

Self-Reflection as a Means for Personal Transformation: An Analysis of Women's Life Stories Living with a Chronic Disease

Birgit Prodinger & Tanja Alexandra Stamm

Key words: secondary analysis; narratives; feminist critiques on health care; standpoint theory; gender; rheumatoid arthritis Abstract: The aim of this secondary analysis is to explicate taken-for-granted practices in the health care system in which the life stories of six women with rheumatoid arthritis (RA) are embedded. A secondary analysis of life stories of six women with RA, which were assigned to a typology named "rheumatoid arthritis as a source for new challenges" (STAMM et al., 2008) in the primary narrative study, was conducted. The theoretical framework applied for the analysis was informed by feminist standpoint theory and feminist philosophy. In the present analysis, each of the women challenged established health care practices and the cognitive authority of medicine at a certain point in their life story reflections. Becoming more conscious about health care practices enabled the women to acknowledge their own knowledge and to make choices about their health. The findings challenge health care providers to engage in critical reflexivity to become conscious about and to transform taken-for-granted practices as embedded in larger systems and to create health care environments that enable dialogue between clients and health care providers.

Table of Contents

- 1. Background
- 2. Method
 - 2.1 Participants
 - 2.2 Data collection
 - 2.3 Data analysis
 - 2.3.1 Theoretical framework
 - 2.3.2 Process of analysis
 - 2.3.3 Translation and representation
- 3. Findings
 - 3.1 Challenging the cognitive authority
 - 3.2 Acknowledging one's own knowing
 - 3.3 Approaches to self-reflection
- 4. Discussion
 - 4.1 Various means for self-reflection
 - 4.2 Implications for health care practices
 - 4.3 Reflections on the study
- 5. Conclusion

<u>Acknowledgments</u>

References

Authors

Citation

1. Background

The World Health Organization (WHO) considers health care services, systems and policies as influential on individuals' health (WHO, 2001). Ideally, health care services provide interventions for individuals that contribute to their physical, psychological, and social health and well-being. These services are embedded in an interconnected web of politics and funding priorities that may affect accessibility and comprehensiveness of services offered. In Austria, for instance, the health care system is separated financially from the social system. In the Austrian health care system the main focus is on disease, whereas the main focus in the social system is on disability. Disease refers to the causes and symptoms that lead to the diagnosis of a certain disease and the initiation of a treatment with the aim to alleviate the symptoms. On the other hand, any bodily, mentally, or psychologically functional or sensorial restriction that is expected to impede participation in social life for more than six months prospectively is considered as disability (BUNDESSOZIALAMT ÖSTERREICH, 2009). Hence, the term disability incorporates the experiences and consequences of living with a disease in a particular socio-cultural context. A diagnosis according to the International Classification of Diseases and Related Health Problems (ICD-10) (WHO, 2007) is normally required before a payment by the health insurance can be ensured. Furthermore, the Austrian health care system may force the medical conceptualization of personal experiences to allow for access to services and support provided by the health care system. In case of disability, the medical account is important to estimate the further course of the disability. Consequently, health care providers may find themselves in a contradictive system. On one hand they are supposed to provide services to clients which enable them to fully participate in their daily life, while on the other hand increased participation may affect the benefits which clients receive from the social system. [1]

Critiques on health care systems and services are not only based on a national system-level, but also on theories and philosophies that inform the provision of services to women and men in general. For instance, several feminists point to the absence of women in science and medicine until recently (KEARNEY, 1999; NAGL-DOCEKAL, 2004; SHERWIN, 1992). SMITH (1987) criticized that current health care fails to consider women's experiences of their bodies and the interrelatedness of body and mind. Her argument is in line with HARTSOCK (1987) who argued that female experiences of for instance menstruation, coitus and pregnancy go far beyond of an experience that can be described in purely biomedical terms. [2]

The relationship between the life context of the individual and the individual's experiences of health is acknowledged in narrative approaches. Narratives are enabled and restricted by the resources and circumstances available in a certain context (CHASE, 2005). In the women's movement personal narratives were frequently used as a primary vehicle to give voice to marginalized and silenced groups such as women and people with disabilities (CHASE, 2005). The personalization of one's experience in a narrative opens possibilities to challenge the social, cultural and political context in which the narrative evolves. Thus, the

act of narrating a life event as well as the narrative itself is a powerful means to facilitate positive change and to empower individuals. [3]

Research should aim to giving voice to people who live with a disease (FRANK, 2001). Listening to their voices may open dialogue about previously unrecognized experiences and enrich understanding about the complexity of their everyday life experiences including positive and negative aspects. The experience of living with a chronic disease is often linked to suffering. The previous use of the term "suffering" bears a negative connotation—it implies that something is wrong with the body (FRANK, 2001). A recent narrative study, however, indicated that over time people with rheumatoid arthritis (RA) may experience even positive aspects in living with RA (STAMM et al., 2008). STAMM et al. explored that women narrated in their life story reflections that RA constituted a source of challenging, and thus also enriching opportunities. These aspects of living with RA are hardly supported by current arthritis-related literature. The aim of this secondary analysis is to explicate the coordinated and taken-for-granted practices in the health care system in which the life stories of women with rheumatoid arthritis (RA) are embedded, who described living with the disease as a source of challenging opportunities in their live story reflections. [4]

2. Method

This secondary analysis draws on a primary narrative study in which the life stories of individuals diagnosed with rheumatoid arthritis were explored (STAMM et al., 2008) from a critical feminist perspective. For this study a modified process informed by two approaches to secondary analysis described earlier by HINDS, VOGEL and CLARKE-STEFFEN (1997) was applied. These approaches refer to on one hand a subset analysis of cases that showed to have shared characteristics in the primary analysis, and on the other hand to a secondary analysis with the focus on a specific conceptual interest that became pronounced in the primary analysis but was beyond the scope of the analysis at this point in time. [5]

2.1 Participants

In the primary narrative study the life stories of six women were assigned to the typology "rheumatoid arthritis as a source of new challenges" (STAMM et al., 2008). Typology refers to a general structure that was shared within several life stories. These six life stories were used for this secondary analysis. In the life stories reflection, the women described RA as a positive challenge within their life context. The six women—Catherine, Linda, Maria, Monica, Rita, and Sarah—had lived for at least ten years with the medical diagnosis of RA. [6]

More detailed descriptions of participants' recruitment for the primary study are given elsewhere (STAMM et al., 2008, 2009). Participants' personal information was altered to protect personal identity. The primary study was approved by the internal review board and ethics committee of the Medical University of Vienna, Austria. [7]

2.2 Data collection

The women were interviewed up to three times, according to a narrative biographic interview style in which the interviewee was asked to tell her life story (ROSENTHAL, 1991, 1995, 1998). All interview data were tape-recorded and fully transcribed. Each life story was analyzed independently by a panel of three researchers who formulated hypotheses about why the life story was told in a certain way and how the told story related to the storyteller's biographical data (STAMM et al., 2008, 2009). For the present analysis, the transcribed interview material and re-written life stories of the six women were revisited by the two authors. A reflexive research journal was kept by both authors independently which was also subject to the analysis. [8]

Both authors have lived for most of their lives within the Austrian cultural, discursive, and linguistic context as the research participants in the primary study. The second author was the leading researcher on the primary study; and the first author also used to work at the Medical University of Vienna from where participants were recruited. The authors' backgrounds ensure that they have a thorough understanding of the research context within which the primary study was conducted and facilitates that data of the primary study becomes not entirely decontextualized within the scope of the secondary analysis (VAN DEN BERG, 2005; TEMPLE, EDWARDS & ALEXANDER, 2006). [9]

2.3 Data analysis

A secondary analysis was conducted to center attention on parts of data which were marginalized in the primary analysis (CORTI & BISHOP, 2005). CORTI and BISHOP (2005) underscore, however, that distinctively described methods for secondary analysis are scarce. Such an analysis is often characterized by a particular reading of the written material (VAN DEN BERG, 2005) that occurred in the present analysis from a critical feminist perspective. [10]

2.3.1 Theoretical framework

Critical feminist perspectives were used to frame the secondary analysis. Feminist standpoint theory inspired by the work of Dorothy SMITH (1987, 1999) and feminist philosophies about the cognitive authority in health care (ADDELSON, 2003; NAGL-DOCEKAL, 2004; WENDELL, 1996) enabled the explication of how practices in the health care system are coordinated and shape the experiences of women who live with RA. [11]

Feminist standpoint theorists propose that knowledge is partial, local, and historical specific, and aim to understand and explicate the structures that are available to a particular social location (SPRAGUE, 2005). SMITH (1987), a feminist standpoint theorist, is particularly interested in explicating the ruling relations which are not simply considered as relations of domination, but rather constitute a complex field of coordinated activities in our everyday life. In her words ruling relations "extract' the coordinative and concerting of people's

everyday/every night activities and subject them to technological and technical specialization, elaboration, differentiation, and objectification" (SMITH, 1999, p.77). SMITH proposes that by explicating the established relations of ruling, we may be able to transform the relations of knowing. We may become aware that some knowledge claims have evolved outside the individual, in SMITH's terms in extra-local settings, while others are characterized by the embodied way of the individual's knowing. [12]

Further to this, feminist philosopher ADDELSON (2003) calls to mind by her philosophy to challenge the often unexamined practices of cognitive authority within social arrangements in science which determine to a large extent what counts as legitimate knowledge. Cognitive authority is enacted when "the specialist offers the correct understanding of reality while the lay person struggles in the relativity of mere opinion" (p.170). WENDELL (1996) argues that in health care medicine holds cognitive authority. The strong emphasis on controlling the body may place medicine's priorities over the individual experiences and needs. NAGL-DOCEKAL (2004) distinguishes between the sensed corporeality, which refers to the inner experience of the body, and knowledge about the body. Physicians have the power to confirm or deny the reality of the client's bodily, everyday experience as valid or not which means that they hold cognitive authority within the system. For instance, medical conceptualizations and naming of daily experiences in a third-person scientific account leave little space for embracing the inner bodily experience of the individual. [13]

Accordingly, the critical feminist perspective which framed this secondary analysis provided the authors with a means to explore how health care practices are authoritative coordinated and organized, to disclose how women made sense of their experiences when ruled within these practices, and enables to further understand the experiences and knowledge about the body of women with RA as described in their live story reflections. [14]

2.3.2 Process of analysis

The analysis involved an iterative process that was inspired by work of HINDS et al. (1997). In a first step each life story was read inductively by both authors independently, as well as reflexive notes were kept independently. Inductive reading implies that the authors read the life stories several times and attempted to understand how the six women with RA actually described and talked about the health care practices and the processes inherent in these practices. These health care processes based on the authors' individual readings of the life story-reflections of the women were then discussed together. In the next step, these processes were further elaborated by the two researchers building upon the theoretical framework. In particular, it was looked upon who has authority within the health care practices, how are various processes coordinated, and how do the women make sense of their experiences of being ruled within these practices. After these discussions, the authors re-visited the texts to elaborate further on how these processes are connected and shape the experiences of women with RA. Simultaneously, the reflexive research journals were analyzed also to

examine political or ideological assumptions inherent in our own writing. The emerging interpretations were discussed extensively between the authors and other colleagues to enhance credibility and trustworthiness of the findings. [15]

2.3.3 Translation and representation

All interviews were conducted in Austria in the German language. Rather than seeing language as neutral, language contributes to the construction of the individual's subjectivity based on historical and local specificity (RICHARDSON, 2000). In narrative research, the language used by the storyteller is considered to be influenced by the social resources and circumstances available to her/him (CHASE, 2005). Concepts may result in different meanings depending on which language is used (TEMPLE, 2005). The effect of changing language because of translation into another language requires a critical reflexive process on how the translation affects the narrative (GONZÁLEZ Y GONZÁLEZ & LINCOLN, 2006; TEMPLE et al., 2006; TEMPLE, 2008). Hence, in this article the participants' quotations are stated in English translation throughout the manuscript, and in addition, the quotations are highlighted in their original language in footnotes. By doing so, we aim to maintain transparency to our analysis and ensure integrity and credibility of the qualitative data. [16]

3. Findings

In the six life stories it became apparent that the women considered RA not simply as a health condition to which they adapted; but rather they felt that they could actively engage in discussions with their health care provider about services of which they would make use of and treatments which they would receive. The women conveyed in their life stories how they became an active agent within the ruling relations of the health care system. Being an active client was not something which was encouraged by the system in the first place. In the present analysis, in particular three interwoven processes evolved: 1) Challenging the cognitive authority: the six women challenged at a certain point the cognitive authorities within the health care system; 2) Acknowledging one's own knowing: becoming and thus being more conscious about the authoritative organization of health care practices enabled the women in this study to partly resist the authoritative voice and acknowledge their own ways of knowing; and 3) Approaches to self-reflection: the women used various approaches for selfreflection which liberated them to become actively engaged in health care and subsequently, to make decisions for their own health. In each of the individual six life stories, the three interwoven processes were apparent with varying emphasis. In the following paragraphs quotations out of these women's life stories are given to illustrate the interwoven processes. [17]

3.1 Challenging the cognitive authority

In the analysis of the life story reflections of the six women, it became transparent that after some time of being a client in the system, the women started to challenge the coordination and organization of the taken-for-granted health care

practices such as the examination for the vocational disability pension. Catherine realized that this examination process was not necessarily meaningful in relation to her embodied experience of living with RA. Catherine went through numerous examinations over many years. At a certain point she started questioning the established procedures.

"I was examined by 'physicians', who were knowledgeable in the field. However, I have to admit, those examinations were really ridiculous. Over time you realize how the examinations are done and what is going to be examined. And the examinations, which are made in regards to the vocational disability pension are a shame" (Catherine, Line 66-72).¹ [18]

Sarah and Rita illustrated how their physicians applied their authority to name either the cause of their health conditions or their experiences of living with the disease. The two women became aware of the cognitive authority of medicine in health care (WENDELL, 1996).

"The rheumatologist mentioned, maybe I got the disease following the vaccination for Thailand. He asked 'Why did you go to Thailand?' I answered 'Because I was interested in North-Thailand.' He responded 'If you would have traveled to South-Africa you would not have needed vaccinations, and you would not have gotten RA.' I said 'I could not have known that before. Those are the things you have to listen to" (Sarah, Line 291-296).²

"I never will forget this in my life: I was labeled as hysterical. Thus, I am not that happy anymore about coming back here [for medical check-ups at the outpatient-clinic]" (Rita, Line 103-105).³ [19]

The quotations of Catherine, Rita, and Sarah also illustrate SMITH's (1999) argument that in extra-local settings such as health care knowledge claims might be embedded in efforts toward technical specialization and objectification and subsequently emerge from a rather disembodied way of knowing. [20]

3.2 Acknowledging one's own knowing

The process of becoming more conscious about the authoritative coordination and organization of health care practices enabled the six women, as became transparent in their life story reflections, to resist the cognitive authority and credit

^{1 &}quot;Ich wurde dann untersucht von 'Ärzten', die da sehr gut Bescheid wissen, und ich muss sagen, die Untersuchungen waren dermaßen lächerlich. Weil im Laufe der Jahre konnte man hier erkennen, wie untersucht wird, und was untersucht wird. Und die Untersuchungen, die da im Rahmen dieser Berufsunfähigkeitspension gemacht wurden, sind eigentlich eine Frechheit" (Catherine, Line 66-72).

^{2 &}quot;Der Rheumatologe hat gemeint, ich hab's vielleicht von der Impfung gekriegt für Thailand. Hat er gesagt: 'Warum sind Sie nach Thailand gereist?' Hab ich gesagt: 'Weil mich Nordthailand interessiert hat'. Sagt er: 'Wären Sie nach Südafrika gefahren, hätten Sie keine Impfung gebraucht, hätten Sie die Polyarthritis nicht gekriegt'. Hab ich gesagt: 'Das hab ich vorher nicht wissen können'. Solche Sachen muss man sich anhören" (Sarah, Line 291-296).

^{3 &}quot;Das werde ich nie in meinem Leben vergessen, man hat mich nur als hysterisch apostrophiert, und das vermiest mir ein bisschen das Herkommen [zur medizinischen Untersuchung in der Ambulanz]" (Rita, Line 103-105).

their own knowing. Sarah referred to two incidents where she received an unexpected response of a health care provider who claimed cognitive authority. These situations made her question the system, and subsequently, it was part of the process where she learned to acknowledge her own knowing and take initiative based on that.

"I received answers such as 'Yes, try it. If it is not helping you, it won't make things worse.' (...) That was my first retreat in my life. It was a terrible experience. Everything which is in fact bad in reference to the disease was made there. (...) Finally, I decided to go for this diet on my own. (...) Throughout the time you realize certain things, things which you still can change even if the doctor may say he does not know about it or is not convinced about it" (Sarah, Line 53-83).⁴ [21]

Maria was uncertain if the treatment options offered to her so far—and which turned out not to be as effective as expected—really captured the breadth of treatments that could have been offered. She challenged the cognitive authority of her physician and trusted her beliefs which in turn empowered her to enter new social relations which offered her alternative perspectives. Becoming active herself was not something which was encouraged or offered to her by the system.

"I bought such a book [clinical dictionary] and attended the rheumatology symposium. He [the rheumatologist] said: 'What are you doing at the rheumatology symposium?' I want to see it once. I can't believe that we can't find any further treatment for me. And the ambition that this cannot have been everything in my life, kept me upright all the time" (Maria, Line 684-688).⁵ [22]

Sarah illustrated how important it was for her to have her embodied experiences of living with RA represented in health care. She referred to a discussion with her physician about what is appropriate to be stated on an official form. Having the actualities of her daily life stated in the form was important for Sarah, and she insisted on that although her rheumatologist questioned it.

"When I completed the form about these new drugs which I take now, I was asked to name 'assistive devices.' He said [the rheumatologist]: 'Are you serious?' I stated there: 'My husband.' He said: 'You can't put this there.' I said: 'But it is so!' That's very important for me! If I would imagine that I would not have a partner, many things would be really, really difficult for me" (Sarah, Line 194-200).⁶ [23]

^{4 &}quot;Und ich hab so Antworten bekommen: 'Ja, machen Sie's, nützt's nichts, schad's nichts'. (...)
Das war also mein erster Kuraufenthalt in meinem Leben. Und das war auch eine entsetzliche
Erfahrung, denn dort wurde alles gemacht, was eigentlich für diese Erkrankung nicht gesund ist.
Ich hab das dann dort auch hinterfragt. (...) Und hab dann auf eigene Faust die erste
[Nahrungs-] Kur gemacht. (...) Und so kommt man eben auf verschiedene Dinge im Laufe der
Zeit drauf, was man also doch ändern kann, auch wenn der Arzt vielleicht sagt, das weiß er
nicht, oder er hält davon nichts" (Sarah, Line 53-83).

^{5 &}quot;Da hab ich mir so ein Buch [klinisches Wörterbuch] gekauft und war auf der Rheumatagung. Hat er [der Rheumatologe] gesagt: 'Was tun Sie auf der Rheumatagung?' Jetzt geh ich mir das einmal anschauen. Das gibt es nicht, dass wir für mich nichts mehr finden. Und der Ehrgeiz, dass das nicht alles gewesen ist in meinem Leben, hat mich immer wieder aufrecht gehalten" (Maria, Line 684-688).

Linda also trusted her personal experiences and knowledge. She was aware how the system works and decided with an increased awareness to not use certain services given the procedures.

"I continued going to work as usual and since last year I am at home. I got the offer from the company that I could stay at home on pension (...). But I have to admit, all the things I did hear already about it [refers to the bureaucratic process of getting pension]. I thought, if there is any other possible way, I would rather avoid those quarrels" (Linda, Line 57-97). [24]

The quotations of Sarah, Maria, and Linda illustrate the discrepancy between the individual, inner, and embodied experience of the women and the endeavor of professionals in health care to control the body and objectively understand the reality of women's everyday life as described by ADDELSON (2003), NAGL-DOCEKAL (2004), SMITH (1999), and WENDELL (1996). [25]

3.3 Approaches to self-reflection

The processes of challenging the authoritative coordination and organization of health care practices, and crediting one's own knowing was through means of various approaches of self-reflection. Maria, for instance, engaged in dialogue with her rheumatologist and reflected on their conversations. She experienced it as very enriching and highlighted how crucial the dialogue with her rheumatologist was for her to become self-reflective and to participate actively in the treatment process.

"You have to teach me, or I have to learn to deal with the situation. What can I do? Then, once we discussed all the matters and each time when we phoned, I made notes and reflected: How did he react, what did he say to me? This would enable me the next time when such an acute phase would occur to help myself. And during that time I talked a lot with Dr. [...]. He was a very crucial person, who somehow achieved that I began to reflect on myself and the disease" (Maria, Line 541-582).⁸ [26]

[&]quot;Wie ich beim Dr. [...] das Formular ausfüllen musste jetzt bei dem neuen Medikament, das ich bekomme (...), da stand 'Hilfsmittel' im Formular. Da sagt er [Dr. ...]: 'Haben Sie das ernst gemeint?' Da hab ich hingeschrieben: 'Mein Mann'. Sagt er: 'Das können Sie gar nicht hinschreiben'. Hab ich gesagt: 'Das ist aber so!' Das ist ganz was Wichtiges. Wenn ich mir vorstelle, ich hätte keinen Partner, wären viele Dinge für mich also ganz, ganz schwierig machbar" (Sarah, Line 194-200).

^{7 &}quot;Ich bin ganz normal weiter arbeiten gegangen und jetzt seit vorigem Jahr bin ich zu Haus. Weil ich von der Firma das Angebot bekam, dass ich mit der Firmenpension zu Haus bleiben kann (...). Aber ich muss sagen, was ich da alles schon gehört hab [bezieht sich auf den bürokratischen Prozess rund um den Pensionsantrag]. Ich hab mir gedacht, wenn es anders auch geht, erspar ich mir die ganzen Streitereien" (Linda, Line 57-97).

^{8 &}quot;Sie müssen mir lernen, oder ich muss selber lernen, mit der Sache umzugehen. Was kann ich tun? Dann haben wir einmal alle Sachen durch besprochen und immer wenn wir telefoniert haben, hab ich mir eigentlich das aufgeschrieben und hab geschaut: Wie hat er reagiert, was hat er zu mir gesagt, damit wenn dieses Übel wieder aufgetreten ist, hab ich mir selber helfen können. (...) Und in dieser ganzen Phase habe ich viel mit Dr. [...] gesprochen – der war eigentlich der Ausschlaggebende, der es eigentlich geschafft hat, dass ich mich mit mir selber und mit der Krankheit auseinandergesetzt hab" (Maria, Line 541-582).

The processes of self-reflection also encompassed reflections on the cultural context in which the women were embedded. In some life stories, it became transparent that the women also reflected critically on cultural values. For instance Rita talked about how she became aware of certain cultural values which she embodied but never questioned before. She experienced being diagnosed with RA as becoming conscious about how much she was shaped by these cultural values. It was a very transformative process for her.

"Somehow it feels as if before I would have been without consciousness. I was raised in a generation where fulfillment of one's duties was everything. You were not supposed to put any disgrace on your mother. Now I try to loosen everything—it is not easy for me. I work a lot with it, and use probably very modern methods. I am going belly dancing to loosen myself from a bodily as well as mental perspective" (Rita, Line 139-154). [27]

Feminist standpoint theorists such as SMITH (1999) acknowledge the importance of engaging in self-reflection to understand our own position in the settings in which we are embedded, as well as to comprehend that also knowledge is partial and situated within a particular context. [28]

4. Discussion

The life stories of the women drawn on in this secondary analysis reflected that women's experiences of living with RA are embedded in taken-for-granted and interconnected practices in the health care system. The narratives revealed that after the women started to challenge the cognitive authority within the Austrian health care system, they were more likely to acknowledge their own knowing. In the life stories of the six women in this study, self-reflection was a means for transformation to become an active agent. [29]

4.1 Various means for self-reflection

Rita realized that her way of knowing of how and what she was actually doing was strongly influenced by the rigid and stiff society in which she was raised. By engaging in the process of questioning her own way of doing, Rita got to know and understand the cultural patterns which she embodied. She liberated herself from her way of doing and engaged in new and alternative ways of experiencing herself. BELENKY, CLINCHY, GOLDBERGER and TARULE (1997, p.101) distinguish between understanding and knowledge. For them: "[u]nderstanding involves intimacy and equality between self and object, while *knowledge* (*wissen, savior, sabor*) implies separation from the object and mastery over it." This notion of understanding ties into NAGL-DOCEKAL's (2004) sense of corporeality—the lived body—in contrast to the known body. GREENE (1995) calls for more arts-

^{9 &}quot;Mir kommt so vor, als ob ich irgendwie vorher bewusstlos gewesen wäre. Ich bin in einer Generation aufgewachsen, wo das Pflichterfüllen eigentlich alles ist. Und der Mutter ja keine Schande machen. (...) Und jetzt bin ich dabei, das ein bisschen aufzulockern und zu lösen, und hab es nicht leicht damit. Ich arbeite viel damit, mache auch sehr modern vielleicht, ich geh auch Bauchtanzen und so, von der körperlichen Seite her, mich zu lockern und zu lösen und auch von der mentalen Seite her" (Rita, Line 139-154).

based methods which enable us to represent our transaction with our environment. She encourages us to engage in our life stories and she states by "breaking through the frames of presuppositions and conventions, we are enabled to recapture the processes of our becoming" (p.130). As transparent in Rita's life story, she reflected on her conventions and was enabled to recapture her processes of becoming, which had begun from her experience in her lived body. [30]

Dialogue was another approach to understand oneself better and the relationship with others. For instance Maria highlighted, the dialogue with her rheumatologist was crucial to think about herself as well as her health condition, and consequently this dialogue influenced how she constructed her sense of self. KINSELLA (2005) and TREDE, HIGGS and ROTHWELL (2009) highlight the transformative potential of dialogue for ethical health care practices, research and education. They point out that harm can occur when health care providers are not reflexive about the power they wield in professional practice. Dialogue does not mean that the individuals engaged in it have to agree all the time or are not supposed to have contradicting opinions. An account of knowledge creation can be seen rather "as dialogic sequences of action in which the coordinating of divergent consciousnesses is mediated by a world they can find in common" (SMITH, 1999, p.127). FRANK (2005) highlights that within a dialogue the unfinalizability of the other has to be recognized. He continues "in a dialogical relation, any person takes responsibility for the other's becoming, as well as recognizing that the other's voice has entered one's own" (p.967). As it become obvious in the life stories of Sarah and Rita it can be very challenging to find a world in common with somebody who holds ruling power within the system. Medicine has the power to transfer bodily experiences into observable causes or rational facts without any reflection on the corporeality of the other person or without a sense of responsible for the other's becoming (WENDELL, 1996). In Sarah's case, the rheumatologist blamed her for traveling to Thailand. He saw the vaccination related to her trip as a likely cause for her disease. She also narrated that stating her husband as an assistive device on the form was questioned. In Rita's experience, she was accused of being hysterical. Her experience is in line with SMITH (1987), who argued that in the past medicine failed to consider women's bodily experiences as legitimate, and WENDELL (1996) who stated that women's experiences were dismissed as insignificant or just "complaints." Engagement in dialogue between a client and health care provider appears to be very enriching. Dialogue can contribute to positive experiences within health care as shown in Maria's life story reflections. The findings suggest that health care providers should become more critically reflexive on their own positions within the system and the responsibility that they hold for the other's becoming. Otherwise the client-health care provider interaction may lead to an invalidation of women's bodily experiences and women's embodied way of understanding. [31]

The six women in this study gained over time knowledge and understanding about their health condition. This understanding liberated them to take over responsibility and make decisions for themselves. Linda decided that she preferred to continue working rather than retiring early as she was aware of how

the system operates. Sarah trusted her own way of knowing and understanding and decided to change her diet although she did not receive any reasonable statement for or against it from her rheumatologist. Maria went to a rheumatology-symposium as she was uncertain about the comprehensiveness of her treatment. The experiences of the women in our study are also in line with findings in earlier research. KEARNEY (1999) highlighted that the more understanding women gained about their own health condition and about the system, the more they learned about with whom to talk to, how to get things done, and which actions within the system were un-/reasonable. [32]

4.2 Implications for health care practices

The six women conveyed stories that explicate the influence of practices in the health care system on their daily experiences of living with RA. Critical reflexivity is recommended for researchers and health care professionals as a powerful vehicle to transform research and clinical practices. Engagement in critical reflexivity exposes existing practices including knowledge claims and the language used. By explicating the taken-for-granted and power relations of established practices, alternative and transformative ways for practice may open up (TAYLOR & WHITE, 2000). SMITH (1999) highlighted that by exploring the ruling relations and by challenging how we rule and are ruled within established relations, we engage in a reflexive critique of what we know how to do and what we actually do. [33]

As shown in this secondary analysis, the women's narratives were very powerful in offering explicit examples of relations of ruling within the health care system. The narratives were used for research purposes in this study, however, narratives are also recommended for use in clinical practice. Telling stories opens alternative ways for representing client's experiences, for making clinical and moral decisions, and fostering new ways of seeing (KINSELLA, 2007), and thus understanding. KINSELLA points to the fact that "often health care professionals have so much scientific content to learn and to remain current with, that the notion of entering the life-world of the client is not highlighted as a priority" (p.47). As researchers and health care professionals, we should become critically reflexive about our contribution in perpetuating established structures. Using chart talk in clinical and research practices, which means focusing on diagnosis and pathology of the client over personal struggles and experiences that clients share with us (MATTINGLY, 1998), contributes to the transformation of individual clients into objects through an objectifying and detaching mode. In using this approach, we actively contribute to distinguish between the lived body (corporeality) and the known body. Consequently, our practices within health care may leave women with the feeling that "there is something wrong with your body" (PLACH, STEVENS & MOSS, 2004). Our practices may contribute that women become more and more alienated from their body rather than encouraging them to trust their embodied ways of knowing. BOLTON (2006, p.209) highlights this tension: "When addressing the very stuff of our lives, only the protagonist—the main character—can tackle it from the inside, with the help of the outside perspectives of peers, and the expert support of tutors." Hence, in our opinion,

we as researchers and health care professionals should keep in mind that we are not in a position where we can change the lives of clients, but rather we are in a position where we can provide support and expertise to the client through dialogue and critical reflexivity. [34]

4.3 Reflections on the study

FRANK (2005) highlights that "any person's story is the site of struggles permeated by multiple voices" (p.972). Consequently, a story is not strictly individual; it is influenced by and influences the construction of a social world. For this study only the life stories of six women were analyzed who considered their health condition as a source of new challenges in the primary study (STAMM et al., 2008). The women had lived at least ten years with the diagnosis of RA. Other women and men diagnosed with RA might experience and narrate their experiences of the social relations within the Austrian health care system differently. [35]

Interestingly, the women in this study mainly referred to physicians when they were talking about their health care providers. This may reflect the dominating position of physicians in the ruling relations of the Austrian health care system. Participants were recruited from the medical university in Vienna. The interviewer (Tanja A. STAMM) is an occupational therapist which may have influenced the narratives which were shared and parts of the narratives which remained silenced. [36]

We acknowledge that our professional experience as occupational therapists in the Austrian health care system has certainly influenced the interest in the analysis of women's life stories using a theoretical framework that is informed by feminist standpoint theory and feminist philosophies about the cognitive authority of medicine in health care. Occupational therapy is considered a female dominated medical-technical service profession which lacks possibilities for graduate education. In contrast, the higher educational possibilities of medical doctors influence the status of the medical profession within the health care system. Furthermore, the strong emphasis on keeping traditional structures may also hinder changes in the health care system (STAMM, 2009). [37]

5. Conclusion

The process of becoming aware of their individual self and their health condition, as well as the ruling relations in the health care system was transformative for the six women whose life stories were analyzed in this study. This transformative process enabled the six women to make choices for themselves and to become active agents for their own health. As health care providers, professionals, and researchers, we need to challenge our own practices and question critically how we perpetuate well-established and taken-for-granted practices. By becoming critically reflexive about the ruling relations in which we operate and to which we contribute, we might be enabled to transform our own practices. Creating environments that invite dialogue may provide a space where clients can share

their embodied experience of living with their health condition. Health care professionals who engage in dialogue with their clients can contribute—based on their expertise—in providing support that enhances the physical, psychological, and social health and well-being of their clients. [38]

Acknowledgments

We acknowledge that a few participants' quotations were referenced in an earlier analysis of the life stories (STAMM, MACHOLD, SMOLEN & PRODINGER, 2010). The analyses dealt with the primary German data material independently and were informed by different theoretical frameworks. The focus of the previous conducted analysis was on how personal and contextual factors such as gender shape the experiences of men and women with RA. We also would like to acknowledge the feedback from Elizabeth Anne KINSELLA on earlier drafts of the manuscript.

References

Addelson, Kathryn Pyne (2003). The man of professional wisdom. In Sandra G. Harding & Merrill B. Hintikka (Eds.), *Discovering reality: Feminist perspectives on epistemology, metaphysics, methodology, and philosophy of science* (pp.165-186). Norwell, MA: Kluwer Academic Publishers.

Belenky, Mary Field; Clinchy, Blythe Mcvicker; Goldberger, Nancy Rule & Tarule, Jill Mattuck (1997). *Women's ways of knowing: The development of self, voice, and mind.* New York: Basic Books.

Bolton, Gillie (2006). Narrative writing: Reflective enquiry into professional practice. *Educational Action Research*, 14, 203-218.

Bundessozialamt Oesterreich (2009). *Behindertengleichstellung*, http://www.bundessozialamt.gv.at/basb/Behindertengleichstellung/Allgemeine_Informationen [Accessed: July 7, 2009].

Chase, Susan (2005). Narrative inquiry. Multiple lenses, approaches, voices. In Norman K. Denzin & Yvonna S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp.651-679). Thousand Oaks: Sage.

Corti, Louise & Bishop, Libby (2005). Strategies in teaching secondary analysis of qualitative data. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 6(1), Art.47, http://nbn-resolving.de/urn:nbn:de:0114-fqs0501470 [Accessed: July 7, 2009].

Frank, Arthur (2001). Can we research suffering? Qualitative Health Research, 11, 353-362.

Frank, Arthur (2005). What is dialogical research, and why should we do it? *Qualitative Health Research*, 15, 964-974.

Gonzalez y Gonzalez, Elsa M. & Lincoln, Yvonna S. (2006). Decolonizing qualitative research: Non-traditional reporting forms in the academy. *Forum Qualitative Sozialforschung / Forum: Qualitative Sozial Research*, 7(4), Art. 1, http://nbn-resolving.de/urn:nbn:de:0114-fqs060418 [Accessed: June 23, 2009].

Greene, Maxime (1995). Releasing the imagination: Essays on education, the arts, and social change. San Francisco: Jossey-Bass.

Hartsock, Nancy (1987). The feminist standpoint: Developing the ground for a specifically feminist historical materialism. In Sandra G. Harding (Ed), *Feminism and methodology: Social science issues* (pp. 157-180). Indiana: Indiana University Press.

Hinds, Pamela; Vogel, Ralph & Clarke-Steffen, Laura (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research*, 7, 408-424.

Kearney, Margaret (1999). *Understanding women's recovery from illness and trauma*. Thousand Oaks: Sage.

Kinsella, Elizabeth Anne (2005). Constructions of self: Ethical overtones in surprising locations. *Medical Humanities*, *31*, 67-71.

Kinsella, Elizabeth Anne (2007). Educating socially responsive practitioners: What can the literary arts offer health professionals education? In Clover Darlene & Joyce Stalker (Eds.), *The arts and social justice: Re-crafting adult education and community cultural leadership* (pp.39-58). Leicester, UK: NIACE.

Mattingly, Cheryl (1998). In search of the good: Narrative reasoning in clinical practice. *Medical Anthropology Quarterly*, 12, 273-297.

Nagl-Docekal, Herta (2004). Feminist philosophy. Oxford: Westview Press.

Plach, Sandra; Stevens, Patricia & Moss, Vicki (2004). Corporeality: Women's experiences of a body with rheumatoid arthritis. *Clinical Nursing Research*, *13*, 137-155.

Richardson, Laurel (2000). Writing: A method of inquiry. In Norman K. Denzin & Yvonne S. Lincoln (Eds.), *Handbook of qualitative research* (pp.923-948). Thousand Oaks: Sage.

Rosenthal, Gabriele (1991). German war memories: Narratability and the biographical and social functions of remembering. *Oral History*, 19, 34-41.

Rosenthal, Gabriele (1995). Erlebte und erzaehlte Lebensgeschichte. Frankfurt/M.: Campus.

Rosenthal, Gabriele (1998). The Holocaust in three-generations. Families of victims and perpetrators of the Nazi-regime. London: Cassell.

Sherwin, Susan (1992). *No longer patient: Feminist ethics and health care*. Philadelphia: Temple University Press.

Smith, Dorothy (1987). *The everyday world as problematic: A feminist sociology*. Toronto: University of Toronto Press.

Smith, Dorothy (1998). Bakhtin and the dialogic of sociology: An investigation. In Michael Mayerfeld Bell & Michael Gardiner (Eds.), *Bakhtin and the human sciences: No last words* (pp.63-77). Thousand Oaks: Sage.

Smith, Dorothy (1999). Writing the social: Critique, theory, and investigations. Toronto: University of Toronto Press.

Sprague, Joey (2005). Feminist methodologies for critical researchers: Bridging differences. Walnut Creek: AltaMira Press.

Stamm, Tanja (2009). Medical versus bio-psycho-social model: Possible reasons why the ICF is hardly used in Austria from an occupational therapy perspective. *WFOT Bulletin*, *59*, 70-75.

Stamm, Tanja; Machold, Klaus; Smolen, Josef & Prodinger, Birgit (2010). Life stories of people with rheumatoid arthritis who retired early: How gender and other contextual factors shaped their everyday activities including paid work. *Musculoskeletal Care*, *8*, 78-86.

Stamm, Tanja; Lovelock, Linda; Stew, Graham; Nell, Valerie; Smolen, Josef; Jonsson, Hans; Sadlo, Gaynor & Machold, Klaus (2008). I have mastered the challenge of living with a chronic disease: Life stories of people with rheumatoid arthritis. *Qualitative Health Research*, 18, 658-669.

Stamm, Tanja; Lovelock, Linda; Stew, Graham; Nell, Valerie; Smolen, Josef; Machold, Klaus; Jonsson, Hans & Sadlo, Gaynor (2009). I have a disease but I am not ill: A narrative study of occupational balance in people with rheumatoid arthritis. *OTJR: Occupation, Participation and Health*, 29, 32-39.

Taylor, Carolyn & White, Susan (2000). *Practising reflexivity in health and welfare*. Philadelphia: Open University Press.

Temple, Bogusia (2005). Nice and tidy: Translation and representation. *Sociological Research Online*, 10(2), http://www.socresonline.org.uk/10/2/temple.html [Accessed: January 12, 2009].

Temple, Bogusia (2008). Narrative analysis of written texts: Reflexivity in cross language research. *Qualitative Research*, *8*, 355-365.

Temple, Bogusia; Edwards, Rosalind & Alexander, Claire (2006). Grasping at context: Cross language qualitative research as secondary qualitative data analysis. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 7(4), Art. 10, http://nbn-resolving.de/urn:nbn:de:0114-fqs0604107 [Accessed: May 23, 2010].

Trede, Franziska; Higgs, Joy & Rothwell, Rodd (2008). Critical transformative dialogues: A research method beyond the fusions of horizons. *Forum Qualitative Sozialforschung / Forum: Qualitative*

Social Research, 10(1), Art. 6, http://nbn-resolving.de/urn:nbn:de:0114-fqs090169 [Accessed: May 23, 2010].

Van den Berg, Harry (2005). Reanalyzing qualitative interviews from different angles: The risk of decontextualization and other problems of sharing qualitative data. *Forum Qualitative Sozialforschung / Forum: Qualitative Sozial Research*, *6*(1), Art. 30, http://nbn-resolving.de/urn:nbn:de:0114-fqs0501305 [Accessed: May 14, 2010].

Wendell, Susan (1996). The rejected body: Feminist philosophical reflections on disability. New York: Routledge.

WHO (2001). *ICF—International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

WHO (2007). International Classification of Diseases and Related Health Problems, 10th revision. http://apps.who.int/classifications/apps/icd/icd10online/ [Accessed: June 16, 2009].

Authors

Birgit PRODINGER is PhD Candidate in the field of Occupational Science at The University of Western Ontario, Canada. Her research interests mainly focus on the everyday occupations of people with chronic disabilities within varying social and political contexts across different European welfare states. Her research is informed by feminist standpoint theory, intersectionality and occupational science perspectives; she draws from ethnographic methodologies.

Tanja A. STAMM is Associate Professor at the Department of Internal Medicine at the Medical University of Vienna, Austria, and the Chair of the MSc Program in Occupational Therapy in Vienna, Austria. Her current research focuses on the interactions of occupational balance, chronic autoimmune diseases, and gender, and how the intersections of these dimensions can be studied within narrative biographic methodologies. Furthermore, she is interested in methodological challenges in conducting cross-national qualitative research studies and has lead several cross-national qualitative research projects.

Contact:

Birgit Prodinger

Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science The University of Western Ontario 1201 Western Road, Elborn College London, Ontario N6G 1H1 Canada

E-mail: bproding@uwo.ca

Contact:

Tanja A. Stamm

Department of Internal Medicine III, Division of Rheumatology Medical University of Vienna Währinger Gürtel 18-20 1090 Vienna, Austria

E-mail: Tanja.Stamm@meduniwien.ac.at

Citation

Prodinger, Birgit & Stamm, Tanja Alexandra (2010). Self-Reflection as a Means for Personal Transformation: An Analysis of Women's Life Stories Living with a Chronic Disease [38 paragraphs]. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 11(3), Art. 6, http://nbn-resolving.de/urn:nbn:de:0114-fqs100363.