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The power of personal knowledge: reflecting on *conscientization* in lives of disabled people and people affected by leprosy in Cirebon, Indonesia

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An epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential. This paper describes the *conscientization* process among disabled and leprosy affected research assistants and lay counsellors of the Stigma Assessment and Reduction of Impact (SARI) project in Cirebon, Indonesia. *Conscientization* or critical consciousness refers here to the awakening of the individual regarding his or her individual and social situation which provokes individual and collective change. A significant factor in this process relates to the newly assumed role of staff in the SARI project. Findings from the literature on personal knowledge, its conceptualization and the role of *conscientization* are first presented, including the political nature of personal knowledge and its significance for social change as well as personal knowledge in the context of disability. Narratives portray practice as the materialization of personal knowledge and affirm the value of reflection, experience, intention, context and geographies of power when searching for individual and social *conscientization.* The conclusion reflects on the importance of *conscientization* of personal knowledge and its contribution to the field of disability and social change and, briefly, to the field of knowledge management for development.

Keywords: disability; social change; leprosy; development projects; *conscientization;* personal knowledge; empowerment; Cirebon; Indonesia

Introduction

We can know more than we can tell. Michael Polanyi

This popularized phrase of Polanyi (Polanyi, 1962a) lies at the heart of personal knowledge theory. The emphasis placed on the 'person' when creating any kind of knowledge helped to challenge the hegemony of neo-positivist empiricism that, for many years, characterised social research production. Neo-positivist empiricism denies individuals their own personal knowledge, granting control to experts with their supposed objectivity. Medical epistemology, for example, is based on the premise that disease is something objective and 'separated from the individual's experiences of the material reality of their everyday lives' (Popay & Williams, 1996:760). Feminist, disability and other social movements claim that personal knowledge needs to be taken seriously, and that no theory which attempts to explain oppressive situations should be developed without involving the individual.

This paper affirms that the disability field needs to recognize disabled people as holders and producers of knowledge (Barnes, 2003). This recognition, however, has not extended to the field of leprosy which is still dominated by medical epistemology. We claim that an epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential. This paper describes the *conscientization* process among disabled and leprosy affected research assistants (RAs) and lay counsellors (LCs) of the Stigma Assessment and Reduction of Impact (SARI) project in Indonesia. *Conscientization* or critical consciousness refers here to the awakening of the individual regarding his individual and social situation which provokes individual and collective change.

SARI is an action research study aiming to reduce the impact of leprosy related stigma. In 2011 people affected by leprosy and disabled people were invited to become SARI research assistants and lay counsellors. The project acknowledged the difficulties of attaining a high response to the recruitment call because statistics from Indonesia indicate that few disabled persons and even fewer numbers of people affected by leprosy have access to formal and higher education. However, keeping in mind the principles underpinning an emancipatory disability research that demands inclusion of multiple voices and multiple knowledges (Barnes, 2003; Brown, 2005), the project continued with this enterprise. Recruited staff have been involved in a learning-through- interacting process (Gertler, 2003) and have become aware of how their personal knowledge has catalysed social change.

The main focus of this article is to look at the process of *conscientization* of personal knowledge as a transformative means. Personal knowledge represents the embodied unique capital of each individual and when marginalized social groups become conscious of such capital, it can provoke changes in both individual and collective life. The SARI project serves as a case study. First, findings from the literature on personal knowledge, its conceptualization and the role of *conscientization* are presented, including the political nature of personal knowledge and its significance for social change as well as personal knowledge in the context of disability. The article continues with a general description of SARI and the methodology used for the present paper. Following this, a description of the process of *conscientization* as experienced by SARI's research assistants and lay counsellors and its impact beyond the initial aims of the SARI project is provided. The conclusion reflects on the importance of *concientization* of personal knowledge and its contribution to the field of disability and social change.

Personal knowledge and embodied consciousness

> *Knowing has to do with an embodied consciousness (not just a consciousness).*
> S. Sontag

Knowledge is a concept with multi-layered meanings (Nonaka, 1994). The definition of being 'solely objective and detached from the involvement of the subject' has been contested by considering knowledge as a discursive formation (Foucault, 1980) in which its creation has a personal mark. The work of Michael Polanyi (Polanyi, 1962a) is of considerable relevance because it criticises the notion of 'complete objectivity' of knowledge which denies the individual's role in its creation. Polanyi recognises that knowing is personal, and this includes scientific knowledge, and that every act of knowing involves a deep personal commitment:

> […] *into every act of knowing there enters a passionate contribution of the person knowing what is being known and that this coefficient is no mere imperfection but a vital component of his knowledge.* (Polanyi, 1962:268)

Supporting the diverse production and diffusion of knowledge, Polanyi makes the distinction between explicit and tacit knowledge. Individuals are the primary repositories of tacit knowledge and explicit knowledge is transmitted formally and systematically by individuals. However, both exist synergistically. In this paper, tacit knowledge is defined as personal knowledge. Personal knowledge is created when 'rediscovering the perception of the world' (Merlau-Ponty, 1962), as body and mind interplay when producing it. Due to the complexity of personal knowledge and the overwhelming importance society attributes to technical performance, personal knowledge has been reduced to 'mere experience'. It is important at this juncture to highlight the distinction between personal knowledge and personal experience. Personal knowledge extends beyond personal experience: it is the product of an internal process which includes intentionality, experience and reflection (Dewey, 1988; Turner & Bruner, 1986). Experience is an integral component of personal knowledge, rendering it authentic, irreducible and irreproducible (Benjamin, 1968). Other components such as individual skills (Polanyi, 1962b) and dialogue with other knowledges (Brown, 2005) are also relevant to personal knowledge. The embodiment of personal knowledge implies dealing with discourses of power embedded in socio-cultural contexts (Foucault, 1980; Gertler, 2003; Haldin-Herrgard, 2003). In this process, difficulties regarding its recognition, codification and transfer into practice emerge as the result of its being:

> *…so practical and deeply familiar to them* [individuals] *that when people are asked to describe how they do what they do they often find it hard to express it in words.*
> Tsoukas (2005:142)

On the one hand, Polanyi recognizes such complexity when stating that personal knowledge 'is not really known by the knower' (Polanyi, 1962b) and some sort of consciousness is essential for its transference into practice. Conversely, Nonaka (1994) proposes that transfer of personal knowledge into practice is facilitated by intention, autonomy, fluctuation and individual's commitment (Gertler, 2003; Ikujiro Nonaka & Lewin, 2013; Polanyi, 1962a; Tsoukas, 2005). Although we agree with both positions, we argue, transfer of personal knowledge demands consciousness or, as we will call it here, *conscientization*. We state that consciousness of personal knowledge leads an individual, emancipated from 'technical formulas for action' (Haldin-Herrgard, 2003:136) to assume his or her role as knowledge producer. 'Geographies of power', the significance of contexts (Gertler, 2003) and, the importance of reflection play a relevant role in such processes of consciousness. Contexts influence its development and implementation. Power relationships are integral to 'interaction-transference of knowledge' (Haldin-Herrgard, 2003). Reflection transforms experience into a significant interaction between an individual and environment. Nonetheless, only when *conscientizatio*n of personal knowledge is 'experienced' by an individual, can personal and collective change occur (Dewey, 1988; Freire, 1998).

***Conscientization*, personal knowledge and change**

In 1969, 'the personal is political' became representative of liberation movements that emerged around the world calling for the emancipation of oppressed social groups including women, black people, workers, homosexuals, indigenous peoples and the disabled (Hanish 2006). It demanded social consciousness and simultaneously secured personal knowledge as a source of change, emphasizing that 'personal problems are political problems' and that 'there is no individual solution for them but collective solutions' (Hanisch, 2006:4). In this context, the concept of *conscientization,* or critical consciousness, borrowed originally from Franz Fanon's '*consienciser*' was revived by Paulo Freire and implemented in areas of educational and social development. To Freire, knowledge emerges when individuals are conscious 'that they are in the world and with the world' (1998:15) implying that transformative power lies in the self. In this sense, a liberating path of learning relies both on personal experience and existing knowledge. Thus, *conscientization*, refers to the process of deepening one's understanding of self and society through learning and reflection (Horton & Freire, 1990). It ensures individuals contextualize personal difficulties in their larger social, cultural and historical settings and provoke change when recognising their own knowledge.

Conscientization of personal knowledge materializes only when 'practice' happens (Freire 1984, 1998) and leads to serious social change when the individual appears as a 'producer and owner of knowledge.' In practice, inimitability of personal knowledge crystallizes the uniqueness of individuals as a sort of 'aura' (Benjamin, 1968). 'Without practice (performance) there is no knowledge, at least it is difficult to know without practice' (Horton & Freire, 1990:98).

Recognizing the contribution of Freire, we argue that having knowledge is not enough as individuals need to be conscious and confident about it. In doing so, we claim that reflection plays a determining role in this process and that there is no *conscientization* without reflection. Reflection emerges as the result of a complex, conflictive relationship between processes of knowledge production and various contexts where the individual exists (Alvesson & Skoldberg 2009). Reflective thinking and personal inquiry, Adorno (1974) argues, have relevance in any learning process. When individuals, especially those who are socially excluded, become conscious of facts that construct their reality by critically reflecting on them, consciousness of change is echoed in their surroundings. Therefore, exploring personal knowledge regarding social change would promote individual and collective *conscientization.* It would transform the relationships of people with the inner self and the collective self.

Personal knowledge, disability and leprosy

The transformative potential inherent in *conscientization* is recognizable in the disability field and in the case study presented in this paper. For more than 50 years, the disability movement has demanded the recognition of knowledge that is produced as a result of being disabled. Claims from disability activists and theorists (Barnes, 2003; Devlieger, 2005; Goode, 1994; Goodley, 2004; Oliver, 1990) that disability is socially, culturally and phenomenologically constructed have challenged the dominant medical epistemology and demanded recognition of disabled people as knowledge holders and producers. This demand (see; Crow, 1996; Morris, 2007; Thomas, 1997) has materialized as emancipatory research (Barnes, 2003; Oliver, 1990). The inclusion of personal experience of disabled people as an emancipatory principle is increasingly recognized, however, the means to enrich this with personal knowledge, is still 'gossip in the corridors' (Rabinow, 1985). Studies of participatory and emancipatory disability research have underscored the need for implementing methodologies that facilitate researchers' understanding of disabled people's lives. More importantly, the principle of working together to encourage transfer of their knowledge to others (Gleason, 1989; Goode, 1994; Klotz, 2004) could be translated into a first call for exploring personal knowledge. A few initiatives have promoted the training of people affected by leprosy as community agents and research assistants (Beise, 2012; H Cross & Newcombe, 2001; Cross & Choudhary, 2005) and yet little is reported about exploring personal knowledge and its impact on individual and collective social change.

In an era where efficiency and success supposedly depends on mechanical reproduction of explicit knowledge (Benjamin, 1968), the elaboration of unique and innovative knowledge depends on the use of individual personal knowledge (Gertler, 2003; Haldin-Herrgard, 2000; Polanyi, 1962a). Barriers disabled people face in being recognised as 'innovative creators' reflects the challenge society faces when attempting to understand 'other minds' (Polanyi, 1962b). Furthermore, the difficulty disabled people encounter in becoming aware of the value of their personal knowledge is a response to these barriers. Understanding how personal knowledge is produced, appropriated and shared will facilitate a move from solely valuing personal knowledge as 'experience' to seeing it as an important component of emancipatory disability research.

Approaching personal knowledge through the voice of disabled and people affected by leprosy

Having established the value of the recognition and transfer of personal knowledge, this article explores the contribution that the personal knowledge of disabled people and people affected by leprosy offers to development projects. It positions the SARI project as a case study and source of analysis. SARI emerged in 2010 as a collaborative action research study between the Athena Institute of the VU University Amsterdam and the Disability Studies Centre at the University of Indonesia (UI). The project aims to implement three Community Based Rehabilitation (CBR) interventions to reduce the impact of stigma that people affected by leprosy face in Cirebon, Indonesia. These interventions comprise: counselling and individual empowerment; contact with the community; and socio-economic development. Exploratory validation of instruments, pilot and base line studies was previously performed. The interdisciplinary team comprises three PhD students, one of whom is blind; nine research assistants, including one affected by leprosy and three who are disabled; and 14 lay counsellors of whom four are disabled and ten are affected by leprosy. Methodologically, SARI employs an Interactive Learning Approach (ILA) which involves an on-going learning process accompanied by continuous training.

The authors of this article are senior researchers, including the blind Indonesian PhD student involved in the SARI project. As trainers and researchers, we have witnessed the changes that the SARI team members have experienced by becoming more aware of their own knowledge. This paper emerged from processes of dialogue and reflection established between the authors and the SARI team members. Incorporating the narratives of the team members has facilitated understanding of personal experiences, personal knowledge and learning processes in which the SARI team and participants are involved. Four written testimonies of the research assistants and 12 tape recorded interviews with the lay counsellors collected in 2012 supported the analysis made in this paper. Testimonies were approximately 12 pages in length each and the interviews lasted up to 90 minutes. Additionally, two focus groups discussions (FGDs) were organized in 2013, one with the four disabled research assistants (two men with physical impairments, one woman with a visual impairment and one man affected by leprosy) and one with 12 lay counsellors (four men with physical impairments and eight people affected by leprosy of which six were women). The FGDs were taped recorded, lasted about three hours each, and were conducted by the blind PhD student in charge of the counselling intervention. In total 16 people between 21 and 30 years of age participated in this study over a two year period. The interviews and FGDs were facilitated by the research assistants who also participated in the elaboration of the questionnaires and in reflection meetings to discuss the data collected.

The implementation of qualitative methods for the research responded to the demand of a 'politics of recognition' (Bauman, 2001) of disabled participants as citizens and producers of knowledge. Notes of the observations taken place during weekly sessions in the field, fieldwork visits and different training workshops have also been incorporated. Data was collected in Indonesian and translated into English. Semantic issues were taken into consideration when translating. The Indonesian team has helped to minimalize those issues. Analysis of data was developed using Nvivo with four points of focus: previous knowledge; knowledge acquired during engagement in the project; knowledge shared; and effects this process has had in their lives. The analysis was validated with both groups and changes were incorporated into the document. We make no apology for the extensive quotes that permit examination of material on which concluding observations were based. Neither the method of selection nor the numbers of participants enable observations to be generalized. Additionally, terminology used in this article 'people affected by leprosy' and 'disabled people' respond to a social model of disability. The term *kusta* (leprosy) appears in some quotes as it is frequently used in Indonesia and by the participants.

Personal knowledge and *conscientization*: stories from the field

The theoretical framework of this article elaborated on the definition and characteristics of personal knowledge and the relevance of *conscientization* for its recognition and transfer into practice. Through the voice of research assistants and lay counsellors involved in SARI, we consider the characteristics of personal knowledge, the difficulties facing the recognition of personal knowledge and the changes experienced. The narratives portray practice as the materialization of personal knowledge and affirm the value of reflection, experience, intention, context and geographies of power when searching for individual and social *conscientization.* Three stages are developed here to show the continuum of *conscientization* of personal knowledge.

Background and the first stage: the role of context and difficulties recognizing personal knowledge

SARI was set up, among various reasons, because 'leprosy [is] one of the major causes of preventable disability' (Brakel, 2007) and initially involved a comparative study of the stigma experience of people with physical impairments and people affected by leprosy. It soon became evident that this was a complex ambition requiring a different approach. The decision was made to recruit disabled people and people affected by leprosy to work in the project, taking a different methodological and content angle than was originally envisaged. A female psychologist with visual impairments was accepted as a PhD candidate (one of the authors) and a professor with physical impairments from the UI holds the position of Principal Investigator in Indonesia. A CBR organization from Solo led by disabled people was designated to select and train the candidates. The position for six research assistants was widely advertised in Cirebon. The job description included data collection, assisting the PhD students on the field, implementation of the interventions and contact with the community. Among the 54 applications, only five were disabled people and two were people affected by leprosy.

The low number of disabled applicants and of applicants affected by leprosy for positions within SARI, despite the explicit call for them to reply, reflects their marginalised position within Indonesia. These groups tend to be overlooked behind the label of a 'hard to reach group' (Beresford 2002). There are more than 3million people with different types of impairments in Indonesia (Susenas 2009) but only a small percentage of disabled people are able to gain access to education. The gap in primary school (35% of disabled children and 85% of non-disabled) and secondary school (17% of disabled children and 75% of non-disabled) attendance rates in Indonesia is significant(WHO, 2011: 207). No provision is made for students with disabilities within the higher education system and no significant data is available on tertiary education participation of disabled persons in Indonesia (Steff & Mudzakir, 2010). Furthermore, the situation of people affected by leprosy and their access to education is not included in the statistics. Three of the five disabled applicants, among whom there was only one woman, were selected. Unfortunately, there were no suitable candidates affected by leprosy.

For the recruited staff, the selection process was highly significant. For the project, selection was a mere administrative procedure but, for them, it was the starting point of a journey into confidence. The research assistants and lay counsellors belong to low income families, 13 are married and three are single. The majority has attended secondary school. Most of their household income is derived from services, such as technical, retail, construction and housework. Two are founders and members of a small disabled people's organisation (DPO) in Cirebon. Early reports revealed negative previous life experiences in which discriminatory practices prevented access to education and difficulties in the work place. This led some to start their own businesses. They were unconscious of the knowledge they had acquired during this time to the extent that they expressed feelings of low self-esteem and insecurity about their ability to perform in this role:

> *Even though I had only finished primary school, I encouraged myself to apply. I was a bit ashamed when I applied because the applicants should have mostly finished a bachelor degree; even the disabled applicants. I was feeling as the only one who was a primary school graduate, the others were middle school [12-15 years] or secondary school graduates. I let that thought go and just put it in God's will. I was accepted in SARI Project while my other disabled friends with higher education were rejected. I don't know why. It must have been something they saw in me. I proudly can say now I work as a research assistant in SARI Project.* (RA2)

Some less confident female candidates attending the interviews embraced this process as a way of proving capacity and willingness to work. Moreover it was an expression of their search for independence despite their impairment and poor education:

> *I read the advertisement and initially I was not confident because the requirements listed English skills. But I was given the support of my sister and I thought this could be my last chance to get a job because it is very difficult to find one especially with my condition of disabled and having only middle school, plus being above 25 years old. So I decided to apply with the aim that I no longer depend on my husband. I wanted to prove my husband that I can be independent without a husband, I do not want to be a weak woman who is just resigned to depend on a man. So I hoped that once accepted in SARI, I would show what I know and what I can do. I had the faith that this would be the gate for me to become a formidable woman and not being under the shadow of a husband.* (RA1)

A different approach was taken in the recruitment of lay counsellors. This recruitment took place few months after the implementation of a base line study. From the study, candidates were identified, based on their willingness to work, availability and skills. Later, Puskesmas (Health Centres) officers joined the training for counsellors as well as four members of the Disability Forum, a new DPO of people with physical impairments. Their tasks included

counselling people affected by leprosy and their families, collaboration with counselling community activities and reporting to the instructor (blind PhD student). Similar to the research assistants, the lay counsellors expressed that they entered the project feeling helpless, embarrassed and with little confidence about their contribution. The experience of disability and leprosy placed them in a paradoxical position. Some of them acknowledged their experience regarding expertise on medication and social effects of leprosy and disability but were shy and lacked confidence about their knowledge and performance. Phrases such as 'I am shy because of *kusta*… I do not have enough confidence to meet people… I just know about the medication but I do not know what *kusta* is… I am afraid of people who know I have *kusta*' were commonly mentioned when the counselling training started. They also attributed little importance to the knowledge, experience and intentionality they had.
All recruited staff indicated they wanted to share their experience, gain confidence and join a social cause. But, overall, they expected to obtain knowledge about leprosy and to deepen their understanding of the way people have treated them. Their fears and lack of confidence blurred the importance of the path they have already walked. One of the lay counsellors explained:

> *Before I joined SARI Project, I was reluctant to discuss anything about leprosy. It was almost like a trauma. I didn't want to hear anything about leprosy. It made me remember when my friends were avoiding me and the society outcast me; even someone actually said how 'disgusting' I was. ..I think I only have little knowledge especially on leprosy. I always thought leprosy was a scary disease; it is not only about losing your health but also losing your friends and losing your confidence. I thought that my knowledge was not enough to become a counsellor… But I needed help and I wanted to learn.* (LC affected by leprosy 1)

Becoming conscious: technical training, personal experience and new roles

Topics inclusive of, research methods, disability, leprosy and human rights and CBR approaches, were included in the training of research assistants and lay counsellors. Research assistants also attended the counselling training in order to implement the intervention. The process was described by the lay counsellors 'as a learning process where they began to recognize their own knowledge and experience'. They were also overwhelmed by difficulties such as language barriers, different backgrounds of participants and the topic of leprosy itself and by the presence of foreign and disabled instructors.

During this process the participants acquired technical knowledge or expert knowledge (Brown, 2005) which provoked reflection on their own life in many ways. Attaining technical knowledge reconfirmed their own knowledge or eliminated beliefs regarding disability and leprosy. This enhanced personal confidence and certainty regarding their situation and their performance when sharing their knowledge with the communities. The majority mentioned that learning more facts about leprosy and disability helped them become more reliable community workers. Additionally, being reliable was a source of pride due to the importance of their work. Recognizing their own knowledge about leprosy, disability and methods of research, something that other people in the community lacked, was also a source of pride and courage. Receiving a certificate from SARI at the end of their training was an affirming action, acknowledging the technical knowledge they acquired and reinforcing their public credibility and recognition.

Issues of power/knowledge relationships were also raised. Feelings of contradiction and hopelessness emerged, when discussing issues with authorities or professionals. After receiving training on how to conduct interviews and focus group discussion, research assistants were asked to organize different focus groups with school teachers and religious leaders. Organizing and facilitating meetings with people of higher educational attainments confronted them with fears and feelings of inferiority and doubts about their knowledge. This happened due to two factors. First, Indonesia's highly hierarchical society is reinforced by gaps in cultural, social and economic capital of people. Second, barriers that disabled and people affected by leprosy face regarding education and access to information is a vicious circle that situates them in unequal positions and perpetuates hierarchical relationships in production of social research (Barnes & Mercer, 1997).

The presence of disabled instructors helped them to overcome such fears. It generated feelings of admiration, courage and initiatives for the future:

> *When I started the training, I was amazed by the experts in SARI Project, especially when they explained the material to increase our skills in performing the project's activities. It was all educational and also very well constructed. But I was so amazed when the instructor was also a disabled person… At that point I committed to follow the training until the end. I accompanied Oni* [a fellow research assistant] *in the training. I hoped Oni could gain knowledge in SARI Project because I believed that this was the place to gain knowledge and skills. That knowledge, I thought, can be used for FKDC* [Forum Komunikasi DAS Cidanau = Cidanau Catchment Communication Forum] *to move forward. I also thought I can make connections with the government, seek information and organize activities to increase the resources of our disabled friends*. (RA 3)

Having a blind instructor had a significant impact on their learning and increased their level of commitment:

> Interviewer: *You also interact with me but I am blind. Do you have problems in interacting with me? […] during the training sessions or when working with me?*
> LC2: *I don't think so. On the contrary, I am proud of you because with your disability you work better than me. I was surprised when I realized that you are blind but you can write and use a laptop. It motivates me to work better.*

These quotes do not imply that the relationship between the disabled staff is always positive and exempt of stressful moments. Ward & Simons (1998) report difficulties facing of collaboration of non-disabled and disabled individuals when doing disability research, and these difficulties may also be experienced by disabled individuals. Some participants have shared anecdotes of situations when describing physical and environmental aspects about the participants to the blind PhD student. This resulted in embarrassment and tension that could have been easily misunderstood as unwillingness to collaborate. Moments of frustration have also emerged when some participants have faced the failure of society to accommodate their needs; this source of frustration is also recognised in the literature (Oliver 1997). Examples included the difficulties of having an adapted motorcycle, being dependent on others to move from one place to another and, on some occasions, having to cancel appointments. Oliver (1997:812) also argues that 'employing disabled researchers can have serious resource implications which have yet to be addressed properly by main players funding disability research and, indeed, the research establishment which receives the grants.'

Recognizing themselves reflected in other stories and witnessing others' living conditions provoked c*onscientization* of personal knowledge among the team members. Both groups explained that attendance in the training and close encounters with people affected by leprosy and disabled people immediately resonated in their own bodies and lives:

> *In short I joined the training. Once I got there, I was surprised because none of the participants had normal physical condition. Even the instructor had had polio. There, I could laugh out loud and let go of my burden. I felt that this is my world. I was motivated when I saw that there are people who live in difficult conditions, but didn't complain. I said to myself, if those people can do things, than I also can do it. I was ashamed remembering how I locked up myself at home for years.* (RA1)
>
> *I knew about the discrimination against people affected by leprosy and disabled people but it never occurred to me, why? If I received an insult, I used to take it and never questioned why. But in SARI, it made me question the discrimination. I learned about discrimination and I realized we have rights.* (RA2)

Meeting people who had had similar experiences and were in similar circumstances was able to contribute to demystification of their ideas about their condition and simultaneously gave them a sense of relief and acceptance of their skills. They became more confident of their own knowledge through reflecting on the situation of others:

> *And it turns out that there are more people who are affected by leprosy, not only me. I used to think that I was the only one who had leprosy. There are many out there. […] I feel more open minded now. I think, well, if others can be confident, why can't I be confident too?* (LC 5)
>
> *I know how they feel. I used to be one of them (I had leprosy), so I know their stories. We share the same feelings. So because I know, I tell them to keep the courage, don't give up. We can be cured. Reduce your feel of embarrassment because mostly they are ashamed of themselves. I know that.* (LC3)

Based on this experience, participants strongly recommend active involvement of people affected by leprosy or disabled people in projects addressing leprosy and disability to avoid purely medical approaches. Reasons for this included better understanding of feelings of people involved, empathy as well as a sense of equality:

> Interviewer: *Do you think that a counsellor should be someone who has had leprosy?*
> LC4: *I think it would be better if they are people who been affected by leprosy. That is my opinion, because people will feel better if they talk to someone who has had leprosy too. It can push them to follow treatment as soon as possible. But I don't mean it is bad if a counsellor is not a person with leprosy. It is good to show people*

> *that they* [people affected by leprosy] *can help to reduce the stigma on the people who are affected by leprosy.*
>
> *I think it would be better if people affected by leprosy are involved in every activity. People would accept counselling more easily if things are explained by people who have experience* [of leprosy]. *People would trust them more and will be more enthusiastic.* (LC6)

Experiencing change: knowledge, reflection and consciousness

> *In Islam, Allah will not change the condition of people if they don't want to change themselves.* (LC6)

Freire asserts knowing should relate to, 'speaking the word to transforming reality, and to man's role in this transformation' (Freire, 1972). In this sense, research assistants and lay counsellors experienced a transformative effect at both an individual and community level during this process of *concientization* of their personal knowledge. This was described in terms of gaining knowledge, respect and status, whilst simultaneously witnessing changes in their wider environment. Research assistants explained their transformation from 'uneducated and incapable' to 'reliable community facilitators'. They consider that reflection has offered them a different perspective on their own contribution when working with people, as well as access to new knowledge:

> *When you gave me a job as a facilitator, at first I was nervous. My hands were shaking and I did not know what to say or what to do. But now I am grateful that I am no longer nervous. I also gained knowledge on computing and on how to organize concepts. I mean, when I performed an activity with people I never reflected on it with them and just did it. But now I learned about planning and concepts. I learned so many things with the other RAs and the friends affected by leprosy.* (RA1)

They also place greater importance on their own knowledge and skills, and what they can mean to others in their communities:

> *I think my knowledge now can make the difference. Once I was asked by several ladies in my neighbourhood about my job. They asked me why I wanted to join people who are affected by leprosy. I took that as an opportunity to explain it to them. I told them that leprosy is not a curse, it is curable and I am someone who already has been cured. I think the knowledge I have gained and shared with the community is useful in reducing stigma towards people affected by leprosy. It is because now that people have knowledge and understand the people who are affected by leprosy, they will no longer be afraid to interact with them.* (LC7)

The knowledge learned whilst implementing research methods and interventions has helped them to recognize the value of action research:

> *I learned from you that SARI implements both research and interventions. While other organizations only perform research SARI can help reduce the stigma with action.*

> *Sari counsels both the people affected by leprosy and the society, so when the people affected and disabled people move on with their life the society can accept them too. I only knew that disabled people are given trainings but that is not enough if they do not try to change the society to accept them. So that is what we learn, to do both.* (RA2)

Knowledge was also perceived of in terms of skills they acquired. The majority summarised these skills as feeling confident and free to talk in public; sharing their stories; finding addresses and approaching people; discussing issues with authorities; independently solving problems ; having more patience and understanding that people have different characters; organizing public events; conducting interviews and focus groups discussions; and asserting their rights and demands.

The recognition and acquisition of knowledge improved the respect and status of SARI team members. They have been welcomed to spaces where their knowledge is valued and they transfer their knowledge in their own way in the houses of clients, health centres and community centres. The majority of lay counsellors talked about the development of positive attitudes in the community and new relationships as a result of their new role:

> *I am happy because I gained more friends. I became more open, especially to those who are affected by leprosy. We can share things, tell stories. I sometimes share thoughts with my clients. We just tell each other stories.* (LC8)

> *The biggest effect is in my study on campus. I became some sort of senior among the students. If they have a problem, they usually come to me; they share thoughts with me about their family or their daily life. There are so many changes in me after I joined SARI.* (LC2)

Their new roles have led to the generation of new knowledge, have given them a new perspective on self as well as encouraging them to share knowledge with others. During training and implementation of the interventions, they attributed meaning to their new roles. According to some, this goes beyond the title of research assistants or lay counsellors. A lay counsellor described communities as perceiving a lay counsellor as “someone who is really useful for the society.’ They also explained their function has evolved within an accepting and familiar environment. After the lay counsellor’s focus group, it was mentioned that being a lay counsellor ‘has to do with promoting change’:

> *A research assistant can be considered as the front line of a project. He/she determines the success of the research. Being an RA is not a simple job. We have to be very sharp in dealing with situations. The RAs also have to develop relationships with the clients* [SARI participants] *and also other stakeholders so the research can be performed well. An RA is also the liaison between the researchers and the subjects researched so the research will have a good result.* (RA2)

Opportunities for reflection have been an important part of the role of SARI team members. Fieldwork and individual issues, urgent cases needing referral, problems encountered during the collection of the data, and administrative problems are always discussed during weekly or monthly meetings. Data collection always involved group reflection and discussion of problems, successful events and funny anecdotes. A similar process was followed during implementation of the interventions, resulting in a constant questioning their role within the project and their communities. The two groups also explained that, as part of their job, they felt responsible for spreading reliable information about leprosy and dealing with difficult situations faced by people affected by leprosy and disabled people:

> *By receiving this certificate it means that I have received a mandate. Because not everybody can receive this certificate […] I received the certificate from SARI Project and the Health Office, which means I have to implement the mandate that has been given to me. I have to make a contribution to the society on the leprosy issue.* (LC8)

Collective knowledge, as well as increased awareness of their own personal knowledge, has had a positive impact on themselves and their families:

> *I am also more aware about my own health and hygiene. My family has gained knowledge on leprosy. They used to think leprosy was a curse but I explained that it is not a curse and we have the cure for that. Every time my family knows someone who has leprosy symptoms, now the first thing that they do is report it to me.* (RA3)

> *There are many changes. In family, I became a better brother and know how to treat my younger siblings.* (LC2)

> *I got married* [laughing]. (RA2)

Personal changes related to their socio-economic situation were discussed. This was especially highlighted by some of the female participants:

> *Honestly this has really helped us. My husband works but has an irregular income. I still have debts, but now they have already reduced. Working in SARI also helps me to give my parents money. My children's education is also paid from my salary, not from my husband. He actually never took care of my children's education.* (RA3)

> *It is the first time I go out of my house. Now I understand leprosy is just a normal disease so I'm not afraid. Now I travel a lot* [laughing]. *I went to* [a colleague's] *house by car, it was so far. I changed public transport four times, imagine that! I didn't know* [that] *neighbourhood until I went to her house. My husband supports me and my family too but I think now they do not like it because I am pregnant and need to rest.* (LC4)

They are also aware that their transformation and *concientization* about issues of discrimination and suffering could lead to collective change. Both groups expressed pride as 'instruments of change' through their transformation. Reflecting on their own knowledge, they conclude that individual change can serve as a catalyst for further change:

> *My parents used to be worried about my future; I used to be a closed person because of leprosy. Now, I changed. I became more active and energetic. My parents like me*

> *now better than whom I used to be. I am just like another normal person. Then I feel so many contributions from my clients. I see that they have also changed from not taking care of themselves into being willing to take medicines, accept treatment and make recommendation to neighbours who also could have leprosy.* (LC10)

Other examples of changes observed within their environment include people affected by leprosy going out the house, being less concerned about what people think of their physical condition, taking care of themselves and their families, making friends, making decisions about their lives, accepting people with impairments and skin patches, talking in public, managing their own money, and even falling in love. These changes were challenging and difficulties mentioned had to be solved before change could occur. Difficulties included: people affected by leprosy being denied the opportunity to grow as a result of discrimination; families hesitant to collaborate due to fears or over protection; and lack of information. Additionally, some reported little support and misunderstanding from their husbands and wives about their role in the communities.

Team members increasingly recognise the transformative process and, in the words of one counsellor, the ‘personal call’ of their jobs. Increasingly, they have become activists. For example, some research assistants have taken action to strengthen the work of a small, recently established DPO, by changing the organization’s name to one with a more human rights perspective, making it more inclusive by inviting people affected by leprosy to be involved and developing of socio-economic projects based on the knowledge they have gained in Sari:

> *I will use my personal knowledge in the future by integrating both, my experience before I worked in SARI and the knowledge I received in SARI to reduce stigma and discrimination towards disabled people. To increase our livelihood, we need to fight for our rights as a disabled people to achieve equality as citizens of the country. To achieve all of that, FKDC have become partners with Social Office to use skill training programs for disabled person both in the region and in the province. We have also started to study how to perform advocacy. My hopes for the future would be that there would be a strong organization helping us* [FKDC] *to achieve all of that.* (RA2)

Final reflections: personal knowledge as means for individual and social change

> *It is of extreme importance […] to give back to man the childish audacity that years of verbal submission have taken away: the audacity to say: I am here.*
> Simone de Beauvoir

In the narratives summarized above, disabled people and people affected by leprosy reflect the positions of many other social groups placed in disadvantaged power positions. Their narratives recount how they are taking the audacity to say ‘we are here’ as holders and producers of knowledge. At that very moment, they are becoming conscious of their personal knowledge. The main argument of this paper is that although such people are not initially aware of being holders of knowledge, individual and collective awareness of the importance of their personal knowledge can be created by interventions, involving a process of awakening. SARI provided a space for learning and teaching; intentionality was a key ingredient; other knowledges interacted; personal experience was valued; and reflecting, creating new knowledge and sharing/interacting with others became possible. Furthermore, it is evident that when recognizing and reflecting on difficulties faced during the process, awakening is possible. This did not occur instantly but rather through a continuous process of reflection, internalization, interaction and sharing. It could be said that tacit knowledge is converted to explicit knowledge through observation, imitation and practice (Tsoukas, 2005) but also it needs the recognition of personal experience valuing the contextualized difficulties involved.

Personal knowledge has been commonly mistaken as experiential knowledge while experiential knowledge is only one component of personal knowledge. In this article, personal knowledge is described as a continuous process that integrates different types of knowledges (individual, institutional, experiential, expert, community) that requires the uniqueness of each individual, their skills, their experience and the possibility that the context offers them for *concientization*. The process of collective consciousness demands dialogue and exchange of knowledge between different social actors as producers of knowledge including those considered to be disadvantaged. In doing so, there is also a transformation of the relationships of social research production (Barnes, 2003; Oliver, 1990). This article calls for greater value to be placed on personal knowledge within the field of disability and leprosy. The core of such exploration has to be the individual and the unique and irreproducible knowledge that individuals can create and transfer (Benjamin, 1968; Polanyi, 1962a). This article has analysed personal knowledge from the perspective of disabled and affected by leprosy SARI staff, reporting the transformative process. Adorno (1974:70) affirms:

> *Knowledge may broaden, only where it persists by the individual, so that its isolation is disassembled by this insistence*

Thus, although the focus of this article is on personal knowledge of disabled persons and people affected by leprosy, it is relevant to a wide number of development interventions because the challenge facing the recognition of personal knowledge is a barrier to development and empowerment of individuals and communities worldwide. By this emphasis on personal knowledge and *conscientization*, it is supporting the field of knowledge management in its understanding of the role played by personal knowledge in conceptions of multiple knowledges (Brown 2010).

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