms of recovery.

The statements of Lysaker and Lysaker (2010), Borg and Davidson (2008) confer with the findings in this research. Most research valued methods focused on speech in the third person. Even the methods of first-person narration sometimes brought the everyday analysis to reduce it to activities of daily living, sometimes standard (quality of life, behavior and functionality tests), not valuing the process of people, so just the uniqueness of the illness experience and how it influences everyday life.

Thus, we can see that different author - Slade, Davidson, Moll, Lysaker - from different cultures and nationalities, defend the qualitative research, with appropriate methods for the construction of narratives in the first person about the illness experience, so as to understand the health/disease/ care so complex process to contribute in a consistent way with forms of care and construction assistance services to enhance the unique everyday life of its members.

To Brown (1995), studying how the disease is socially constructed, how social forces shape the understanding and actions on health, exploring the effects of class, race, gender, language, technology, culture, politics and institutional economics, structures professionals and standards in the formation of knowledge are necessary to understand the assumptions about the prevalence, incidence, treatment and significance of the disease. Thus, some scholars sought to discover the interactions of everyday life and illness from the experience of people. They start investigating social activities (organizations, institutions) and construction experience of the disease; decisions regarding treatment; understanding of what constitutes results. However, the discovery of a diagnosis is often a challenge, which provides many social conflicts around the medical and health issues (BROWN, 1995).

The diagnosis of schizophrenia has particular impact in the social and everyday life of people. However, there is little research about what people do in their social context and what characterizes their participation in social processes. The Psychosocial Rehabilitation is concerned with three main axes to people's lives: living, exchange identities and the produce and exchange goods and values (SARACENO,

2001). Some paradigms, as centered recovery in the client in occupational therapy, stress the importance of supportive relationships and therapies, including trust, respect for the choices and customer priorities, active listening and empathy (MÂNGIA, 2002; YILMAZ et al., 2009).

Some anthropological studies that discuss symptoms in schizophrenia have been identified. In these works with Indigenous Australians, Suryania, Welchb and Cox (2013) researchers saw that the participants considered significant, and positive voices sometimes provided guidance on issues of everyday life and related to the presence of ancestral spirits. In this indigenous group, the presence of voices was not considered bad and stigmatizing. This indicates that, when working with people who experience auditory hallucinations, it is important to recognize the presence of the voices in people's lives, and how they impact the life about self-esteem, behaviors and interpersonal relationships (SURYANIA; WELCHB; COX, 2013).

Although the authors mentioned above remain in a specific symptom, not exclusive and decisive for the diagnosis of schizophrenia, they reveal that the cultural construction sets different names and different ways of dealing with certain physical phenomena. However, whatever the phenomenon, it should be considered in its everyday life dimension, the lived experience of subjects in their sociocultural context.

One of the most quoted and most articles found in accessible databases researchers is Larry Davidson researcher, professor of psychology in the Department of Psychiatry at Yale University. His research focus on recovery/rehabilitation and mental health interface, investigating recovery processes in psychosis, using the support of others⁴ and other social engagement strategies, the development of methods of qualitative and participatory research and psychosocial community-based interventions.

Davidson et al. (1997) and Davidson (2002) work with the concept of everyday through two authors: A. Schutz (1972) and M. Gullestad (1989 apud DAVIDSON et al., 1997). Schutz (1972) conceptualizes everyday life as "the world of life" based on phenomenology, one of the authors cited in the articles of this research, and Gullestad (1989 apud DAVIDSON et al., 1997), a follower of Schutz, believes that life every day can be invisible to be very visible. Gullestad suggests two perspectives on everyday life: 1. Organizational/functional. 2. Lived/Subjective, or phenomenology denominated "the world of life", focusing on the significant experience of the human being.

In studies of Borg and Davidson (2008), treatment and recovery process are the trivialities of everyday life, which cannot be considered as trivial, because the practical problems arising from mental illness affect everyday life.

In Brazil, the first Brazilian articles (SALLES; BARROS, 2009; MOLL; SAEKI, 2009; NASI; SCHNEIDER, 2011) who studied the illness experience in schizophrenia and impacts on everyday life dating back to the early twenty-first century and treat the concept of everyday by A. Heller (2004) and also A. Schutz (1979). Salles and Barros (2009) choose to be based in Agnes Heller, as this author makes a critical analysis of the real, providing the foundation for the knowledge of social practice activity concrete historical subjects. Already Nasi and Schneider (2011) seek the theoretical basis for their research in the phenomenological sociology of Alfred Schutz.

Few national and international authors explain the everyday life definition. Most of them did not describe how they conceive this notion in their articles, but the references to the articles are clues from the authors used. In addition to Schutz and Heller, the most cited in bibliographies are references to De Certeau, Lefebyre, and Maffesoli.

The least amount of qualitative work and narratives that address the everyday life concept associated with the field of mental health and illness experience in schizophrenia can find explanatory arguments in Costa (2005). This author states that the everyday life can be fluid and difficult to define, so maybe there are few works on everyday life at the interface mental health/sociology, being mostly descriptive texts of daily activities without depth in the singularities of affective relationships, social, economic, among many others that we cannot grasp.

Costa (2005), studying Deleuze and Guattari, reflects on the everyday life with the dilution of borders and barriers, the lack of social demarcations, the increasing mobility of everything and everyone, the dispossession, nomadism, the "non-places" of contemporary man. He is anonymous, but there are global references (same drink brands, food, clothing). Still, "non-place" can be found the possibility of generation of alternative living spaces with its characteristics, rich with complex social relationships and experiences.

Moreover, the mental illness experience can profoundly change perceptions of themselves, the world and others. However, people with a mental illness, as any other citizen, seek a meaning in life. Thus, mental health services should support everyday solutions to all the daily problems of people (SLADE, 2012).

Therefore, studying the everyday life of people with a diagnosis of schizophrenic spectrum in contemporary society becomes even more challenging and more complex due to our culture constantly changing and borders as tenuous as the reason/illusion.

The structuring of services and their professionals need to prepare to receive, understand and contribute to the solution of complex problems and contemporary everyday challenges and ever-changing presented by people with schizophrenia and value the "small" daily achievements that involve a world of meanings and help strengthen the meaning of life for everyone.

Campos (2009, p. 69) shows that the task of health services is not only meet the disease. This means that it is up to health professionals not only the ability to help people fighting the disease, but also help them to transform, so that the disease, even being a limit, do not prevent them to experience new possibilities in life, combining clinical/health rationale and interests/ desires of users, "[...] that depends on the adoption of the share of the construction of a narrative and its interpretation between the worker/specialist and the subject/user".

Thus, there is the need for territorial mental health services to organize for continued long-term care for people who experience the illness, given the relevance and need of care, but also the need for special attention to the changes the cycles of life impose on the everyday lives of these people.

The mental health care cannot focus only on training and evaluation of social skills and performance, but in creating and maintaining spaces of being, living and dwelling (SARACENO, 2001), such as social, work and meaningful leisure activities for people. The Psychosocial Rehabilitation aims to reflect and act on this complex set of places, service organizations, interventions in health and social structures of the territory, setting up a process that involves opening of trading spaces for the user, with family, with the surrounding community and the services dealing with the user and the expansion of its contractual power (SARACENO, 2001).

Thus, recognizing the importance of significant experience in everyday life and its various components, the biggest challenge is to recognize, capture and explicit the simplicity of everyday life, the complexity of everyday life among people with mental illness experience (BORG; DAVIDSON, 2008).

4 Conclusion

From this narrative review, it is noticed the relevance and responsibility in the contemporary setting of research/investigation in mental health-centered in experiences by users in treatment under the new model of care, looking not only for the same dialogue, but with singularities, listening to and respecting the different experiences of illness, seeking to enhance the subjective dimension and empowering people with severe mental illness in the Brazilian socio-cultural context.

The number of qualitative studies publications that value narrated experience of people who experience schizophrenia is growing, but still much lower compared to the number of quantitative studies that value the biological aspects, focusing on the effects of drugs, or to assess the changes behavior of an outside perspective to that experienced by the illness. The everyday concept also presents a challenge to the research because of its complexity and a strong trend to reduce it or understand it as synonymous DLAs.

Reflecting on the disease process in schizophrenia in society and its impact on the daily lives of people who experience it (stigma, prejudice, invalidation) is required. The recognition of the everyday life in its complexity/all from narratives of studies on the experience of illness, contributes to the care provided to people with schizophrenia in territorial health services like CAPS, as well as in other social spaces, considering the point of view of those who live the disease process and their needs, strengthening the Mental Health Public Policy and the Brazilian Psychiatric Reform.

Everyday life provides feedback in social life. It cannot have the same gestures, actions and ways to carry out the activities, but this should be understood not as exclusive possibilities and powers, but as natural phenomena, where walking with the difference may reveal new understandings of illness experiences and contribute to the construction of a treatment that dialogue with the real needs of users. Occupational therapy as a core of knowledge oriented/centered in everyday action people accompanying is committed to developing studies to consider the everyday from the experience, thus seeking to contribute to the construction of dialectical therapeutic relationships processes health/disease/care, as well as new research in the field covered by this article.

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Author's Contributions

Ellen Cristina Ricci was responsible by the concept, organization and analysis, writing and text review; Erotildes Maria Leal performed the design, writing and revision of the text. Both authors approved the final version of the text.

Notes

- 1 This material is part of the master's research of the first author of the article approved by the Ethics Committee of the Faculty of Medical Sciences, number 870/2009 Addendum 06/24/2014.2
- ² Daily life (DLA) It is the term used as a concept of "atividade de vida diária" in Portuguese.
- ³ Everyday life It is the term used as a concept of "cotidiano" in Portuguese.
- ⁴ Peer support: term used to denote the participation of people who suffer or have gone through the disease process in academic research not only as research subjects but as researchers.