

PATIENTS CAN BE RESEARCHERS TOO
REFLECTIONS ON THE POSITION OF A
PATIENT RESEARCHER
AS GO-BETWEEN

*Denn nichts ist für den Menschen als Menschen etwas wert,
was er nicht mit Leidenschaft tun kann.*

Max Weber,
Wissenschaft als Beruf (1917)

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ABSTRACT

The roles of patients as partners in health research evolve over time. As a person with a rheumatic condition I (first author) became involved in research and acquired a second identity as a health researcher. This transition process covered more than a decade and culminated in a doctoral study. Ongoing dialogues with my supervisors (co-authors) taught us that the theory and values of responsive evaluation provide a useful framework for becoming a patient researcher. Reflective discussions revealed the unique value of this position as a go-between, connecting the worlds of patients and researchers and enhancing mutual understanding. Through the role of interpreter, teacher, facilitator and Socratic guide and complying with the imperative of a multiple partiality, I could create conditions for a real dialogue between patients and researchers. Three cases illustrate the sometimes conflicting nature of these roles in practice and how to deal with the risks of over- and under-identification with stakeholders.

Introduction

In the last decade patients have developed different roles as collaborative partners in health research ¹. In the role of co-researcher patients join a research team as equal members with the purpose of providing the patient perspective in every phase of the research process. Studies that have analyzed the role of co-researchers conclude that their participation brings benefits to the research project, the researcher and the patient ¹. Patient involvement strengthens the process of empowerment and mutual learning ².

Sometimes patient research partners develop skills that are equivalent to those of academic researchers. Karen Schipper reflected on this process as a person with a hereditary kidney disease. She developed interview, moderation and research skills that finally ended in a doctoral study ³. There are more examples of patient researchers who initiated research or conducted research in their own disease area. Cees Smit, also a patient researcher, has collaborated in many scientific studies on the treatment and social impact of hemophilia ⁴. The term “patient researcher” is gaining ground in the world of health research ⁵. Doing research from the perspective of a patient researcher is challenging because of the supposed competing responsibilities of “being a good researcher” versus “being a good patient representative”: Is it possible to “objectively” collect data from a medical or health care practice while at the same time trying to change and improve that practice? As a person with a rheumatic condition who gradually got involved in research and ended as a patient researcher, I (the first author) found these dilemma’s fascinating and at times confusing.

To evaluate the impact and process of patient participation in rheumatology research I completed several qualitative studies, including in-depth interviews with a variety of stakeholders. In these studies I followed the methodology of responsive evaluation ⁶⁻⁸ which seemed to me an adequate approach for a patient researcher. Responsive evaluation aims to understand a practice from a diversity of stakeholder perspectives by facilitating a dialogue between all involved and enhancing their mutual understanding as a basis to improve that practice. It emphasizes the responsibility of a responsive evaluator in complying with a multiple partiality to guarantee that all relevant perspectives are captured ^{7,8}. A multiple partiality means engaging simultaneously with both the patient and research community and developing empathetic relationships ⁹.

Several authors have reflected on their own journey of becoming a responsive evaluator ¹⁰⁻¹². Acquiring the competence to engage with multiple stakeholders and create conditions for dialogue and collaboration is not easy. There is always the risk of over- and under-identification with a particular group ². A patient researcher has an innate loyalty toward fellow patients that might result in over-identification with patients’

interests and under-identification with those of researchers. The phenomenon of over-identification is well known in the literature of anthropologists who speak about “going native” or “over-rapport.” It means that the researcher identifies him or herself too much with “the natives” or cultural group and is no longer able to establish a professional balance between proximity and distance. Obtaining the skills to preserve this balance is a challenge for many qualitative researchers because it is expected that they will reconstruct an emic or insiders’ perspective¹³.

The objective of this article is to reflect on the added value and potential risks of my position as patient researcher. After the methods section I will introduce the distinct roles of a responsive evaluator and highlight different contexts in which they were advantageous in my position as patient researcher. Three cases will show the sometimes conflicting nature of these roles. The first case describes a successful example of the role of facilitator and creating conditions for dialogue. The second case will analyze potential blockades to engage in an unconstrained dialogue as a result of over-identification and the conflict between the roles of participant observer versus change agent. The third case deals with the discrepancy between the role of Socratic guide versus the role of interpreter. Finally, I summarize the benefits of the position of a patient researcher.

Methods

This article follows a relational constructionist approach¹⁴ in which reflexivity is not an individual activity of the researcher at the end of a project, but an ongoing dialogue with all stakeholders during the entire research process¹⁵. Because reflective inquiry is a relational responsibility¹¹ Tineke Abma and John Kirwan appear as co-authors on this manuscript. As my supervisors, representing two different disciplines, they have been vital in building and articulating my double identity as a patient researcher. Their critical and constructive feedback during many extensive conversations have steered my education as a researcher without sidetracking my identity as a patient. TA has a background in the social sciences and humanities and has conducted many qualitative studies in the fields of chronic conditions. Her approach is grounded in the tradition of hermeneutic philosophy and responsive evaluation⁸. JK is a medical scientist, practicing rheumatology for over thirty years and has been the patient coordinator for the Outcome Measures in Rheumatology (OMERACT) conferences since 2002¹⁶.

I obtained my academic education about professional socialization, social institutions and critical theory from Wilfried Gottschalch, my professor at the University of Amsterdam during the late eighties. He taught me the importance of an hermeneutic approach in health care and research in accordance to the theories of Wilhelm Dilthey,

Hans-Georg Gadamer and Jürgen Habermas¹⁷. These scholars have emphasized the need to reflect on the interdependencies between researchers and their object and to discuss their own prejudices as interpreters¹⁸. My teacher also introduced the complementarist method, which urged me to recognize and respect ambiguities within individuals, including ambivalent feelings within the researcher regarding the object of his or her interest¹⁹. The virtue of a critical solidarity, a balance between engagement and detachment, would become second nature.

According to Gadamer (1960), a researcher can take three stances. The objectivist looks at the world from an outsider perspective, judging and explaining behavior and perceptions relying on the existence of universal laws. The subjectivist observes the world from an insider perspective and acknowledges the unique experiences of the other and tries through the use of qualitative methods to better understand individual motives and decisions. Only in the third stance the researcher is not a neutral observer but relates to his object through a dynamic and dialogical process. As a patient researcher I followed this last approach in my dissertation by choosing the methodology of responsive evaluation. This methodology of knowledge production is philosophically grounded in a social constructivist perspective^{20,21}. In this perspective all participants are considered as active interpreters and constructors of their own world. By giving meaning to the world they shape reality in interactions. Participants will bring their own life experiences, education and prejudices into the process of meaning construction. Because of this diversity reality is in principle multiple and this multiplicity may lead to struggles over the meaning of the word “true” in different situations²². As a patient researcher, I was interested in the process of meaning construction in the context of patient-researcher collaboration at a scientific conference.

From a constructivist perspective the researcher and the object of research are reciprocally influencing each other and will change as a result of this process. Because of this dialogical process, where both the researcher and the participants engage in a joint learning process¹, evaluators cannot be objective. For this reason I discussed regularly with my mentors the potential benefits, challenges and pitfalls inherent to my position of a patient researcher, and my educational pathway, including the need for additional training.

Traveling back and forth between Bristol and Amsterdam I attended several meetings with PhD fellows focusing explicitly on the issue of reflexivity in health research, supported by a review of relevant literature²³⁻²⁷. Most of these conversations in smaller groups were audio-recorded and transferred into summary reports. I wrote down my observations, experiences and thoughts in a logbook. Here I will distinguish between my

own interpretation of what I found inside myself and what that meant to me, and what I have deduced from some of my observations. Conducting a self-analysis as part of my doctoral work aligns with what I learned at university, what I discussed with JK and TA, and with the methods that I applied in my own studies.

Becoming a patient researcher

In 1999 the Dutch Arthritis Foundation invited me to become a member of their Medical Advisory Council with the purpose of providing a patient perspective in the selection of grant applications. At that time I was trying to get my life back on track after a serious episode of increased activity of inflammatory arthritis, several orthopedic operations and social withdrawal. This voluntary work seemed a good option to fill the gap after giving up my career as a company trainer.

Two years later I was invited to participate in an international research conference on Outcome Measures in Rheumatology (OMERACT) in Brisbane, Australia. OMERACT is a data-driven and consensus-based initiative that is held every second year. The first conference took place in 1992. The conference promotes a multi stakeholder approach and is attended by a maximum of 170 delegates representing a broad spectrum of health researchers, methodologists, trialists and representatives of health authorities and the pharmaceutical industry. Since 2002 OMERACT has been instrumental in developing new ways of involving patients in all their activities and has made involvement of patient research partners an integral part of its vision, culture and procedures¹⁶. My participation coincided with the start of a new effective treatment and I felt privileged for the opportunity to give something in return. This adventure became a life changing experience. My role as one of the eleven patients with rheumatoid arthritis (RA) was to review the existing RA core outcome-set^{28,29}. This core-set contains seven outcomes that are recommended for use in RA clinical trials. Our workshop concluded that this core-set was too limited, focused too much on physical signs and symptoms and insufficiently on the impact of the disease on daily life. Unchanged, this core set had little relevance as it did not capture all domains that limited me and fellow patients to fulfill the traditional roles of spouse, parent and contributive citizen.

What made this experience such an awe-inspiring event? Definitely the fact that all the patients felt welcome at the conference³⁰ and professional delegates, all authorities in their field, were interested in our stories. The small size discussion groups were an ideal forum for all of us to speak up. It was also special to have contact with patients from other countries who shared the same interest in collaboration with professionals and who became good friends. After returning home, some of them, like me, started building

local networks of patient research partners. I remained active in OMERACT and consequently started my own doctoral study in 2009, evaluating a decade of patient involvement in rheumatology research. I called myself a patient researcher.

Performing a variety of patient roles in the research community had made me an insider in the world of health research. As a volunteer of national and European arthritis patient organizations and becoming involved in research initiatives, I learned along the way the limitations of my representativeness: becoming an *expert* patient did change my experiential knowledge and made me less certain about the authenticity and value of that knowledge. I noticed that this specific knowledge transformed into an insider's knowledge of the patient group. I started to believe that this expert knowledge, combined with my academic and professional background, provided a unique asset in the context of health research.

Roles toward participants

As a responsive researcher I perform different roles, depending on the particularities of the research context³¹: As a teacher I provide information and try to create understanding for the values and perspectives of the various stakeholders; As an interpreter I try to illuminate the tacit knowledge that is hidden in the daily experiences of the respondents and to formulate their often unconscious meanings in a particular practice, procedure or structure; In the role of facilitator I try to create conditions for an unrestrained dialogue; Taking on the role of Socratic guide means working toward consensus when there is diversity or discussing taken for granted notions when there is too much homogeneity. Below I will give examples of the roles that helped me to move away from the traditional hierarchy between the researcher and the respondents. These examples show that the roles of a responsive researcher converge closely with the position of a patient researcher. In other words, I became aware of the unique value of my experiences as a patient representative in performing the roles of a responsive researcher. Being known as a patient delegate at previous OMERACT conferences made it easy to create a rapport with participants. Most delegates did not look differently at me in my new role as patient researcher and all were willing to cooperate; nobody refused to participate in my interviews. I used breaks, dinners and social events to listen to participants and to discuss guiding principles of participatory research. I answered questions about recruitment, training, support and acknowledgement of patient research partners. If participants experienced difficulties I suggested solutions or undertook concrete actions.

During interviews with patients who attended the OMERACT conference for the first time I recognized the need to provide information (chapter 7). Most of them did not

understand the objective of the conference and how they could contribute. One of the patients said: “I have no program. I do not know the different things (. . .) you have to tell me!” By sharing my own experiences as a patient during my first conference I took the role of teacher, providing reassurance and reinforcing their self-confidence. And by explaining the layout of the program, the aims of the various workshops and how they could contribute to the breakout sessions, I could prepare patients for their role as a collaborating partner.

When I was confronted with the story of a miraculous recovery from RA as the result of drinking organic tea twice a day, I felt I had to prevent the patient from making himself look foolish. I warned him that his personal experience would be challenged by the professionals: “This product has not been scientifically tested: That is what you will hear at this conference. Because all the people here are dedicated to evidence based medicine!” It caused confusion with the interviewee who answered: “If you stop me from telling them, then I don’t know how to help.” At the time, I believed that, by clarifying the data-driven character of the conference, misconceptions about research and researchers could be prevented, leading to a better understanding of what was expected from him.

Another patient felt reassured by talking to me. She expressed feelings of insecurity after being thanked and praised in a plenary session for her valuable contribution. She felt this had set her apart from the rest of the group: “I feel I’m leaving the conference now believing I’ve done something wrong.” Talking about her experience put her mind at rest: “Your feedback on my particular problem has been reassuring that patients don’t see me as a self-serving, attention seeker.” She admitted that “It was a pleasure to assist with an interview. In fact, I found it a therapeutic way to end the conference.” At the time I felt a growing confidence that my role as a patient researcher was accepted and that my approach as a teacher and facilitator was appreciated by the respondent.

Case 1 - Facilitating dialogue

Based on the ethical imperatives of responsive evaluation I strongly believed that merely educating and supporting patients was insufficient: It is essential to engage with researchers in the process of implementing more patient-oriented research through dialogue and collaboration (chapter 2). Because of my personal experience as a patient in many workshops and breakout sessions, I became aware of my competence to create optimal conditions for open dialogue. I remember one occasion where a researcher approached me to help structure his workshop. The following case is a summary of our conversation in advance of the workshop. The text is derived from my logbook.

First author (MW): What is the purpose of the workshop and what kind of input do you expect from the patient delegates?

Researcher (R): I want them to give their opinion on the questionnaires that we have sent them.

MW: Is that what you expect from all the participants?

R: Yes, but the patients should of course give feedback from their own perspective.

MW: How did you adjust the layout of the workshop to accommodate the participation of patients?

R: What do you mean?

MW: Without more specific questions for the patients I don't think they will be able to give meaningful feedback during the workshop.

R: Why do you think that?

MW: It is my experience that in a breakout session with many academic experts patient research partners find it difficult to express their opinions. Most professionals are aware of the value of their expertise. Patients are less confident because they are not always convinced that their experiential knowledge has any relevance in the discussion. If you are interested in the patients' opinions, it is your role to encourage patients to speak up.

R: But how can I support the patients?

MW: Getting the patients' input requires an extra effort. You could help the patients by creating a safe environment and formulating a clear question that can only be answered by the patients. If you put that question explicitly on the agenda and approach patients individually, it makes them feel responsible for answering that question and to take co-ownership over the workshop.

As a patient researcher I helped the researcher in preparing a dialogue that could bridge the culture of patients with that of researchers. In my role as a teacher, facilitator and Socratic guide, I acted as a sparring partner or change agent, but never as a patient advocate. I respected the concept of a multiple partiality, not favoring the opinion of one party above the other but only making sure that all involved would have equal opportunities to take part in the discussion. I had learned that skepticism and resistance to patient participation might be based on lack of knowledge and practical tools rather than fundamental objections. Therefore I did not have to persuade researchers but merely open their horizon to what it takes to realize participation.

During meetings, interviews or in the corridors I was able to explain the world of patients: What they find important, what kind of support they need and what helps them to feel respected and listened to. I made researchers aware of the restraining impact of scientific jargon, differences in social status, subtle ways of exclusion, and lack of recognition, and advised them how they could remove these obstacles for participation. By explaining how patients perceive and experience their role in research, researchers became sensitized to the perspective of patients and developed a better understanding of their needs.

Many researchers don't consider the contribution that they expect from patients and are not aware of the support that is needed to make patient participation meaningful. Adopting the role of a responsive evaluator enabled me to help researchers with creating conditions for dialogue and working towards a reconciliation of the perspective of patients and that of researchers.

Case 2 - Over-identification with the patient

For a patient researcher the role of interpreter is more challenging compared to other health researchers because of the double hermeneutic process³². Participants reported their own interpretation of what they perceived and experienced, and it was my task to re-interpret their stories in the light of my research questions. Listening to their stories while at the same time turning off my own personal experience as a patient was not easy. Finding a balance between distance and engagement became even more complex when I had to distinguish between the role of interpreter and that of facilitator. I wanted not only to understand the perspectives of the participants, I also wanted to change current research practices; not only to listen, but also to motivate and support participants. During the analysis of interview transcripts we identified some passages where I might have lost this balance.

Although the great majority of my encounters went well, and because I think that one could learn most from difficult situations, I present below two cases where a real tension between the patient, the researcher and the patient researcher prevented an open dialogue.

To better understand how patients adjust to the requirements and expectations of the conference, I decided to have three interviews spread out through the conference with each of the three patient delegates who were invited for the first time. One of them expressed a great commitment during the first interview at the start of the conference. In the next two days he often joined me during the coffee breaks for a talk. I became a kind of buddy for him. Half way through the conference, he experienced a lot of pain, physically suffering from the intense program, and mentally frustrated after

uncomfortable experiences in two breakout sessions. During the second of our planned interviews he told me that he wanted to “give up.”

Patient (P): Like now what we are talking, I tell you my definition of a flare and remission. To me, even though I have a bit of pain, a bit of swelling or heating, I still think that is ok. When I feel it is ok, it is remission. It’s not the pain that counts, ok. That is how I feel. So yesterday, when we discussed remission, that doctor (. . .) practically he just brushed me aside.

Researcher (R): That was scandalous, no, I mean (. . .) he didn’t listen, he didn’t respect you . . .

P: He thinks he knows everything, number one. Number two, he doesn’t respect me at all, he doesn’t hear what I say, he thinks he’s the super professor and I am a primary class student. But actually, I am trying to express it as a patient: What position I am in, this and that, what is remission and a flare to me (. . .). He said ‘that is not remission!’ That is the doctor’s point of view but the patient’s point of view of a remission means that he is comfortable even though he has a bit of pain.

R: And he didn’t take that on board.

P: He didn’t take that on board, so I nearly walked out of the meeting because I was treated....

R: And I didn’t support you. There was the other patient, she was also not pleased by that meeting. It was a bad meeting (. . .) the professor just wanted an outcome that he already had in mind.

P: That is exactly the truth. His mind was already set.

Two elements in this case are important: my relationships with the interviewee and the professor; and my responsibilities as a patient researcher. I felt ashamed of what happened after having explained on the first day the OMERACT core values of equality, consensus and dialogue. Because of the close relationship that had developed over the last few days, I felt the need to apologize for his poor condition and to acknowledge his feelings of anger and despair. I did not do anything wrong by expressing my solidarity with him and the patient community. I did not say he was right in his definition of remission or a flare, but tried again to share my ideas of the conditions for a good dialogue: respect, an open mind and willingness to listen to the perspective of the other.

In retrospect, the question is whether there was a diminution of the appropriate distance in my role as interpreter, and whether this was the result of over-identification with the interviewee. On a relational level it was my responsibility to create rapport and

to help the interviewee feel understood, but obviously this was at the expense of the professor. Let us focus on my responsibility toward the latter. I had got to know him as a widely respected though at times supercilious authority. During the breakout session I did not raise the problems caused by his communication style. Instead, I openly expressed my prejudices toward the professor in the interview, which I now consider I should not have done. It is not only disrespectful—ultimately it is at odds with the requirement of multiple partiality^{8 11}. I wanted to be a patient researcher and I am not sure what I was ashamed of most: the fact that I did not manage to prevent the patient from experiencing two discouraging moments during the conference, or that I blamed the doctor in his absence to disguise my own inability to address the traditional hegemony of a researcher.

Habermas (1981) emphasizes the absence of power imbalances as an important condition for rational dialogues in which participants have equal chances to present different kinds of validity claims. The interviewee was confronted with a strongly-opinionated personality and an authority in the eyes of his colleagues. He must have doubted the introduction to the meeting I had given him previously. I had failed to contribute to any dialogue between both participants. I succeeded in obtaining a better understanding of the process of adversarial growth of a patient, but at the same time felt powerless regarding my responsibility to actively intervene on a relational level during the breakout session. I was confronted with two conflicting responsibilities of a patient researcher: first during the meeting the responsibility of a participant observer versus a facilitator or change agent; and during the interview I struggled with my double loyalty toward the patient versus the professor. Would I have dared to compromise the relationship with the professor by arguing his dominant behavior in the discussion? I sympathized with both perceptions on the content level because I could understand both viewpoints. In the end I struggled with my own inability to create an opportunity for equal collaboration. I should have made the traditional hierarchical relationship between the different groups of participants and the different kinds of knowledge that they represent the subject of reflexive dialogues³³.

One further reflection: Like values and norms, prejudices guide our thinking and the construction process of scientific knowledge. According to Gadamer (1960) research cannot progress without prejudices, which are in essence not bad: We all have them. In our work it is important to acknowledge the existence of prejudices, to interpret them well and to confront them with the purpose of adjusting our thoughts if they appear not to be true. This is not what happened during the interview. Stopping asking questions was not very constructive. It would have been better to respond less confirmative and suggestive regarding the judgmental statements of the interviewee, and be more

reflexive, asking open questions and probes that would have supported a better understanding of what happened during the two sessions and the impact on the interviewee.

Case 3 - Avoiding under-identification with the researcher

As a patient researcher I sometimes challenged the prejudices of researchers regarding the benefits and feasibility of participatory research. Especially in situations where researchers took for granted beliefs that hindered them from successfully engaging with patients, I acted as a Socratic guide³¹. In August 2010 I spoke with a clinical researcher and rheumatologist who had attended several OMERACT conferences. I only knew him by name. He was selected for his critical perspective on patient participation. When I invited him, he answered “I am not sure you want to hear this.” I was intrigued and became determined to acquire a comprehensive picture of his objections. The interview lasted almost 80 minutes. The following text is a collage of literal statements derived from the transcript.

Although I fully acknowledge the importance of patient reported outcomes, it doesn't imply the dominance of patients determining the OMERACT research agenda. Their influence is increasing to an extent that it jeopardizes the aim of the conference, which is improving the methodology of rigorous scientific research. If we would always follow patient priorities, like some years ago when patients didn't see any added value of X-rays, it would have ended our research in the area of radiology. In that case we would never have been able to prove the effectiveness of new biologic agents to stop structural joint damage on the long term.

In my opinion the Executive Committee promotes patient participation to act politically correct. They follow socially desirable arguments, but they don't believe that it will contribute to advancing methodologies in outcome research. They just don't want to acknowledge the fact that patients are the weakest link in the chain. Patients slow down the process because they can't follow the complexity of the validation process of outcome measures. I don't blame the patients for this; I think we have to protect them against unrealistic expectations. For researchers it is frustrating to contribute to patient update sessions and to explain every detail, and to conclude that at the end you haven't achieved anything.

OMERACT has to choose: Or to go for full patient involvement, which means that you recruit highly educated expert patients with some knowledge of methodology and statistics and a long term commitment, like you are, or to stop forcing researchers

to include patient research partners in all working groups. If this policy will not change, a small group of participants is considering leaving OMERACT.

Directly after the interview I felt satisfied. Such a critical perspective had not been reported in my previous interviews and, through the firm statements on the motives of the OMERACT leadership, the tendency to favor patient issues over urgent methodological concerns, and the inappropriate influence of patients on the research process, I had obtained a more in-depth understanding that brought me nearer to an acceptable level of saturation. Instead of questioning his arguments and trying to change his opinions, I had listened with an open mind. Rather than a Socratic guide, I had only used probes to elaborate on opinions that no respondent had expressed before. For my study I felt it was important to attend to values and experiences that might have been seen by others as controversial.

Initially I thought that I had been able to gain a level of credibility that made the interviewee answer all my questions honestly. It might have pleased him that at last there was someone taking his fundamental concerns seriously without being rejected or condemned. When analyzing the transcript, I started to doubt whether I had completely succeeded as patient researcher. I had obtained a valuable account of his objections but had not engaged in a dialogue that could have prepared the ground for creating mutual understanding. Especially the warning in the last sentence made me wonder: Had I really been able to create an equal relationship with the interviewee, not affected by differences in status, or had I been used as a platform to deliver a message that could otherwise not be said?

By renouncing the role of change agent and fully complying with the imperative of a multiple partiality, I avoided under-identification with the researcher. But this clearly happened at the expense of my responsibility to engage in a dialogue and to change practices. Was it wrong with following his story without questioning his arguments? In retrospect, how could I have responded in a way that would have fostered a genuine dialogue? The approach of a Socratic guide, questioning controversial opinions or arbitrary certainties, would have seemed appropriate to challenge him and to explore together why these concerns were never expressed aloud in OMERACT meetings. Why had I never been exposed to these counter arguments at the conference or in my interviews? Or should I have doubted my own competences as a qualitative interviewer? Had he accepted my new role as a patient researcher? Was he able to discuss the issue on an equal footing with me, one of the former patient delegates? Bringing in other perspectives might have challenged him to open up the discussion about his perceptions

and prejudices and to enter a more reflexive dialogue about the assumed equality of patient delegates, the transparency of the OMERACT research process and prejudices regarding the value of experiential knowledge in the context of outcome research.

From the systematic document analysis of OMERACT proceedings I had learned that most authors wrote enthusiastically about the introduction of patient participation at OMERACT (chapter 5) and through my interviews I knew that the Executive Committee had regularly debated on this issue (first author, 2013d). It would have been worthwhile to find out why the interviewee did not utter his concerns openly in OMERACT or why this counter story was never reported or published before. Although his view was important to include in my report, his behavior during the interview may be interpreted as strategic, positioning himself in a scientific environment that is also political.

The last two cases taught me that it is not easy to create the ideal circumstances for rational dialogues. Interactions are influenced and disturbed by irrational power imbalances based on differences of status, hierarchical relationships and implicit prejudices. In retrospect this awareness strengthened my belief that patient participation requires an explicit and continuous reflection, not only on the quality of the collaboration between patients and researchers, but also on the values that go behind this concept. A methodology of responsive evaluation might facilitate and enhance the process of reflexive dialogues.

Advantages of a patient researcher

I have felt that the benefits of a patient researcher outweigh the risk of bias. Many of the benefits shown in the presented examples were unique for my position as a patient researcher and could not have been achieved by a researcher without a personal background as a patient with arthritis. My personal experience with the disease and having been a patient representative for many years made me more inclined to feel the impact of power imbalances between patients and researchers, and between respondents and myself. That knowledge and sensitivity enabled me to prepare patients for their role as research partners, prevent misunderstandings and provide insight information and reassurance. Many of the skills I had acquired over the years by performing different patient roles seemed useful in the context of research. I had learned the methodology of responsive evaluation, and creating conditions for dialogue and collaboration had become an essential responsibility in all my projects. The example of the miraculous recovery illustrated the benefit of my double identity. This identity comes with a dual loyalty toward patients as well as researchers. The more I became engaged in both communities, the more I discovered that this double identity brought important assets to

responsive research. Speaking both researcher and patient “languages” and knowing many participants was helpful in the process of recruiting respondents for interviews or focus groups. Having longstanding experience with the treatment of rheumatic diseases saved time when talking about diagnoses and drug regimens. The impact of side effects or disease symptoms did not have to be explained in detail, which made it possible to start almost immediately to focus on a particular topic. I thus experienced my patient background as a supportive condition for getting quick and easy access to the experiences of respondents, resulting in enhanced quality of the data collection. In a short period of time in-depth information could be obtained. Moreover, I found that my interviews fulfilled multiple purposes. It was not only about collecting data, but also changing expectations and perceptions, and building sustainable partnerships.

My research over the last four years had taught me more about rheumatology and the expectations, ideas and motives of patients and researchers. I had familiarized myself with their jargon, culture and prejudices, and by active interaction with both communities, I had become an insider in both worlds. Patient participants did not see me as a researcher insensitive to the needs and preferences of patients³⁴. Participants expected me to contribute to the empowerment of the group whose voice was heard the least. It became clear that the ability to adequately support patients and researchers prepared the ground for an open and reflexive dialogue between both. I believed that the position of patient researcher, together with the condition of a multiple partiality, made me an ideal *go-between*. In a mixed group of patient experts and professionals I was able to bridge the gap between both perspectives because I knew what was important in both worlds. I was also able to open up the world of researchers in the presence of patients and the other way around. This resulted not only in mutual understanding of the needs, expectations and limitations of the other, but also more than once in what Gadamer (1960) described as the *melting of horizons*.

Challenges of a patient researcher

Some people might argue that doing research as a patient researcher brings additional risks of subjectivity such as blind spots, selective recruitment of respondents, coercion of participants, cognitive dissonance, and prejudices during the phase of data collection and analysis. It is true that as a patient researcher I am not neutral: I feel a particular loyalty towards patients and endorse the concept of patient involvement. Listening to patients might be seen by other stakeholders as favoring them, which made me, as a consequence, extra alert not to identify with patients only. As a patient researcher I had to explain that it is my responsibility to advocate for dialogue and participation and to

address the traditional power asymmetry between different stakeholders. However, being able to include all stakeholders in this process required a multiple partiality, including an interest to understand the perspective of other stakeholders who might not be embracing participation.

I found that many of the additional risks are not different in nature from those occurring in other contexts and reported by qualitative researchers¹¹, although our case examples show that their intensity may vary. These risks can be dealt with by applying rigorous procedures for qualitative research (table 1) derived from cultural anthropologists and medical sociologists^{24,35}. Some risks may be unique to the position of a patient researcher compared to any other researcher. First, because I feel a priory a loyalty towards fellow patients, which is not only a psychological and sociological phenomenon but also a normative responsibility. Second, because the environment tends to judge a patient researcher more critically than other researchers. There is always a shadow of bias or partiality around this position, a partiality that is expected and at the same time seen as problematic. As a consequence, not the risk of subjectivity, but the fear of being accused of subjectivity is more challenging for a patient researcher. Because of existing prejudices in society, I feel more inclined to avoid potential allegations of partiality and to preserve an equal engagement with all stakeholders. Especially the last two cases illustrate that engaging with all stakeholders requires dealing with several internal ambiguities and role conflicts that are less complex and intense for other researchers. In particular the use of reflexivity³⁶ and respecting the concept of a multiple partiality may help patient researchers to address these potential challenges.

Discussion and conclusions

In this article I reflected on the value of responsive evaluation for the position of a patient researcher. We learned that responsive evaluation provides a useful framework of roles when conducting research as a patient researcher. The patient researcher is not just an advocate for the patient community, but aims to enhance mutual understanding by facilitating the dialogue between patients and researchers and supporting the process of relational empowerment. Several examples showed the benefits of the position of a patient researcher to create conditions for dialogue and to engage with all parties without favoring one perspective over another. Three cases showed how complicated the requirement of a multiple partiality can be when different roles conflict with each other.

Table 1. Methods for Reducing Bias When Evaluating as a Patient Researcher

PHASE	POTENTIAL BIAS / RISKS	METHODS TO REDUCE BIAS
Preliminary conditions	Unclear position of the evaluator because of multiple roles; Relationship between the evaluator and the various stakeholder groups; Relationship between the evaluator and the tutors.	Establish a diverse research team, including 1 or 2 patient research partners; Articulate the role of the evaluator at the start; Guarantee adequate supervision and make “reflexivity” a recurrent topic on the agenda; Document observations, meetings and decisions (logbook; audit trails).
Preparation	Starting with personal, pre-conceived ideas and assumptions about the topic under research.	Start with a systematic literature review; Formulate open research questions; Study principles of reflexivity.
Selection of interviewees	Selection of respondents might be biased by personal preferences or prejudices.	Selection together with tutor; Purposive sampling: aim at broad variety of perspectives.
Introduction	Influencing people beforehand by selective introduction (e.g. creating unrealistic expectations).	Providing factual information; Help patients to better understand the research process.
Data collection	Over-identification with patient group; Selective approach of respondents; Privilege patients' accounts; Trying to convert researchers; Lack of professional alertness for sensitive issues; Cognitive dissonance.	Use distinct interview protocols; Independent transcribing of interviews; Responder check; Use of probes; Be empathic though critical; Tolerate politically incorrect statements; Create understanding for the perspective of patients among researchers, and the other way around.
Data analysis	Personal prejudices; Influenced by emotional responses or other personal factors; Presence of traditional perceptions (archetypes) of researchers and people with a chronic disease.	Double coding and code checking (inter-rater reliability); Use peer review and reflexive evaluations; Use of triangulation; Accept ambiguity and plurality.
Report	Leaving out data that are not congruent with desirable outcomes; Trying to be “objective”.	Mention potential conflicts of interests; Summarize the process of reflexivity; Acknowledge the role and contribution of patient research partners.

In contrast to what people might have expected, it was never my intention to prove that patient participation in research is always feasible and beneficial. I had seen processes of tokenism before and could understand the skepticism regarding the added

value of patient participation in the absence of adequate conditions. I was sincerely interested in exploring how patients engage with researchers and I was eager to learn more about facilitating factors and barriers that prevent patients and researchers to build sustainable partnerships.

Are patient researchers, compared to other researchers, sufficiently competent to professionally deal with the additional risks and to comply with a multiple partiality? It is my experience that building an identity as a patient researcher is a process of professional socialization and empowerment, not by replacing the patient identity by that of the researcher, but by integrating both responsibilities, competences and identities on an aggregated level. A thorough education in qualitative research together with more substantive attention to the roles and methods of responsive evaluation and the importance of reflexivity and research ethics provides the ideal skills to optimally utilize the unique benefits of a patient researcher. Acquiring a reflexive attitude may minimize the risks of subjectivity, over-identification and blind spots. This development should be supported by continuous guidance from appropriate supervisors. It might be that this support should even be continued indefinitely to maintain effective reflexivity. In particular literature around qualitative interviews may help patient researchers to deal with all kinds of differences in perspectives.

The cases discussed in this article illustrate that reflection on patient participation is not easy. In the absence of reflexivity no dialogue or mutual understanding can be established. Training patient researchers in the skills and attitude of a responsive evaluator is recommended. It creates the ability to coach, mobilize and empower all participants in a particular context. Furthermore, adequate supervision, preferably by two professionals representing medical as well as social science, can prevent one identity overriding the other. And finally, the absence of time pressures, teaching obligations and other institutional tasks and responsibilities allow a patient researcher to concentrate on the conduct of research.

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