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FROM THE EDITORS

Welcome all readers to Issue 14 of the Innovia Foundation Newsletter. I am pleased to have the help of Malissa Shaw as co-editor once again. The contributions for this issue, though addressing different topics, all have mutual relevance for each other and in regards to the core agenda of Innovia.

As always, Stuart Blume opens the Newsletter with Innovia related news and publications, followed by an announcement for an upcoming conference which may be of interest. Stuart also raises some interesting questions about the nature of patient group participation in shaping and influencing governmental decision making, a topic addressed by the second contribution in this issue. Vololona Rabeharisoa and Madeleine Akrich outline the early findings of an ongoing multi-country research project into patient

organisations and user groups' engagement in knowledge related activities. The project looks at how and under what premises such organisations have transitioned from engaging in advocacy and support work, to participating in and even funding research specific to their interests. The authors then pose the question of whether such activities actually constitute a new form of 'evidence-based activism'.

Following this is a piece by Dr Brigitte van Lierop, program manager for CrossOver in the Netherlands, an organisation which has conducted an international study looking at successful policies and practices for improving the employability and life prospects of young people with disabilities. Dr van Lierop's contribution offers a summary of the findings, distilled into nine key points offering best practice examples. The recommendations provide a useful 'how to' guide for developing effective and appropriate solutions to increase the participation of young people with a disability in both workforce and leisure activities.

The third contribution comes from medical anthropologist Aisha Oron, who discusses her master's research on the experiences of asthma and COPD sufferers of homeopathy in The Netherlands. Many asthma/COPD patients' experiences within the mainstream medical system lead them to homeopathic alternatives – not as a replacement for but rather complementary to biomedicine –

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and they derive different benefits from each approach. Aisha provides an insightful examination of the interaction and intersection of alternative, holistic health approaches with pharmaceutical based biomedicine, from the perspective of the patients themselves.

Finally, I want to close with a reflection. Stuart Blume, in his introduction, speaks specifically about the British government's plans to work more closely with civil society groups, including patient organisations. This brings to my mind an issue that has not received enough attention or met with sufficient controversy, which is the British government's intention to cut by twenty percent public spending on disability, as part of its new austerity measures. The main target will be the Disability Living Allowance (DLA), which covers personal devices and services to allow increased independence and mobility for people with disabilities. From 2013, a new assessment will judge eligibility based on

specified medical criteria. Anne Begg, the first wheelchair user elected to the British parliament, has spoken out against the proposal on the basis that "The one [welfare] benefit which we have in this country which actually operates on the social model of disability is DLA, and to turn it into something which you only get if you actually have a medical diagnosis detracts from the whole purpose of DLA". The proposed changes go squarely against the advancements made in disability theory and policy of the recent past, and may have a potentially huge negative impact on the lives of many people with disabilities in Britain. It also runs contrary to the recommendations in Brigitte van Lierop's contribution in this issue, and in general demands ongoing reflection on the role of research and knowledge sharing in relation to policy, and the notion of 'evidence-based activism'.

Zoe, Malissa and Karina

NEWS FROM INNOVIA

Stuart Blume

2010 came to a disappointing end. Just before Christmas I was informed that our application to hold a conference at the Rockefeller Foundation's Bellagio Center had been unsuccessful. We'd worked hard on it. The response to the call for abstracts relating to the theme of 'prevention' had been gratifying, and we had received more than could be fitted in. They'd come from all corners of the globe: from social scientists, ethicists, historians, specialists in public health. So...to everyone who submitted an abstract, and whom we had hoped to meet in Italy in the course of 2011...alas it isn't to be.

It's a new year now, and the issues we had hoped to discuss have lost nothing in interest or relevance. I might mention a few of them. How and why has the concept of

prevention changed meaning? Once associated with states' responsibilities for collective well-being, in much of the world the term has increasingly been assimilated into clinical medicine [1]. In place of populations, the focus is on preventing individuals from becoming sick, and on behaviour related risk factors. What shapes the preventive health agenda? Why is violence, the source of so much suffering and disability in much of the world, generally excluded? To what extent, and in what ways, is the agenda influenced by new technological possibilities, such as genetic testing? In how far, and under what circumstances, is coercion (e.g. quarantine, compulsory vaccination) justified? What role can and do civil society organizations play in the field of prevention? We are going to look for other ways in which the conference could take place. If anyone has a suggestion to make in this regard – for example if his or her institution might be interested in co-organizing such a

meeting – I do hope you will get in touch with me.

A number of new studies and reports should be of interest to many readers of this Newsletter. A project called EMILIA (Empowerment of Mental Illness Service Users: Lifelong Learning, Integration and Action), funded by the European Commission's 6th Framework Programme, looked at the effects of employing mental health service users in a variety of teaching and research-related roles [2]. The study was conducted in eight European countries with very different social welfare traditions. A number of interesting conclusions emerged. It was found, for example, that employing mental health service users as trainers made the training more credible in the eyes of students as well as giving service users a sense of empowerment. "The EMILIA project has developed a suite of innovative tools to help achieve goals of increased employment and social inclusion among disadvantaged groups". Much more information is available at the project's website.

Via the Communication Initiative Network [3] I learned about a technique called participatory photo mapping (PPM), developed by researchers in Canada and the USA. As reported on the Communication Initiative website, the aim of PPM "is to engage people in participatory processes that are grounded in their lived experience of place in order to generate and transfer knowledge about how the attributes of people interact with attributes of place". Community-based research on environmental health is one application proposed. PPM combines photography with narrative interviews and with mapping to address people's perceptions of their neighbourhood environments and to identify environmental factors that impact health and well-being. Much more can be learned from some lectures and conferences that can be followed via You Tube. See: <http://www.youtube.com/watch?v=8DS-sXOc2pE&feature=related>

What role can community groups and civil society organizations play in the field of

health care provision? With its commitment to what it calls the 'big society', the British government is anxious to see such organizations take a larger role. Nine hundred such organizations were surveyed by 'Patient View' to find out what they thought of these plans. Although the results of the survey aren't publicly available, an editorial in the September 2010 issue of the *Health Service Journal* points to some interesting findings. Unsurprisingly perhaps, the survey disclosed that many community groups are worried that government plans are likely to involve a cut in funding. More interesting here is the assumption regarding what health related civil society organizations are set up to do. In contrast with what the British government appears to assume, most don't see themselves as contributing to service provision. The majority are there to advocate and campaign; arguing for changes that would benefit those they represent. Given current interests in the working of patient organizations in different countries (discussed by Vololona Rabearisoa and Madeleine Akrich in this issue), it is intriguing to reflect on how governments perceive and support (or fail to support) such organizations.

Finally, I must draw everyone's attention to Renée C. Fox's most recent book, *In the Field: A Sociologist's Journey* (Transaction Books, ISBN: 978-1-4128-1443-0). Here, Renée reflects on a long and illustrious career, in which she pioneered both hospital ethnography (a half century ago) and the study of transplantation medicine, contributed to the development of bioethics, and inspired many of us in so many ways. I am certainly one of those, and I am deeply grateful for the support Renée has given to Innovia since its beginning.

[1] Starfield, B. et al. (2008) The concept of prevention: A good idea gone astray? *Journal of Epidemiology & Community Health* 62:580-583. (Thanks to Chee-Khoon Chan for this reference.)

[2] See <http://www.emiliatraining.net>

[3] See <http://www.comminit.com>

[4] Thanks to Bob Keizer for drawing my attention to this survey.

CONFERENCE ANNOUNCEMENT

On the 24th March 2011 a conference on *The Optimal Role of Patient Organizations in Drug Development* will be take place in Amsterdam, The Netherlands. The full day conference will cover a wide range of topics, including: the influence of patient organizations on research agendas; the role of patient organizations in patient registries/databases; the role of patient organizations in 'biobanks'; clinical trials,

including recruitment of patients, outcome measures, and trial design; and codes of conduct in communication between companies and patients/patient organizations. International speakers will come from industry, patient organizations, and regulatory bodies. Reduced registration fees are available for academics, patient organization representatives, and students. For more information and registration, see: <http://www.themeeting.eu>

EPOKS PROJECT: INVESTIGATING PATIENT ORGANIZATIONS AND USER GROUPS' INVOLVEMENT IN KNOWLEDGE-RELATED ACTIVITIES ACROSS CONDITION AREAS AND NATIONAL CONTEXTS

Madeleine Akrich and Vololona Rabeharisoa

Over the past two decades, social scientists have renewed their interest in patient organizations and user groups in the domain of health and medicine. This is due to a series of transformations that have dramatically affected the dynamics of these organizations and groups. In particular, an increasing proportion of them are no longer content merely to represent their members, to advocate for their rights and interests, and to provide social and emotional support. They now actively engage in knowledge-related activities, and claim to be part of networks of experts on their conditions, standing both as 'lay experts', e.g. as credible speakers about science, and as 'experts of experience', e.g. as producers of 'experience-based evidence'.

EPOKS (European Patient Organizations in Knowledge Society) [1] aims at examining this phenomenon across various condition areas and national contexts. EPOKS is funded by the 'Science in Society' Initiative, under FP7th of the European Commission. It is coordinated by

the *Centre de Sociologie de l'Innovation* of Mines-ParisTech (France), with associate research teams from University College Cork (Ireland), Coimbra University (Portugal), Durham University and Lancaster University (UK). Its objective is to compare the modes of intervention of patient organizations and user groups in knowledge-related activities across four condition areas – Alzheimer's Disease, Attention Deficit Hyperactivity Disorder, Childbirth, and Rare Diseases – in the four above-mentioned countries.

EPOKS addresses three series of interrelated research questions. Firstly, how to account for similarities and differences between patient organizations and user groups' (hereafter referred to simply as POs) engagement in knowledge-related activities? At the very least, it is fair to say that these activities depend on the causes that POs stand for. These causes also unfold differently in various national contexts, since national welfare regimes, the functioning of national institutions, and the maturity of civil society in different countries all impinge upon POs' concerns and behaviors. Secondly, could one say that POs' intervention in knowledge-related activities entails a new form of activism? How should we characterize this new form of activism and its consequences on the role of POs in the governance of health issues? Thirdly, do knowledge-related activities serve as a rationale

for POs' coalitions, particularly at the European level? How do these coalitions impact on the dynamics of causes, as well as on the European health and medicine landscape?

EPOKS is still in progress. The project was launched in 2009, and will end with a final conference gathering of all partners, PO representatives, and a few social scientists in Lancaster in 2012. So far, our observations have led us to formulate provisional statements that we will refine in the coming months.

The variety of POs' knowledge-related activities

We have identified different modes of POs' intervention in knowledge-related activities. Each mode can be characterized along two dimensions: (i) POs' proximity/distance to biomedical knowledge; (ii) POs' mobilization of patients' experiences. We cannot detail all these modes in this short piece, but let us consider two contrasting situations: POs for rare diseases on the one hand, and childbirth organizations on the other.

Rare diseases POs are engaged in a war on their diseases. This results in POs' proactive support for biomedical activities. Take the case of the small *Alliance Sanfilippo* in France [2], representing those with a genetic disease which results in progressive neurological degeneration. The association wants to accelerate clinical trials on promising drugs. From the very beginning they have contacted researchers, doctors, pharmaceutical firms, and regulatory bodies, and pushed their agenda forward. They have been directly involved in the design of one clinical trial, and provided substantial financial support to it. *Alliance Sanfilippo* was not content simply to facilitate the recruitment of patients; rather, it was very much a co-investigator in the scientific, medical, and therapeutic research. This is an extreme case, but rare diseases POs more often than not act as catalysts in the emergence of what we call 'knowledge communities', bridging different actors.

In the case of childbirth, the situation is different, although it also implies a high level of

scientific literacy. In order to defend their position on childbirth as a life event, which implies that medical professionals and practices must only have an auxiliary role, several childbirth organizations are engaged in a critical review of the biomedical literature. As a way of illustration, the French Childbirth Collective systematically collects and analyses biomedical publications with a two-fold objective: (i) to raise awareness of the fact that medical practices are doing more harm than providing well-being to mothers and babies; (ii) to demonstrate that evidence-based medical methodologies are not always robust and reliable. The French collective also investigates social science literature with the aim of showing the big differences in the management of deliveries in France and other European countries. Thus, knowledge, and notably biomedical knowledge itself, is mobilized as a weapon for contesting the medical establishment and for advocating childbirth as a physiological process.

If we now turn to the way POs mobilize patients' and users' experiences, contrasts are less salient. All POs draw on these experiences to argue for changes in care provision. However, we can point to a number of specificities.

Many rare disease organizations conduct surveys and publish white papers on various aspects of their diseases. Not only do they highlight the impact of the diseases on daily life, but also dimensions that are often tackled by medical professionals such as aetiology, epidemiology, side effects of medications, etc. This serves as a basis for dialogue with researchers and clinicians, as well as with health institutions. In the case of 22q11 deletion syndrome, for instance, observations made by patients and families contributed decisive information on the high prevalence of schizophrenia, a co-morbidity that had long been ignored by specialists.

In the case of childbirth, women's and parents' experiences are mobilized as a repertoire against the medical discourse. Women's voiced experiences also help to

contest the fact of their supposed 'demands' for safety and comfort, which medical practitioners are keen to 'offer' through epidural or even C-Section. Recently, a member of a French association on C-Sections published a paper in a medical journal on the so-called demand for C-Section [3]. Drawing upon testimonies from the members, the article demonstrates that women's authentic demands for such comforts are very limited and that obstetricians more often than not are the ones who actually voice this demand.

Towards 'evidence-based activism'

The variety and intensity of POs' knowledge activities provide convincing evidence for the existence of a new form of activism that we propose calling *evidence-based activism*. We would say that evidence-based activism features three main characteristics.

First of all, for POs, evidence-based activism consists of formatting a space within which expertise is an object of mobilization. This means that instead of just aligning with or contesting expert knowledge, POs are actively contributing to the shaping of an expertise that echoes their preoccupations. They collect and analyze various corpora of expert knowledge, and contrast them with people's experience. They sort out issues and concerns on which expert knowledge and people's experience are dissonant. All this aims at grounding and articulating epistemic and political claims for renewed evidence. Throughout this process, the causes that POs stand for are also debated. If we refer to childbirth collectives, for instance, it is interesting to note that their intensive critical analysis of evidence-based medical literature eventually raises discussion about what exactly they claim for: the demedicalization of childbirth or a redefinition of the content and role of medical practices and practitioners?

Secondly, in this process, social scientists play a crucial role, insofar as they engage in a reflexive collaboration with POs and various stakeholders. They help formalize patients and users' experience. They also contribute to the exploration of issues on the fringes of medical

knowledge and interventions. They sometimes point to situations for which medical understanding and practices do not correspond to real world experiences and concerned groups' wishes. They thus maintain the complexity of issues and leave open the question of what should count as appropriate expertise on these issues. This is very much the case for childbirth issues, but even for rare diseases we now witness the emergence of concerns that biomedical research put aside, such as issues of quality of life or parenthood.

Thirdly and consequently, evidence-based activism amounts to collective investigation, including all concerned groups in the exploration of diseases and their consequences. From an analytical point of view, this process invites us to abandon dichotomies between lab research and 'research in the wild' [4], lay knowledge and expert knowledge, knowledge production and knowledge mobilization. This is clearly the case for rare diseases. This is also the case for childbirth, although in a different way. Childbirth organizations closely collaborate with a carefully chosen list of experts whom they feel are 'on their side', notably social scientists. Furthermore, it is pretty clear that a medical experience of childbirth is now part and parcel of women's personal experience, at least in France. This is why collaboration with certain medical experts and contestation of others are conjointly possible.

We will deepen our analysis of this evidence-based activism in the coming months and will figure out how it impinges on the role of POs in the governance of health, notably at the European level. As stated above, evidence-based activism consists of renewing evidence through collective investigation. This has one remarkable consequence that we observed in all of the cases we have studied so far: the emergence of notions that articulate matters of fact and matters of concern, such as a 'normal birth', for instance, that has come to constitute a sort of motto for childbirth organizations in various countries. To what extent do such concepts circulate? How are they adapted to

different national contexts? Do they help shape a European space for mobilization? Those are a few questions that we will tackle in the near future.

[1] See: <http://www.csi.ensmp.fr/WebCSI/EPOKS/Website>

[2] For more information on *Alliance Sanfilippo* see the website of EURORDIS (European Organization on Rare Diseases: <http://www.eurordis.org>)

[3] Heimann, S. (2009) La césarienne sur demande maternelle: Quelle est la vraie demande de la mère? *Revue de Médecine Périnatale* 2(1):8-11.

[4] 'Research in the wild' is a term coined by Michel Callon and Vololona Rabeharisoa to designate both research in the field and/or research conducted by patients (surveys, collection of testimonies, etc.). See: Callon, M. & V. Rabeharisoa (2003) Research "in the wild" and the shaping of new social identities. *Technology in Society* 25(2):193-204.

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IMPROVING EMPLOYABILITY OF YOUNG PEOPLE WITH A DISABILITY: LESSONS FROM ABROAD

Dr Brigitte van Lierop

Approximately 50 million people in Europe are reported to have a disability, to a greater or lesser extent. About half of them are working; much less compared to people without disabilities, and the number of people that work decreases when the disability is more severe. This information can be found in reports that the EU produces annually to get an idea of the situation of its inhabitants. In addition to the information about work, the reports contain information about participation in education and leisure time. Young people with disabilities participate less in education and their educational level is lower than people without disabilities, especially when they have a congenital disability; while one in two people with a disability has never in his life participated in sports or leisure activities. When asking the average European citizen how he thinks about the situation of people with

disabilities, virtually all (97%) say that they believe that steps must be taken to improve the social integration of people with disabilities.

What is important and how this can be improved, is the question. In order to find out, we – the CrossOver Centre of Knowledge and Innovation for young people with a disability and work – searched in different European countries for successful practices. At the same time we studied the literature, looking for successful elements around finding and keeping work for young people with disabilities. In this contribution, we describe, in a comprehensive way, nine successful strategies that we have extracted from both successful practices and the literature search.

1 Personal guidance

All recommendations from experts and all available studies show that personal assistance is essential for success. From this point of view, guiding activities must not be seen as part of a 'transition or reintegration process', but much more as a specific reintegration strategy embedded in policies aimed at improving the labour market position of young people with

disabilities. This personal guidance strategy does not stop at placement; during work, personal assistance often remains necessary. This demands qualified counsellors that are recognized and have the competencies and skills necessary for their guidance activities and an ability to relate to the specific situation which the young person is in. One role of the personal counsellor is always necessary: that he sees the young person with a disability as a future worker with potential and treats him with respect. According to the recommendations from experts and various reports, it is also important to involve the young person when defining the role of the counsellor.

2 *Promotion of career management skills*

We are increasingly moving towards a more flexible labour market, and different studies mention the importance for young persons to learn skills to cope with this. This applies to all young people, including young people with disabilities (to the extent which this is possible, of course; though it is known that professionals underestimate the capacities of persons with disabilities). At the same time, it is important that professionals involved in the education and transition process are able to support young persons in learning these skills.

Part of their job consists of stimulating youngsters to focus and work towards their future and to support them in this, as well as having knowledge of the significance of the disability for their future work situation, and to anticipate in a timely way possible problems. Professionals should be given the opportunity to develop this knowledge and these skills. Training in career management skills, including a first orientation on working life, should be part of the standard offer for school aged individuals: young people learn about the world of work and employers learn about young people in general, and more specifically about young persons with a disability, with all their potential.

3 *Knowledge of support possibilities*

Young people with a disability and their parents benefit strongly from relevant information about the support that can be delivered to them during school enrolment and in the transition from school to work. Often, both the young person and parents are not aware of the possibilities and have no idea where to find support. Furthermore, the support, when offered to the young person and his parents, should fit their needs, questions, and understanding. In policies aimed at promoting the participation of young people with disabilities, a structural emphasis on adequate information is of great importance for success; both local information and web based information.

4 *Quality of services*

The quality of services available to a young person with a disability plays a crucial role in the success of his education and working career, and as such content quality should be part of policies aimed at improving access to such opportunities. Cost-benefit analyses that show the 'profit' of these services for the young person can help provide support for the development of adequate services. It is therefore essential that new services are monitored and evaluated to determine whether they meet expectations, and can be customized if needed. In case of the proven success of a new service, the service should be structurally embedded somewhere and implemented nationwide. This is to prevent the many ad hoc projects that die a gentle death when the subsidy tap is turned off.

The support of the young person must be tailor made and, where necessary, come from different disciplines and be provided by counsellors who are experts in assisting young people with disabilities in school or work. Where necessary, young persons with disabilities should also receive support in living and leisure time, since their well being in school and work can be greatly influenced by the

situation at home.

When local businesses and schools work together in assisting the transition from school to work, the chances for young people with disabilities of finding a job increase. Intermediaries can also play a role in this. It is important to keep the lines short and the collaboration as effective as possible. And of course, never forget as an organization to 'ask the user'.

5 *Suitable work*

If the work is appropriate, the employee will be happy to work and able to keep it up. This counts for everyone, including young people with disabilities. During the search for work it is therefore important to look at the possibilities and wishes of the young person, taking into account the present limitations. The young person should also get the chance to 'practice' in the real work setting. If necessary, there should be the possibility within companies to create jobs, for instance by job carving.

6 *Permanent development opportunities*

Young people in general, and therefore also young people with disabilities, should have the opportunity to develop continuously by following trainings and gaining experience. The acquired knowledge and skills need then to be translated into certifications that are recognized and acknowledged by employers. Following training should be possible in different places, not only in existing educational institutions. This is necessary to increase the flexibility and accessibility of the education and training opportunities and to deliver more tailor made programs.

7 *Support for employers*

Employers are generally not 'just like that' willing to hire someone with a disability. It is therefore important that they receive adequate information about the meaning of the young person's disability for their functioning in the work situation. Guidance of the young worker with a disability by professionals from outside

the work environment increases the chances of maintaining the job. If employers are compensated for low production by the young worker with a disability, this again increases the chances of adoption. Employers are also assisted by many different forms of contracts for all employees, including the young employee with a disability.

8 *The role of the parents*

Parents play an important role in the lives of a young person with a disability. It is the parents who should think along with their child about his school and working career, and they should encourage and motivate him. Policies aimed at promoting the participation of young people with disabilities should include more measures aimed at stimulating the role of parents.

9 *The life cycle of the young as a starting point*

Last but not least, policies aimed at promoting the participation of young people with disabilities can only be successful when taking the life cycle of the young person, his position and viewpoints, as the starting point: these are the various issues at play during different periods, and the transitions that the young person experiences. Only then does it become clear what the young person needs, where bottlenecks are, and where solutions lie. If future policies are shaped based on the life cycle of the young person, chances in the long term will improve, in education and labour participation.

Finally

Our years of experience with research abroad and carrying out comparative studies has taught us that it is very difficult to simply take over what is elsewhere successful. Just copying a successful intervention 'from abroad' doesn't guarantee success. Each country has its own regulations, laws, and cultural aspects, and this can make the difference between a strategy that is successful or that is doomed to fail. However, the nine successful strategies have been

distilled from the successful interventions that we found in different countries in Europe and in the literature, and can be used as a good starting guide for developing interventions for young persons with disabilities to increase their chances in education and in work.

This article is based on *Een schets van het buitenland: een oriëntatie gericht op de situatie van jongeren met een beperking in school en werk in een aantal landen in Europa*, CrossOver, 2010.

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HEALING AND CURING IN PROCESS: HOMEOPATHY EXPERIENCED BY ASTHMA/COPD PATIENTS IN THE NETHERLANDS

Aisha Oron

In the world of healing there is no room for exclusivity, professional egotism and pedantic manoeuvrings – the patient comes first [1].

Worldwide 300 million people suffer from asthma and 210 million from COPD [2]. The WHO has warned that asthma is on the rise everywhere and new estimates have stated that COPD may become the third main cause of death by 2030. Asthma/COPD are lung ailments characterised by periodic obstruction of airflow to and from the lungs. In asthma, breathlessness and wheezing may be induced by many stimuli, including emotion, and sensitivity to allergens is common [3, 4]. Like many patients with chronic ailments, the use of complementary and alternative medicine (CAM) among asthma/COPD patients is common. Even though in academic circles it was long assumed that the use of unorthodox health systems in modern society would decrease and slowly make space for the western biomedical system, the use of CAM has been on the rise for the last decennia [5, 6, 7].

In the Netherlands, homeopathy is among the most popular forms of CAM [8]. The

name derives from *homios pathos* (Lat.), which refers to the practice of treating diseases with high dilutions of substances that produce symptoms similar to those of the disease in a healthy person. This makes homeopathy fundamentally different from orthodox medicine, which explains why the efficacy of homeopathic medicine is continually contested by the medical establishment. For modern patients, however, who are increasingly autonomic and critical of medicine in general, the most important basis to evaluate health interventions is their own experience [9, 10]. The focus of this study, initiated by the Dutch asthma patient organisation VbBA/LCP and conducted as part of my medical anthropology and sociology master in 2008, was therefore the embodied experiences of asthma/COPD patients of homeopathic treatment. The main method was semi-structured ethnographic interviews. As most patients were selected through homeopathic doctors, the majority preferred the use of a combination of orthodox and homeopathic treatment. Seeing a homeopathic general practitioner is a way for them to access the integrated care they desire: the best of both worlds.

For the patients in this study, orthodox medicine is the first resort, after the popular sector [11]. Experiences with orthodox medicine then become the major incentive to resort to homeopathic treatment. Patients are labelled as 'chronic' by orthodox medicine, and the medication offered does not offer them a

permanent cure; the drug regimen they have to follow is often perceived as a life sentence. To complicate matters, the medication is experienced and perceived as 'chemical' and 'risky', which makes long-term use even more daunting. Apart from this, orthodox medication does not always provide enough relief from particular symptoms, such as head colds, which are felt to be highly uncomfortable and impeding to daily activities. In some cases, trust in the safety and efficacy of orthodox medicine has been damaged by intrusive and ineffective tests and interventions, such as the proposed freezing of the nasal mucous membrane to treat chronic head colds, which has loss of sense of smell as a side effect. Even though orthodox medicine and its pharmaceuticals have a solid place in patients' lives and health regimes, they decide to look for treatment that may provide a long-term solution for their ill health; a treatment that uses methods that are more in line with their explanatory model and which they perceive as both safe and non-intrusive.

For patients, the label asthma/COPD obscures a personal illness experience that is not confined to the physical body, but reaches into all spheres of the person and their life. In homeopathic treatment, patients find that integration of the physical, emotional, personal, and contextual aspects:

[Homeopathy offers] a very different approach, in that you are really a person and not just a sick person that's sitting there.

The efficacy of homeopathic treatment is experienced as a combination of the use of homeopathic remedies, in the form of pills, and consultations with the homeopathic doctor. The consultations, which can last for over an hour, have a therapeutic effect of their own and provide the basis for the choice of homeopathic remedies. They give centre stage to patients' embodied experiences and illness narratives. In orthodox medicine, essential aspects are lost in the translation from *illness* (ill health from the patient perspective) to *disease* (ill health from

the doctor's perspective). This does not happen in the homeopathic consultation, which enhances the trust the patient has in the remedies. Because homeopathic remedies are found after many personal characteristics are taken into account, they are seen as less threatening than standardised orthodox medication. Formed of a high dilution of naturally occurring substances, patients see them as 'natural' and 'safe'. One patient explains:

A lot of questions were asked. But much broader than in conventional medicine, where it would be very short, like: 'What are the complaints, what medication are you on'. And here all kinds of connections were made between background and, well, all kinds of things were combined. So that, well that gave me a pleasant feeling because of the time that was taken and that it went a lot deeper than, let's say, 'What is your problem and what spray shall I give you for that this time'.

Because of the deep personal nature of the homeopathic treatment, patients state that trust and confidence in the homeopathic practitioner is vital for success. A bond has to be formed between doctor and patient.

Even though patients sometimes experience the effects of the homeopathic treatment in a short period of time, they generally perceive it as a slow working treatment that gradually works its way down to the deeper cause of the ill health. It is a process, unfolding in different phases, that is unique to each patient. That's why it is more time consuming, as this patient explains:

You don't get asthma just like that, without a reason. It's proven that there's a genetic component to it, but emotional and other factors definitely play a role. And it takes time to find

the right homeopathic treatment for that.

Another patient compared this process to slowly peeling an onion, where each layer brings one closer to the underlying cause and solution. For most patients, the process entails a lifelong change in the way they live and treat their health. Insights are gained during the hours of the consultation, which are integrated into daily life. In combination with the homeopathic remedies, the complete illness experience is addressed: from physical and emotional aspects, to the beliefs and attitudes of the patients regarding their life, themselves, and their illness.

The homeopathic treatment process not only fits patients' multi-dimensional experiences of their ill health, but is both *healing* (relating to the social, spiritual, and emotional dimensions of the illness) and *curing* (relating to the pathology of the disease). "Peeling off the layers" spurs on curing on the physical level, ranging from total recovery of all complaints to the diminishing of the complaints to a level which the patient finds acceptable, sometimes to their own surprise:

And I think it's just absurd, because it's just one little pill that I take a week. And that allows me to go without using all kinds of inhalers every day.

The efficacy of homeopathic treatment was found especially in treating chronic complaints, such as head colds and wheezing. Orthodox medication, on the other hand, was perceived as more powerful in treating acute complaints in which time is a factor, such as in the incidence of Status Asthmaticus [12]. In contrast to orthodox medicine, patients experience homeopathic treatment as more than just taking "little pills". Patients feel it is up to them to integrate the self-knowledge and lifestyle changes they have gained in the treatment into

their daily life, thereby becoming active partners in their own treatment:

Homeopathy isn't a miracle drug. It also depends on your own responsibility and effort. The whole is a process of becoming aware.

They see a difference in the goal of both medical systems, from what they see as symptom control in orthodox medicine, to homeopathic treatment, which has the improvement of general health at heart. In this way, both medical systems have their own function in the lives of patients and complement each other.

Even though the battle for the evidence base of homeopathic medicine in logical-positivistic terms rages on, it may be more meaningful to try to understand what the treatment means to the patients who make use of it. Certain qualities, like the personal doctor-patient relationship and attention to the life-world of the patient, could be taken on board by doctors in orthodox medicine as well. This may improve their ability to cater to the needs of modern patients who experience chronic ill health. Other qualities, like the homeopathic remedies themselves, and the integrated, holistic approach to healing and curing, will always be unique to homeopathic treatment. Therefore, for patients who experience chronic ill health, homeopathic treatment can be a valuable healing method that deserves its place in modern medicine.

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[2] COPD stands for Chronic Obstructive Pulmonary Disease, which is an umbrella term for several chronic lung diseases.

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[11] The 'popular sector' refers to methods of self-treatment or care provided by other lay people in the patient's social surrounding.

[12] Prolonged attack of severe asthma.

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