Putting patients into the Centre:

Patient Empowerment in Everyday Health Practices

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Abstract

Patient empowerment is a key topic in public health, medical sociology, and in public debates on the modernisation of healthcare. This article joins the on-going discussion on public and patient involvement by offering a patient-centred perspective on patient empowerment outside the usual institutionalised context of chronic disease management.

We present results from a qualitative study on individuals’ practices of dealing with acute non-life-threatening medical conditions conducted 2012–2017 in Denmark. Based on 34 home visits including in-depth interviews and participant observations with a sample of 28 informants, we uncover a spectrum of four patient tactics governing these practices: delegating, informing, consuming, and resisting.

The findings suggest disruptive changes to the role of the patient-physician relationship as well as the existence of practices indicative of patient empowerment outside the context of patient empowerment initiatives. Some patients are found to take over responsibility for their health, employing tactics where the role of general practitioners is severely demoted.

These empirical contributions lead to the two theoretical contributions of the article: an extension of an existing model of patient empowerment and a conceptual reconsideration of patient empowerment, advocating viewing it as emerging from a bricolage of tactical interactions with social environments rather than as the consequence of an external strategic process.

Keywords

patient empowerment, public health, ethnography, primary care, patient-physician relationship
Introduction

Patient empowerment is widely seen as a key topic in the modernisation of healthcare towards “self-management of health and illness” (Fox and Ward, 2006: 464). Consequently, patient empowerment has been the subject of both public debate and intensive research, with a recent meta-study surveying a total of 286 scientific articles (Fumagalli et al., 2015).

The phenomenon of patient empowerment is often viewed as an attempt to optimise resources and offload health professionals (Salmon and Hall, 2003). Thus, patient empowerment can be seen as just the latest instalment in the century-long “vigorous debate about the boundaries of medical responsibility” (Nuland, 2008: 145) and the seemingly unstoppable expansion of the power of the medical profession (Moynihan and Smith, 2002). In this view, patient empowerment provides a chance to confine and even retract this boundary by re-assigning some medical responsibility to patients. Salmon and Hall (2004: 55) observe that “sociological analysis has long been concerned with the advance of the boundary of medical responsibility, but it has been less concerned with its retraction”.

Medical sociological research on patient empowerment typically takes a medically-centred perspective (Fumagalli et al., 2015) by focusing on institutionalised contexts such as chronic disease management and patient-physician interactions. This article takes a patient-centred perspective by focussing on individuals’ health-related everyday practices in acute non-life-threatening episodes of sickness. Such a perspective allows for transcending institutionalised contexts by offering an integrated view of individuals’ therapy management (Janzen, 1987) in the form of both professional healthcare and self-care. Further, it allows for including healthy individuals when they are dealing with acute non-life-threatening episodes of sickness or even are simply preoccupied with maintaining their health (Crawford, 1980).

Through a qualitative study, we aimed to uncover what governs individuals’ therapy management when they are dealing with acute non-life-threatening episodes of sickness. This aim necessitated an investigation of different types of (power) relations in the patient-physician relationship, including the extent to which patients exhibit empowered behaviour.

Studying therapy management from a patient-centred perspective provides a novel perspective on the boundary of medical responsibility and on the micro-sociology of patient empowerment. Ultimately, this allows us to contribute to the on-going discussion by advocating a view of patient empowerment as emerging from tactical interactions with social environments, with potential implications for theory and practice of patient empowerment.

Theoretical Background

The literature does not offer clear conceptualisations of patient empowerment (Spencer, 2014) and there is no widely agreed-upon definition of or model for it although overviews and classifications of patient empowerment models exist (Fumagalli et al., 2015; Ouschan et al., 2000). The term is used broadly, referring to either a process, a state, or behaviours (Fumagalli et al., 2015).
Patient empowerment is commonly studied from a doubly medically-centred perspective: it is the institutionalised interaction with health professionals that is imparting power on the patient (Fumagalli et al., 2015), and patients are commonly viewed as homogeneous groups sharing (chronic) medical conditions such as diabetes (Scambler et al., 2014).

Allen et al. (2016: 187) observe that “assertions about the benefit of patient involvement have been based on experiences of chronic disease management, rather than acute episodes of care”, where in the latter focus rather is on safety and quality during life-threatening events. Patient empowerment in the form of self-management regarding chronic conditions is attractive to policymakers as it allows for shifting the day-to-day burden of disease management to patients (Scambler et al., 2014). It is consequently well-studied in this context. Prigge et al. (2015) recently presented an extensive data set of 1622 patients, grouped by five chronic conditions. The medical field is starting to recognise that patients manage chronic conditions to a large degree independently of health professionals.

Likewise, the burden of managing acute episodes also begins to fall on otherwise healthy individuals, catalysed by the explosive growth of freely, publicly, and instantly available e-escaped health information (Nettleton and Burrows, 2003) and online communities (Fox et al., 2005) as well as health education and promotion campaigns (Ayo, 2012).

Even the concept of a “healthy individual” can be questioned. Moynihan and Smith (2002: 859) observe that “advances in genetics open up the possibility of defining almost all of us as sick, by diagnosing ‘deficient’ genes that predispose us to disease”. This blurring of boundaries between the healthy and the ill necessitates adding a patient-centred perspective to the prevailing medically-centred one.

The medically-centred perspective is also evident in the extensive existing body of research on patient empowerment in medical sociology focused on patient-physician relationships (Newman and Vidler, 2006), health policies (Greener, 2008), or healthcare structures (Nettleton et al., 2005). Here, patient empowerment is typically viewed as the intended result of health professionals’ interaction with the patient, heavily influenced by the health professionals’ approach to the patient-physician relationship.

Emanuel and Emanuel (1992) define four models of such relationships: paternalistic (power of decision-making and knowledge belong exclusively to the health professional), deliberative (shared decision-making and knowledge), interpretive (patients decide while health professionals interpret), or informative (health professionals just provide information).

The importance assigned to the role of the health professional is also reflected in Ouschan et al.’s (2000: 106) three dimensions of patient empowerment: patient control (“patients’ perceived control over the illness”), patient participation (“participation in medical decision making”), and patient education (“patients’ perception of education that takes place during medical encounters”). Here, in particular, there is no room left for the patient to make decisions or gather medical knowledge independently of the health professional.

Salmon and Hall (2004: 54) criticise this focus on the role of professionals and found patient empowerment to often be “a professional construction: it existed in the
minds of clinicians and researchers and did not reflect patients’ experience”. They argue that patient empowerment in some cases “can be disempowering and can impair patients’ care”.

Historically, more patient-centred perspectives can be found. Dunst and Trivette (1996) view patient empowerment as a process influenced by the social environment, family, media etc., rather than solely mediated through health professionals. Johnston Roberts (1999: 85) adds a behavioural aspect by considering patients as “empowered when they have the knowledge, skills, attitude, and self-awareness necessary to influence their own behaviour and that of others”. We aim to revive this more inclusive patient-centred stream of research on patient empowerment.

The process of empowering patients or the state of being empowered cannot directly be studied empirically. Instead, we have to rely on observing practices of empowered behaviours (Fumagalli et al., 2015). To delineate the practices relevant to such observations from other everyday practices, we employ Janzen’s (1987: 68) concept of therapy management denoting the practices “whose aim is to formulate a diagnosis, to select and evaluate the treatment at the time of a sickness”.

While this concept was developed for institutional contexts, it is exactly the rise of the reflexive, self-diagnosing patient who is actively engaged in evaluation and selection of treatment possibilities that makes it useful, as we suggest, to speak of therapy management not just inside but also outside institutionalised contexts. This way of considering patients’ own “therapy management” owes a lot to prior studies of “patient consumerism and medical technologies” as formulated by Lupton (2013: 257), and indeed in many ways builds on Lupton’s “digitally engaged patient”. However, whereas Lupton looks primarily on the patient-technology interaction, we address the consequences of this interaction for therapy management as it is exercised by patients in the patient-healthcare system nexus.

This way of distinguishing between institutional and patient agency is highly reminiscent of de Certeau’s (1984: xix) micro-sociological discussion of strategies and tactics in everyday practices. In this framework, a strategy is a “calculus of force-relationships” emanating from an institutionalised context, e.g. a public health system or other institutionalised healthcare. Here, “calculus” refers to a system determining practices in the face of a subject being exposed to multiple forces, e.g., a national medicine policy having to balance between expectations of optimal treatment and rational use of financial resources. Strategies generate relationships with others (citizens, customers, etc.) exterior to themselves based on political, economic, and scientific rationalities.

In contrast, a tactic is an individual, opportunistic, and adaptive calculus of force-relationships, “which cannot count on a […] spatial or institutional localization” (de Certeau, 1984: xix). When patients engage in therapy management practices in order to play with and assume agency towards the medical authorities, that is exactly what is meant by “tactics”. In other words, tactics are those ways in which meanings and practices are “poached” from institutional discourses, and in turn, twisted and recomposed by individuals in contact with but also with an asymmetrical power relationship with the (in our case medical) institutions.

**Methods**
The first author collected qualitative data on individuals’ therapy management through a variety of ethnographic methods including in-depth interviews and participant observations in Denmark from 2012 to 2017. Ethnographic methods in medical sociology have a long history (Charmaz and Olesen, 1997) and are particularly appropriate for explorative studies (Goodson and Vassar, 2011) such as this one.

Primary elements of the fieldwork were extensive visits to key informants’ homes of 3 to 5 hours duration each. During these visits, in-depth open-ended interviews between 2 and 4 hours were performed. These interviews were supplemented by participant observations of informants’ therapy management, where possible. Our research focus included but was not limited to: practices regarding online searches for information on acute symptoms or medicine; practices regarding their interaction with family members on health problems; practices of choosing, storing, and consuming medical products; practices of interaction with general practitioners (GPs) as the providers of primary healthcare in the Danish context.

As the study was conducted outside of an institutional setting, an intrinsic serviceable sampling frame was not available. We used non-probabilistic network sampling based on the snowball method (Bernard, 2011), allowing us to benefit from existing trust relations while researching an intimate and sensitive topic such as health-oriented practices.

The pool of initial informants was purposively sampled through the researcher’s secondary and tertiary network, striving to ensure variety regarding age and gender as well as educational and occupational backgrounds. We considered at most two referrals per informant and excluded referrals without recent experience of dealing with acute episodes of sickness as well as physically or cognitively severely incapacitated individuals.

Table 1 presents our sample of 21 key informants, living in rural areas, medium-sized towns, and the three largest Danish cities. The highest educational certification obtained was either a high-school diploma, an undergraduate degree, or a postgraduate degree.

Table 1. Key informants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arta (^a)</td>
<td>female</td>
<td>46</td>
<td>high-school</td>
<td>unemployed</td>
<td>town</td>
</tr>
<tr>
<td>Casper</td>
<td>male</td>
<td>39</td>
<td>postgraduate</td>
<td>site manager</td>
<td>rural</td>
</tr>
<tr>
<td>Digambari (^b)</td>
<td>female</td>
<td>52</td>
<td>undergraduate</td>
<td>unemployed</td>
<td>town</td>
</tr>
<tr>
<td>Ellen (^c)</td>
<td>female</td>
<td>70</td>
<td>high-school</td>
<td>retired</td>
<td>city</td>
</tr>
<tr>
<td>Flemming</td>
<td>male</td>
<td>25</td>
<td>undergraduate</td>
<td>carpenter</td>
<td>rural</td>
</tr>
<tr>
<td>Gitte</td>
<td>female</td>
<td>47</td>
<td>postgraduate</td>
<td>public administrator</td>
<td>city</td>
</tr>
<tr>
<td>Hanne (^d)</td>
<td>female</td>
<td>48</td>
<td>high-school</td>
<td>unemployed</td>
<td>town</td>
</tr>
<tr>
<td>Hans</td>
<td>male</td>
<td>33</td>
<td>postgraduate</td>
<td>team leader</td>
<td>town</td>
</tr>
<tr>
<td>Ivan</td>
<td>male</td>
<td>55</td>
<td>postgraduate</td>
<td>engineer</td>
<td>city</td>
</tr>
<tr>
<td>Jesper</td>
<td>male</td>
<td>62</td>
<td>postgraduate</td>
<td>lawyer</td>
<td>city</td>
</tr>
<tr>
<td>Kira</td>
<td>female</td>
<td>43</td>
<td>high-school</td>
<td>cleaning assistant</td>
<td>rural</td>
</tr>
<tr>
<td>Lasse</td>
<td>male</td>
<td>37</td>
<td>postgraduate</td>
<td>biologist</td>
<td>city</td>
</tr>
<tr>
<td>Lise</td>
<td>female</td>
<td>43</td>
<td>postgraduate</td>
<td>lab technician</td>
<td>rural</td>
</tr>
</tbody>
</table>
Lone   female  31  undergraduate  customer service  town
Marcus  male    35  postgraduate  teacher  city
Maria   female  47  postgraduate  military service  city
Mikkel  male    41  postgraduate  project manager  town
Pernille female  37  undergraduate  cosmetologist  city
Sanne   female  32  undergraduate  student  city
Sara    female  41  postgraduate  IT consultant  city
Victor  male    36  postgraduate  health professional  city

a) posttraumatic stress disorder  b) chronic back pain  c) chronic obstructive pulmonary disease  d) diabetes

None of the key informants had been part of any patient empowerment initiatives beyond those aimed at the general public, and only 4 out of 21 had chronic non-life-threatening conditions (cf. Table 1) in addition to the acute episodes considered in this study. These episodes revolved around acute conditions such as common cold, sore throat, tonsillitis, bronchitis, middle ear infection, back pain, knee sprain, rectal fissures, constipation, and acid reflux. In addition to the key informants, 3 of their children and 4 of their spouses participated actively in the study, bringing the total number of informants to 28.

One informant gave permission to be observed during her interaction with her GP, and another informant allowed observation during an interaction with the out-of-hours medical service while dealing with an acute condition of her child. Furthermore, 7 informants participated in follow-up interviews of varying length over the course of several years, providing a longitudinal element to the study.

The primary data consists of interview recordings, transcriptions, and extensive field notes covering both observations and reflections. This triangulation (Denzin, 1978) of methods and data was used to ensure internal validity through “accounting for the relationship between ethnographic interpretation and field note evidence” (Arnould and Wallendorf, 1994: 196). In particular, the field notes proved valuable in uncovering discrepancies between the utterances of the informants and their actual observed practices.

Verbal consent was obtained for recording interviews as well as for publishing short, non-identifiable excerpts from interview transcriptions. To ensure confidentiality, we assigned pseudonyms to our informants. The study was approved by the Danish Data Protection agency under the general permission of the research institution of both authors. Ethical clearing by the Danish National Committee on Health Research Ethics is not required for this type of research.

For the data analysis, we formed a hermeneutic community, where the first author took the expert perspective and the second author challenged assumptions from a naïve point of view (Arnold and Fischer, 1994). First, we used open coding to code, conceptualise, and categorise the data (Corbin and Strauss, 2014). Second, we theorised the categories drawing upon and extending existing theoretical categories from Ouschan et al.’s (2000) three dimensions of patient empowerment as well as Emanuel and Emanuel’s (1992) models of patient-physician relationships.

Findings
The findings of the study are presented in the following five subsections, starting with four tactics distilled from the data analysis: the delegating tactic, which is characterised by a paternalistic patient-physician relationship and lacks indications of patient empowerment; the informing tactic, which strives for knowledge while leaving decision-making to GPs; the consuming tactic, which shifts the power balance towards the patient achieving patient empowerment; and the resisting tactic, which completely excludes GPs from the picture. The final subsection reflects theoretically on our results and proposes an extension of Ouschan et al.’s (2000) model of patient empowerment.

Delegating Tactic: the Traditional Approach to Therapy Management

The calculus of the delegating tactic mirrors the historically formed expectations to the patient-physician relationship, where control, decision-making, and knowledge reside exclusively with health professionals. This tactic is verbalised by unemployed 48-years old Hanne:

“I cannot do anything myself, only my doctor decides what should be done […] I do not understand what it is all about.”

Discussing this point, she also shows little engagement in active therapy management but seems satisfied with such a paternalistic patient-physician relationship, where medical responsibility resides with health professionals. Reflecting on her last interaction with the regional hospital, she expresses a direct connection between feeling safe and the number of health professionals around her:

“I felt safe among so many doctors.”

Here, the specialisations of the health professionals as well as whether they are actually in charge of her treatment seem to be immaterial.

Another informant relying heavily on the delegating tactic is 70-year old Ellen. Like Hanne, she does not perceive herself to be educated about or responsible for her therapy management:

“I trust the doctor […] I have no understanding of what is going on with me. Only the doctor and God know.”

Ellen does not engage in intentional therapy management and relies on support for her family in connection with an episode of hospital treatment. Her husband and her daughter mediate between her and public authorities in general, and GPs in particular:

“I think it was good just because my husband was with me all the time in the hospital […] he made sure that everything was all right.”

The observed practices aligned with this tactic hint at an unreflective approach to medication, exemplified by informants’ inability to discriminate between nutritional supplements and strong prescription-only drugs. Medicine is at most grouped by which body part they think it should affect. Ellen is rather explicit about her limited knowledge:

“I only use what the doctor has prescribed and what I get from the pharmacy. […] I know nothing about it.”
Hanne’s corresponding lack of understanding and her paternalistic patient-physician relationship result in an almost dangerously passive approach to medication:

“I went to the doctor and he told me to take seven pills of this medicine at once. I did not understand why. But on the first day, I took seven.”

Hanne’s son clarified that the pills were supposed to be taken over the course of a week, meaning that Hanne’s misunderstanding with the GP resulted in severe overdosing.

To summarise, the delegating tactic is closely linked to a paternalistic patient-physician relationship, where control and responsibility for decision-making reside with the GPs. Patients remain in the historically assigned roles of passive recipients of treatment, but not of education, with little or no performance of practices indicative of patient empowerment.

Informing Tactic: Consequence of the Information Age

The informing tactic takes its onset in the on-going transformation of our society towards an information society:

“We all do the same. We care about our health and we search for [medical] information. We are used to googling everything.”

This statement made by 43-year old Lise demonstrates how the emergence of the Internet has actively challenged what can be viewed as normality. Lise’s motivation to research her medical condition is based on her wish to gain a “better understanding of what is going on” and to “relate it to other people’s experiences”. Her GP remains the unchallenged decision maker: “in the end, we do exactly as my doctor has said”. Informing herself is mainly a vehicle of being able to feel in control by understanding the decisions and their ramifications:

“I needed to know if I really needed surgery […] I read and read. But at last I talked to my doctor and he convinced me.”

Lise educates herself by browsing “medical portals” offering access to online doctor manuals, by keyword searches, and even by reading scientific articles, and can be seen as medically self-educated. She seems to prefer a deliberative patient-physician relationship, where her GP interprets his findings and deliberates decisions with her. Generally, she is satisfied with the outcome and uses her competence only passively to understand but not to control the diagnosis and treatment process.

Likewise, Marcus is using the Internet, and in particular medical portals and keyword searches with Google, to educate himself regarding a better understanding of acute medical conditions:

“I would typically read everything: from symptoms to diagnosis, then treatment, and then post-treatment […] What should I do to cure myself? What should I do to prevent? What are the side effects of the treatment?”

Although Marcus points out that “doctors are experts and I’m not” and that he trusts them, a later statement shows that he favours a deliberative over a paternalistic patient-physician relationship, as he does not blindly trust his GP:
“I think it is important to check up […] I trust the expert [GP]. But I think I can understand it myself, and I trust myself more. I try to check if the expert gave me the right answer or not.”

His approach does not simply consist of educating himself to find possible diagnoses for his symptoms, but he actually describes it as a structured two-stage process involving a GP as an expert interpreter:

“First, visit the expert. He will tell you what is wrong with you. And then you go and document what that means.”

The goal of Marcus’ approach is to correct and deepen the outcome of the “10–15 minutes” consultation with the GP, making “sure that the doctor has not forgotten some details about this disease”. By this, Marcus assigns a new role to his GP, namely to be an expert provider of medical keywords:

“The point is – it is easy on the Internet to search for keywords. […] I need to know this is tonsillitis, and then I read all about it. So, the doctor should tell me the keywords!”

While the informants have spent considerable time and energy on thinking about how to approach medical situations, their intrinsic motivation to educate themselves regarding their conditions and treatments should not be mistaken with a desire to take over decision-making from GPs.

Some GPs seem susceptible to this line of thought, though, as described by Sanne:

“I actually came to my doctor with quite some pain [after childbirth]. And she just asked me: ‘Have you been considering the opportunity to get it corrected by surgery’?”

By this, her GP not only acknowledges that Sanne is able to educate herself about her condition but also assumes she wants to participate in decision making:

“I did not expect her [GP] to ask what I, as the patient, had already considered in dealing with this problem. […] I am ready to be responsible and follow her prescriptions and take care of my body. But how a purely medical problem should be solved – will it be my task now as well?”

Sanne prefers a deliberative patient-physician relationship and experiences her involuntary involvement in the decision-making process as putting an extra pressure on her: “Before I am going to the doctor, I feel like I am preparing for an exam.”

To summarise, the informing tactic centres on the tension between traditional and new roles of patients and GPs. In spite of their desire to feel in control based on their ability and motivation for self-education regarding medical aspects, the informants primarily relying on this tactic do not want to challenge the decision-making power of GPs.

**Consuming Tactic: Demanding and Challenging the Health System**
The consuming tactic departs from the view of patients as consumers on the health market. The informants using this tactic generally expect individualised and caring healthcare service from their GPs:

“My GP does not care about me at all. […] Doctors are not treating people; they are getting problems out of their heads.”

This is the experience of Lasse, criticising GPs for not providing an adequate service level:

“They [GPs] have no complex approach to diagnostic! My problem was that I was coughing a lot […] she [GP] made a blood test […] She did not even listen to my lungs […] she has to listen to them […] I think I was not diagnosed properly.”

Unsatisfied, Lasse feels “lonely with the [medical] problems”. This motivates him to regain control by taking over responsibility and applying a more diversified problem-solving approach than solely relying on GPs: “I have to be more responsible for my health and my family and I need my medicine”.

Consulting a GP is only seen as one of the possible choices in the consumption of health services, as further exemplified by Hans when asked about a random bottle in his significant medicine collection:

“Ah, this, this is something for disinfecting throat and mouth. I use it mostly when I have problems there. Or when I feel I am catching a cold. Usually, it prevents, or I think at least it does, more serious infections.”

Not only does he know the purpose of the medicine, but he also knows what the active ingredient is (“chlorhexidine gluconate”). Asked about his reasons for storing such a big amount of medicine at home, Hans answers that “it is a kind of security”. In other words, he is storing it as a means of alleviating future risks, both concrete and more hypothetical ones, thus increasing his feeling of being in control. It is interesting to note that Hans has no chronic medical condition.

Hans prefers at most an informative patient-physician relationship, claiming “they [GPs] do not have much time for the patient”, and is critical regarding medicine prescriptions and GPs’ decision-making:

“I always start to ask: ‘Ok, what are you prescribing me? Why do you prescribe this? What kind of illness do I have? Is it a good medicine for this illness? Is there a better medicine?’ […] I do not take any medicine just because some doctor thinks it is a good idea.”

This distrust is a driving force in Hans’ desire to take over responsibility for his therapy management, and to educate himself to be able to do that:

“I need information before taking medicine. […] I will not use it before I will understand what it is, how does it affect the illness, and what side effects it might have. […] I know how to perform differential diagnosis, at least for simple cases.”

This competence is further increasing Hans’ feeling of control and empowering him to proudly declare “I’m the expert in my own health”.

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Gitte uses a similar approach. In an episode with back pain, which her GP and the physical therapist she was referred to could not solve, she decides that it was time to take over responsibility:

“If they [GP and physical therapist] cannot help me, I do not need them. I can help myself.”

Using the opportunities provided by the market, she chose to educate herself:

“I had to take a course as a professional masseur to understand my body better and be able to deal with my [back] pain.”

When she quit smoking after nearly 30 years, because she suspected her lung function to have deteriorated, and based on the mistrust earned in the above episode, she decided to not check the conditions of her lungs by consulting her GPs. Instead, she decided to climb Mount Kilimanjaro in order to diagnose her lungs:

“I do not need my doctor [GP] to diagnose my lungs. It is only I who can experience how well they [lungs] work. When I climb higher up, there are different pressure levels. There I can check them [lungs].”

In general, informants using the consuming tactics were found to be resourceful individuals. Beyond self-education, some of these informants were drawing on family members with relevant medical education or experience. Ivan, who immigrated to Denmark from Eastern Europe shortly after the collapse of the Soviet Union, points to “trust and professional level” as criteria for a good GP. He heavily relies on his wife for educating himself about his therapy management:

“Actually, I do not need doctors and their medicine, I have my wife, and she has her knowledge.”

Asked whether his wife has a medical education, he simply answers:

“No, she has a PhD in physics.”

Like Hans, Ivan also points out the importance of understanding what medicine one is taking, referring to his wife:

“She would never take anything if she did not understand what it was and how it worked, and what the main components of the medicine are. She knows all the important medical terms.”

When asked how he and his wife research medical conditions on the Internet, Ivan explains the decision-making in his therapy management in detail, clearly leaving no role for GPs in it:

“She is reading some medical forums, and she reads many scientific articles about illness and medical news. […] Then we make a decision together and go with this decision to a doctor and ask for the medicine.”

Not only is Ivan confronting his GP with finalised decisions, but he also ensures that these decisions are implemented, if necessary, against the judgement of the GP:

“He [GP] did not want to send me to the hospital by issuing a referral for a [knee] surgery. But I pushed him!”

To summarise, the consuming tactic is characterised by patients taking over control and decision-making. The informants predominantly using this tactic actively educate
themselves and “consume” GPs mostly as service providers, e.g. for diagnostics and other information/interpretation, for getting access to prescription-only medicine, or for referrals to hospitals.

**Resisting Tactic: between Non-Compliance and Self-Regulation**

The *resisting tactic* is unified by resistance to established medical authority, often influenced by individual or cultural beliefs. While Hans is predominantly using the consumer tactic, his aversion towards taking medicine is based on individual beliefs:

“I do not take painkillers when I have a headache. Because I believe that any medicine that we use somehow changes the body’s balance and has many side effects. And why should we change the natural balance?”

Another informant resisting medical authority is Digambari, who came to Denmark as a refugee from South Asia 22 years ago. Her GP prescribed her medication for her chronic back pain, which she decided to abandon in favour of Indian medicine, slightly increasing her perception of being in control:

“I used to take a lot of Danish medicine, but it did not help. Now, I have my medicine from India and I am very happy with it! It is very good for my back and it helps me when I have severe pain. It is really strong.”

Also, when dealing with an acid reflux problem, she abandoned the prescribed medicine (identified as metoclopramide) in favour of some herbs (identified as fenugreek) she considers helpful for stomach problems.

Asked whether her GP knows that she is using alternative medication, she hesitates, becomes shy, and claims, “he says it is ok”. Talking off the record, her daughter confirms the researcher’s suspicion: her GP is unaware of her dropping the prescribed medication and is actually concerned about the lack of improvement regarding her conditions. Moreover, Digambari describes her medical philosophy, explaining that chemical medicine is not good for the body, akin to the preference for “natural balance” expressed by Hans. Instead, she believes in home-made medicine, which is primarily based on traditional spices, for which she got the recipes from her mother.

Individual beliefs are also at the forefront for Maria. After an unexpectedly complicated surgery and hospitalisation, she was referred to a clinical psychologist in order to deal with this traumatic experience. This collided with her beliefs about her own power to deal with mental challenges:

“I can let them treat my body, but I could never let others treat my brain. This is my responsibility.”

She collected information about self-treatment of traumatic experiences from websites of self-help communities. As a consequence, instead of the proposed treatment, she ended up “painting the pain away”, with the picture still hanging in her bedroom and “not mattering to others but meaning a lot to me”.

Another situation resulting in resistance to health professionals’ recommendations is reported by Sara. Faced with severe acute pain in the intestines,
she was set up for an intestinal endoscopy, requiring the use of antibiotics for eliminating a certain sample-diagnosed bacterial strain.

“I do not believe in antibiotics. I believe in my body, and I believe that I can do this myself [her body getting rid of these bacteria].”

Her resistance to undergo the antibiotic treatment resulted in the endoscopy being cancelled. She says, not without an element of denial, “it still hurts but they cannot figure out what it is.”

Resisting practice transitions to another dimension when individuals take responsibility for choices in the therapy management of patients under their guardianship. Such a situation was related by Lone, regarding her 2-year old daughter:

“My daughter had a fever of 39.4 degrees […] The doctor checked her, and he told me he thought it was a bacterial infection and prescribed us some antibiotics.”

The idea of giving antibiotics to her daughter did not fall on fertile ground with her: “Why should I give antibiotics to my baby?” Lone was “not sure she [the daughter] had a bacterial infection” and once more read “everything about middle ear infection and its treatment” on the Internet.

“I decided to wait before starting [antibiotics]. My husband was worried and would rather follow the doctor’s recommendation. But I convinced him that antibiotics were not necessary.”

It could be argued that Lone’s uses medical information from the Internet to support (or post-rationalise) decisions made according to her beliefs. Such practice should be taken seriously, as we need to “be concerned with what people believe, not with the correctness of these beliefs” (Hochbaum, 1958: 5) if want to improve our understanding of patient agency.

To summarise, the resisting tactic transcends Emanuel and Emanuel’s (1992) model as patients are unwilling to adjust their therapy management to GPs’ recommendations. Their therapy management is often based on individual beliefs supported by online media, with a tendency to favour “natural balance” over medical intervention. Informants using the resisting tactic take over decision-making and educate themselves in order to feel in control. Their practices should be viewed as empowered, even though their feeling of control and their self-education are in some cases related to “notions of health and illness in contrast to a biomedical or professional perspective” (Fox and Ward, 2006: 464) and can be view as a demedicalisation of society (Fox, 1977).

Towards a Fourth Dimension of Patient Empowerment

The spectrum of therapy management observed in this study was distilled into four tactics differing in terms of their relation to various expert systems. Our analysis cuts across Ouschan et al.’s (2000) three dimensions of patient empowerment. The delegating tactic is low on control, participation, and education; the informing tactic is low on participation, intermediate on control, and high on education; both the consuming and the resisting tactic are high on all three dimensions. Thus, while Ouschan et al.’s dimensions originate from and depend on the mediation of health
professionals, in the analysis of our data we found them valuable also outside of institutionalised contexts.

Likewise, the tactics emanating from our study add to the insights provided by Emanuel and Emanuel’s (1992) model of patient-physician relationships: the delegating tactic induces a paternalistic relationship; the informing tactic induces a deliberative relationship; both the consuming and the resisting tactic induce either an informative relationship or no relationship.

The trait that allows distinguishing the consuming and the resisting tactic from each other is the patient’s autonomy from the GP. We could assert that the consuming tactic rests on an intermediate level of autonomy with patients taking over the final decision-making, but still depending on GPs for many elements such as diagnosing. The resisting tactic demonstrates a high level of autonomy with patients acting either against or independent from their GPs; both the delegating and the informing tactic lie at a low level with patients depending heavily on their GPs.

Based on these findings, we suggest a new model of four dimensions of patient empowerment also applicable to therapy management and patient education outside of the patient’s interaction with health professionals:

(i) patient control, i.e., the extent to which patients perceive to be in control over their medical condition,
(ii) patient participation, i.e., the extent to which medical decision making is performed by patients,
(iii) patient education, i.e., the extent to which patients acquire medical knowledge, and
(iv) patient autonomy, i.e., the extent to which patients operate independently of health professionals.

This new model is an extension of Ouschan et al.’s (2000) three dimensions of patient empowerment. Our dimension (i) of patient control is equivalent to Ouschan et al.’s dimension of patient control. Our dimension (ii) of patient participation extends Ouschan et al.’s dimension of patient participation by allowing for decision-making without the involvement of a health professional. Our dimension (iii) of patient education extends Ouschan et al.’s dimension of patient education by allowing for (self)-education outside the patient-physician interaction. Finally, our dimension (iv) of patient autonomy reflects the observation that the technological development allows for an ever-growing amount of (acute) healthcare to be performed independently of the interaction with health professionals. Note that dimension (iv) is independent of the other dimensions of the new model. In particular, patients can operate autonomously from health professionals, but still delegate decision-making power to third entities (e.g. to family members).

Our observations are in correspondence with Nichter's (2002) discussion of the relative independence of the patients in therapy relations and the multifaceted economic, social and cultural dimensions as well as the negotiation of power, beliefs, consensus and disagreements involved in the analysis of therapy management, “a concept in need of refinement” (Nichter, 2002: 82).

The following table summarises the application of our analytic framework extended by the additional dimension of “patient autonomy”:
This extended model of patient empowerment facilitates more nuanced evaluations of patient empowerment initiatives, in particular with respect to the observed differences regarding the impact on its participants. Furthermore, a reflexive inclusion of the four tactics has the potential to improve and customise the design of health promotion, health education, patient involvement, and other public and patient involvement initiatives. For example, it could be instrumental to develop individualised perspectives on health promotion (Ayo, 2012) towards more personalised ones.

Rethinking Patient Empowerment

This study has brought together a number of insights concerning the importance of patient empowerment (Johnston Roberts, 1999), the intricacies of therapy management (Nichter, 2002), the role of consumer logics in health care (Henderson and Petersen, 2002), and the general relation between cultural logics and health care systems as studied by medical anthropology. While these general observations are not new, our application of de Certeau for our study of therapy management in acute non-life-threatening episodes of sickness from a patient-centred perspective has contributed to the abovementioned streams of literature with a particular portfolio of tactics.

Patient empowerment initiatives are commonly based on a medically-centred perspective (Fumagalli et al., 2015), targeting medically homogeneous groups of patients (Scambler et al., 2014). They are initiated by institutions of authority, i.e., by “subjects of will and power”, and based on models of “political, economic, and scientific rationality” (de Certeau, 1984: xix), where each individual plays a negligible role as part of population-level statistics. Clearly, practices related to patient empowerment initiatives are strategic in character, and we refer to such forms of empowerment as strategic empowerment.

Strategic empowerment is not limited to patient empowerment but encompasses all empowerment processes where someone in a role of authority employs strategic practices to empower others. When the goal is to encourage expected “empowered” practices, this can be seen as an instance of classical Foucauldian governmentality, where governments or medical institutions try to reshape (sick) individuals to make them work more efficiently as parts of the (healthcare) system.

On the one hand, we uncovered a portfolio of rather differentiated tactics regarding patients’ therapy management. Based on this, it seems implausible to expect that strategic patient empowerment initiatives targeting patients by medical conditions would be able to produce homogeneous patterns of patient control, participation,
education, and autonomy, i.e., homogeneous levels of patient empowerment. This echoes Gibson et al.'s (2012: 531) considerations regarding the “major inherent weaknesses of a monolithic, single-track model of patient and public involvement”. It is interesting to note that in our study all informants with chronic conditions were using either the delegating or the resisting tactics. However, given only four such informants and our focus on acute episodes, we do not feel that we have sufficient data to warrant any conclusions based on this. How tactics differ between chronic and non-chronic patients is a topic of further investigation.

On the other hand, we found that patient empowerment can occur outside of patient empowerment initiatives, and in fact not even necessarily requires mediation through health professionals as exemplified by the resisting tactic. This supports the need for a more inclusive perspective on patient empowerment along the lines of Dunst and Trivette’s (1996) work, where they view patient empowerment as a process influenced by social environments.

In our findings, we found ample evidence for social structures other than healthcare systems supporting the empowerment of patients. Examples include spouses providing medical knowledge and sparring, medical portals providing professional diagnosis and treatment guidelines, and peers in online communities discussing and inventing alternative treatments.

Following de Certeau’s (1984) distinction between strategies and tactics, we advocate viewing patient empowerment less as an outcome of a strategic process, but as emerging from a bricolage of tactical interactions with a multitude of social environments. We refer to such empowerment as tactical empowerment.

The ability for individuals to be empowered then depends on the adoption of suitable tactics to engage with social structures relevant to their healthcare. These structures can be the health system, but they can also be found in e.g. the form of the individual’s embeddedness in a society that simultaneously displays traits of the consumer, information, and risk society. Ultimately, we would argue that all empowerment of individuals is tactical in nature, with strategic empowerment initiatives in the best case facilitating the individual tactical empowerment and in the worst case leading to disempowering and impairing effects as described by Salmon and Hall (2004) and Scambler et al. (2014).

Our distinction between strategic and tactical empowerment allows for theorising Spencer’s (2014: 6) main opposition between the “official” (strategic) and “young people’s ‘alternative’” (tactical) framing of patient empowerment. It also adds a useful perspective to Greener’s (2008) critique of the idea behind many patient empowerment initiatives: the assumption that patient empowerment is a deterministic consequence of providing patients with sufficient information to make rational decisions does not fit the empirical experience with patient empowerment initiatives, where only parts of the target groups responded in the desired ways and became empowered patients. The need for an adoption of relevant tactics could provide an explanatory framework for this observation.

One such tactic is the resisting tactic, which our findings indicate allows for non-compliance with GPs’ instructions and consequent tactical empowerment enabling different forms of self-care. This resonates with Conrad’s (1985: 36) view of non-compliance with medication regimes as self-regulation. Where Conrad concludes that “medically-centered compliance research presents a skewed and even distorted
view”, this study finds the assumptions underlying strategic empowerment at odds with actually empowered patients. For example, all informants using the consuming tactics are empowered, but none of them has any (chronic) conditions that would target them for empowerment initiatives. Viewing patient empowerment as tactical allows and mandates us to move to the patient-centred perspective demanded by Conrad and Salmon and Hall (2004).

Conrad (1985: 31) also empirically found that “doctors had very little impact on people’s decisions to alter their medications”. Similarly, we find that some individuals de-emphasise the significance of GPs and their authority in therapy management, with GPs in some cases being reduced to suppliers of medical keywords, as exemplified above in the informing tactic, or operators of diagnostic technology and dispensers of medical prescriptions, as exemplified in the consuming tactics. The “e-scaping” (Nettleton and Burrows, 2003) of medical information leads to therapy management transcending the patient-physician relationship. Patients using the consuming and resisting tactics are taking over power/knowledge from the medical profession, abandoning their “lay beliefs” and starting to consume and produce health knowledge (Nettleton and Burrows, 2003) online.

We have found patient self-education to be a strong catalyst for tactical empowerment in both the consuming and resisting tactic. However, the ability to obtain medical knowledge on its own seems insufficient as showcased by the informing tactic. Already Hochbaum (1958: 15) found little difference “between well-informed and poorly-informed respondents” and considered a need to uncover “more complex relationships between what people know and what people do”. Hochbaum postulated the necessity to relate one’s knowledge to one’s needs in order to obtain a “motivating force”. Following from our view on patient empowerment, patient education can only precipitate tactical empowerment in combination with patient autonomy and patient participation in decision-making.

It is straightforward to assume that the interrelation of these dimensions is influenced by sociological factors. Regarding non-compliance, Conrad (1985: 29) summarised that “factors as social class, age, sex, education and marital status” have not been useful in determining such a relationship. In contrast, our data indicate a role for at least age and educational background. Armstrong (2014: 164) also identifies an “on-going reflexivity about illness both actual and potential” and risk factors both embodied in one’s health and hidden in hazardous behaviour as relevant factors.

Our data indicates another significant factor: consumerism was found to enter the picture on several fronts – in the consumption both of medical information and of medical services. This is in line with Fox et al. (2005: 1300) finding the patient being transformed “into a reflexive consumer, making active decisions concerning treatment procedures”.

Viewing the four tactics through the prism of consumerism, they provide a fertile ground for Fox and Ward’s (2006) health identities: their “expert patients” rely on the informing tactic and remain primarily patients and only secondarily experts or empowered patients; their “technology consumers” rely on both the informing and the consuming tactics; their “resisting (anti-)consumers” rely on both the resisting and the consuming tactics. The additional dimension of “patient autonomy” introduced here, is analogous to Fox and Ward’s dimension of “autonomy/dependence”.

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Conclusion

The aim of this study has been to explore, present, analyse, and theorise the therapy management of patients outside the institutionalised context of chronic disease management. Four tactics were distilled, showcasing both disruptive changes to the role of GPs and empowered behaviour outside of patient empowerment initiatives. The differences among the tactics led to an extension of Ouschan et al.’s (2000) model of patient empowerment by the fourth dimension of patient autonomy. Based on these findings, we advocated viewing patient empowerment as emerging from a bricolage of tactical interactions with social environments rather than as the consequence of an external strategic process.

Our distinction between strategic and tactical empowerment provides an explanatory framework both for conceptualisations of patient empowerment and for critical analysis of actual instances of patient empowerment initiatives. Furthermore, the patient-centred perspective taken in this article contributes to the on-going discussion on patient empowerment by widening the scope to healthy individuals and patients with acute non-life-threatening medical conditions, i.e., beyond the scope of conventional patient empowerment initiatives and research. Furthermore, the tactics we identified can inform public health and health promotion initiatives regarding the impact on therapy management in acute non-life-threatening situations, in particular when these initiatives built upon patient education.

On a macro-scale, the heterogeneity of tactics applied by contemporary patients uncovered in this article presents a challenge both to public and patient involvement initiatives and the daily routines of health professionals in general. A more fine-grained approach considering the role of tactical interactions with different social environments could contribute to aligning the boundaries of medical and of individual responsibility.

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