The Emergence of Perfect[ing] Patients

An exploration of Patient Advocacy

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People who think they know everything are a great annoyance to those of us who do.

Isaac Asimov
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Abstract

Taking a patient advocate role, some patients organize other patients, or guide them to navigate their disease. As patient representatives they influence science-based activities, interacting with regulators, public health institutions, pharmaceutical companies, healthcare professionals and academics. These roles are increasingly carried out by patients or their relatives who have experienced the disease and inevitably have deeply emotional experiences of suffering, (un)fairness, courage, hope, and support. In this thesis, I explored how patient advocates take their role, how it evolves, the interplay between the role and their identity, and what the role might be serving for themselves, other patients and the broader health system. I conducted semi-structured interviews with seven patient advocates. Through the Interpretative Phenomenological Analysis (IPA), I identified four themes. 1) From encountering the disease, and taking the patient advocate role, individuals are exposed to a continuum of optimal inner conflict that increases their capacity to hold contradictions and take personal authority independent from external expectations; 2) Their values act as a driver to step into the patient advocate role, and they demonstrate the ability to self-care by setting suitable boundaries between their [patient] identity and the role; 3) As a change agent, they engage with both the emotional and the technical aspects of the health system to enable adaptive change; 4) In their role, patient advocates serve the function to help the development of the health system by engaging with the anxieties triggered as a result of the tension between scientific rationality and social aspects. Overall, the patient advocates take their role firstly as “perfect patients” to awaken the ‘helpless patients’; they then transform to “perfecting patients” in order to tackle the shortcomings of the health system that fails to treat the humans as a whole and is being disrupted by major developments in science and technology.

Key Words: Patient Advocacy, Patient-centricity, Patient Empowerment, Mortality, Adult Development, Identity, Health System, Adaptive Challenges, Social Defences

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1. INTRODUCTION

In June 2021, US’s FDA approved the first Alzheimer’s drug in decades subject to verifying the results in a further study (Food and Drug Administration, FDA). The decision was made despite the fact that the regulator’s advisory panel recommended non-approval. Three of the 10 panel members quit over this decision (Drug approval sparks resignations, 2021), while the patients celebrated their victory. The patient advocacy groups had fiercely lobbied for the approval (Alzheimer’s Association), because they found the results meaningful for patients. It gave the patient community hope that the drug might slow down the loss of memory due to its effect on the underlying disease process although the studies had not directly proven this. Contrary to patient groups, the scientific advisory panel had found the data unconvincing to warrant approval in that broad patient population. This was the first time in history that patients’ voice prevailed robust scientific evidence-based assessment. However, the patients’ voice had been gaining increasing importance in every aspect of healthcare and related industries in the preceding decades.

Taking a patient advocate role, some patients now organize other patients, and guide them navigate their disease. They also advise and influence science-based activities, such was the case that led to the Alzheimer’s drug approval. In the role, they interact with people from regulatory authorities, public health agencies, pharmaceutical companies, medical institutions, academia and policy-makers. The patient advocates are sometimes recognized as the “expert patient” or “professional patient”. Some even consider patient advocacy as a new industry (Kingston, 2017).

The patient advocacy role is mostly performed by patients or their relatives who have experienced the disease. Inevitably they bring their own and other patients’ deeply emotional experiences of suffering, (un)fairness, courage, hope, support, and generosity. In the role, they operate at the intersection of deep emotions and scientific rational decision-making. Unlike the non-advocating patients, they step forward to become change-agents for better healthcare for everyone.
At first glance, it may come as no surprise to see the emergence of patient advocates in the age of patient empowerment and patient centricity. The old model of the helpless obedient patient is preferred to one where the informed patient can take decisions for themselves utilizing shared decision-making with their physician; the physician bringing their expertise and the patient their values and experience (Emanuel EJ, 1992). Is this really the case, or, is the emergence of the patient advocates, and the power of their voices telling a different story?

The task of individuals taking patient advocate role, with or without any association with a patient organization is very diverse. They may, 1) help raise money for drug research and support recruitment of patients for clinical research (Herper, 2008); 2) participate in programs to ensure an enhanced level of healthcare service (Henthorne, Henthorne, & Alcorn, 1994); 3) act as contacts for the concerns and suggestions of patients (Emrich, Fröhlich-Güzelsoy, Bruns, Friedrich, & Frewer, 2014); 4) raise awareness of these diseases, correct misconceptions, and empower millions of people affected by specific diseases (Shapiro, 2020); and 5) voice the needs for treatment and approaches to diagnosis and treatment (Kingston, 2017).

It is courageous for an individual to accept living with a patient label that created such disruption in their life. Besides the physical aspects such as managing pain, going through surgical and non-surgical interventions, being a patient also requires having to navigate the healthcare system (for example local hospital, insurance company), and interact with specialists, and healthcare professionals. It also means confronting uncertainty, perhaps facing death, revisiting desires for their future, re-experiencing the helplessness of dependency on others like was the case as babies. Ross (2016) indicated that being a patient to him was a time of radical helplessness: “I could eat, drink, talk, smile, cry but moving was difficult. … I was learning to wait, sometimes with good grace and understanding, but sometimes with anger, even rage” (p. 275).

Being a patient, however, is not sufficient to step into patient advocacy role. To enable these advocates in their role, a number of training programs have been developed by, for instance, existing patient networks, to provide them with the knowledge and the language
of the systems with which they interact. Some other programs are also available to train establishments on how to engage patients in their activities (The European Patients’ Academy on Therapeutic Innovation (EUPATI)).

Even though there is some research about patient advocacy tasks and goals of their activities, there is no literature that examines – psychodynamic or not- the individuals stepping into this role. In this sense, this research is foundational. Taking this role, these individuals re-live and expose their personal and highly emotional stories, express their wishes and hopes for a better future for themselves and others, and most importantly aim to create change in an evidence-based rational system that they don’t consider to be serving their individual and collective needs. In the role, the patient [relative] label follows them. What makes them willing to accept it? Is it an insignificant sacrifice in the face of the change they would like to see in the broader system? Do they become the Galileo’s of the modern world to shake deep beliefs of the scientific establishment?

An exploration of the patient advocacy role from inside out, and outside in could provide insights about human development, and give clues about underlying challenges in social and health systems.

In the next section I discuss Objectives and Research Questions. In the third section, I then provide a Literature Review related to patient advocacy, and patient centricity and patient empowerment as well as summarising the conceptual framework. It should be noted that the literature review section is complemented by other literature in subsequent sections as I explore the research questions in light of the data. In the next section, Research Context, I set the scene in terms of methodology, participants, myself as the researcher and an overall discussion around these. In the fourth section on Findings and Discussion, I present and critically evaluate each of the finding. In the final section, Conclusions, Implications and Future Research, I discuss the essence of the lived experiences of patient advocates, and what it means.
2. **OBJECTIVES AND RESEARCH QUESTIONS**

In this research, I explored how patient advocates take their role. In exploring the role, I looked for “patterns of attitude, meaning, feeling and behaviour that characterizes their way of living and working within the various systems of activity. … The nature of [their] role will be determined by the interplay of forces between what[they] bring, individually, and the expectations of the system” (Biran, 2006; Newton, 2013; Newton, 2013). In his work, Lawrence (2019) indicated that the meaning of how one manages oneself in the role could be a force for “social change, which implies an inspection of social realities, … [it] starts from the individual considering his or her authority for being in a role in an institution in society” (p. 42).

The patient advocacy role is, in fact, an integration of two roles. The first one being the patient role, which, to an extent, is a well-defined, scripted role (and intertwined with their identity). The second is the advocate role which emerges within the social system and the script for it is shaped by the individual, circumstance and the system. “Just as newcomers bring their own personal attributes and qualities to the roles, so roles, too have an impact on their incumbents, usually at the less than conscious level” (Long, 2013, p. 234). The study of the patient advocacy role and the meaning attached to it would also provide insights regarding the unconscious aspects of the system they operate within.

For the purpose of this study, I use the term “health system” per the definition of the World Health Organization (WHO). WHO defines health system as:

“A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities. A health system is therefore more than the pyramid of publicly owned facilities that deliver personal health services. It includes, for example, a mother caring for a sick child at home; private providers; behaviour change programmes; vector-control campaigns; health insurance organizations; occupational health and safety legislation. It includes inter-sectoral action by health staff, for example, encouraging the ministry of education to promote female
education, a well-known determinant of better health.” (World Health Organization, 2007, p. 2) In this sense, patient advocates interact with all aspects of the health system, per WHO’s definition, by interacting with other patients, and their relatives, as well as individuals in regulatory authorities, public health agencies, pharmaceutical companies, medical institutions, and the academia. They influence, and are influenced by the system as they take the role. My central research question is:

- How do patient advocates take their role?

The framework of questions below supplemented the primary research question in order to achieve a more in depth and multifaceted understanding:

- To what extent their experience of the disease motivates them in taking the role?
- How does their identity influence how they take the role?
- What is the interplay between the role and their identity? How does this evolve throughout the disease, treatment, recovery and as they step into the advocacy role?
- How does the role emerge? What might it be serving at micro, macro and meso levels?

3. LITERATURE REVIEW

3.1 ADVOCACY AND PATIENT ADVOCACY

According to Innovation Network, a non-profit dedicated to “transforming evaluation for social change,” advocacy encompasses the wide range of activities used to influence decision makers, such as litigation, lobbying, public education, capacity building, network formation, relationship building, communication, and leadership development (Fagen, Reed, Kaye, & Jack, 2009).

McConnell (2004) explains that “Advocacy is the reason most non-profit organizations are created. The desire to bring about a change in a human life or in the lives of a community is most often the driving force for creating an organization in the first place. Organizations, through advocacy can change entire social systems and even cultures to
make life better for one person or millions.” and adds that “the words advocacy lobbying and public policy are viewed as slightly suspect. These refer to mysterious concepts that suggest shady practices, special interest, influence peddling, and back-room deals” (p. 25).

For some, health advocacy is a concept defined in the context of activities of the medical profession, and is linked to related foundational concepts of social determinants of health and health inequalities (Hubinette, Dobson, Scott, & Sherbino, 2017). For others, patient advocacy is studied where nurses act as a patient advocate (Bu & Jezewski, 2007). This and other studies (Faust, 2008; Beart, Hardy, & Buchan, 2004; Fitteron, 2015) are mainly focused on navigating the system via the support of a “knowledgeable” person acting on behalf of the patient. Others see patient advocacy to teach patients and their families how to be their own healthcare advocates (Miller, Hansen, & Miller, 2006), or to advise assessment bodies of the health-care systems on how particular therapies will impact the patient population (Addario et al., 2018). However, in the recent years, there is an increasing trend for patients to speak for themselves.

3.2 PATIENT-CENTICITY AND EMPOWERMENT

Weston (2005) explains that when teaching the patient-centred method, they advise their students and residents to “follow the patient’s lead by picking up on cues to enter into the patient’s world to understand the illness from his or her own unique perspective. In addition, of course, the physician must also follow any leads or cues to disease” (p. 389). There is a distinction between disease and illness. “Medicine focuses primarily on the sick body (disease), medicine ignores many of the concerns and needs of sick people. By listening to the stories of patients in the clinic, on the Internet, and in published book form, health care providers could gain a better understanding of the impact of disease on the person (illness), what it means to patients over and above their physical symptoms and what they might require over and above surgery or chemotherapy. Only by familiarizing themselves with the entire emotional landscape of illness, which includes fear, anger, shame, guilt, and above all loneliness, can the healthy-medicine as well as society in general-hope to heal in a comprehensive manner” (Biro, 2012, p. 41). Four
models to physician-patient interactions have been described, that include paternalistic, informative, interpretive, and deliberative, and each one of them provide autonomy to patients (Emanuel EJ, 1992).

Despite widespread belief in the importance of patient-centred care, it remains difficult to create a system in which all groups work together for the patients’ benefit (Kreindler, 2015, p. 1139). This brings empowerment of patients into focus which many patient advocates promote and sometimes it is questioned. Kingston (2017) indicates that “With [patient activists’] access to medical research, medical professionals and social media mobilization, they’re more accurately “impatient.” Closer examination of recent patient activism, however, reflects a more complex story of systemic failures, establishment backlash and evidence that the mandate to “listen” to patients doesn't always mean they're being heard” (p. 66). Besides, patient advocates are operating in a very complex and multiparty situation. Kingston (2017) adds some critical questions to highlight the tension as a result of the changing power of patients’ voices. “How do you base patient demands on “evidence-based” science? How will the changing role of patients affect doctors’ roles? Who decides health care spending? And, ultimately, who tells the story of disease?” (p. 67)

4. CONCEPTUAL FRAMEWORK

In my research I utilised concepts from inside out and outside in domains of inquiry simultaneously based on Petriglieri’s review of systems psychodynamics in organization studies (Petriglieri & Petriglieri, 2020).

The conceptual frameworks within the inside out domain of inquiry include role as hosts for selves, transference on leaders, and leading with presence and negative capability (Petriglieri & Petriglieri, 2020, p. 429). As patient advocates take on the formal role and transition in their role, they will have a valance to take on certain roles and attract certain projections. They can “amplify their followers’ fears and ideals (e.g. the fears and ideals of patients and other parties they interact with). They will engage with their tasks preferably with psychological presence rather than under the influence of their past. And
finally negative capability would allow them to engage with emotions and use them as data instead of repressing them or acting them out (Petriglieri & Petriglieri, 2020, p. 429).

I leaned on two concepts regarding the outside in domain of inquiry which included sociotechnical systems (Trist, 1981), and social defences (Menzies, 1960). Integral to these concepts, in particular for the exploration of source(s) of anxiety, I explored adaptive challenges (Heifetz, Linsky, & Grashow, 2009a). The health system that the patient advocates interact with and are part of consists of technical aspects (such as the policies, medicines, and treatment guidelines) and social aspects (such as relations between patients and different parties). The lived experiences of patient advocates might point to some collective arrangements as a social defence against anxiety generating conflicts and threats prevalent in the members of groups that these advocates interact with.

5. **RESEARCH CONTEXT AND DESIGN**

5.1 **METHOD: INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)**

IPA describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon (Lewis, 2015, p. 75). It is an appropriate method because my research focuses on how patient advocates take their role and the meaning they associate with it.

I started my research with layers of wonder. I wondered what was triggering these individuals to take the role to represent others. I wondered what was making it more and more important for patients to have a strong voice. I wondered where that leaves the experts, including healthcare professionals, policy-makers, regulators, scientists, and drug developers, who might have devoted many years to train, practice and continuously learn to serve the patients while developing more and more sophisticated ways to collect and analyse big data. Patient advocacy role appeared to be a phenomena that was worthwhile to explore.
5.2 RESEARCH PARTICIPANTS

5.2.1 Identifying participants

Because of the foundational nature, in this research, I invited a diverse group of patient advocates to participate, irrespective of the disease they experienced, of their duration in the role, and of the types of tasks they engage with. I included people who:

- are fluent English speakers,
- identify as a patient advocate,
- have had experience of disease in their lives as a patient or as a close relative of a patient,
- are based in a European country or the US to ensure the health systems and cultural norms are not vastly different.

I had not met any of the participants before. Most of them were contacts of a contact. To increase the diversity I also searched patient advocates in social media and invited a few who are 3rd degree contacts to ensure broader reach. Before talking to the participants, I conducted a mixture of exploratory discussions and practice interviews with 9 people in my network who work with patient advocates. I call this the exploratory group. It included a person from a communication agency, two people from two different patient organizations, two from pharmaceutical industry, one working with regulators, one from a not-for-profit academic project, a healthcare professional, and finally a close relative of a patient. After the practice runs with the exploratory group, I refined my inclusion criteria and interview questions.

To my surprise it proved to be difficult to recruit participants. I invited more than 20 patient advocates to participate. Overall 7 accepted. One of my exploratory group contacts indicated that “the burn out rate in patient advocates is very high”. Another informed that one of their contacts would be open to participate but they were going through a period of being in and out of hospital. Another person declined the invitation to participate, informing me that her days as a patient advocate were over due to her declining health. Disease, hospitals and treatments are unfortunately part of the lives of patient advocates, which partly explains why the recruitment was challenging.
Politics is potentially another reason why recruitment might have been difficult. Many patient advocates and patient organizations are competing for funding from the public and private sector. The more credible they are, the more likely they will secure regular funding, or the more influential they can be to forward their agenda. Their unwillingness to participate becomes understandable in the context of how their funder may view other affiliations they may have or appear to have. Those who declined were alert to a potential conflict of interest, and for some, being affiliated with me as an employee of a specific pharmaceutical company might pose a risk to their credibility, despite the confidentiality and academic nature of my research. In the research, I refrained from exploring sensitive aspects, such as politics, funding, dynamics with funders, and impartiality.

5.2.2 Demographics of participants

Overall 7 participants who met the inclusion criteria above are included in the formal IPA analysis. They were between 30 to 60 years of age, and were located in various countries. These included US, UK, Germany, Spain, Ireland, and Switzerland. All but one were female. They had a diverse educational background. All but one were university graduates, more than half had post graduate degrees. Participants also had varied professional backgrounds. These included a courier, guest relation manager, dietician, engineer, corporate executive, coach, consultant, model, film director and artist. At the time of interviews, all worked for at least one non-profit or charitable patient organization on a volunteer, part-time or full-time basis.

Three were patient advocates relating to cancers, the others were focusing on traumatic brain injury, spondyloarthritis, a genetic form of dyslipidaemia, and Parkinson’s disease. One participant was a close relative of a patient, who died due to the disease, and the remainder had the disease themselves.

The focus of their advocacy work was also diverse. All supported other patients and their relatives, four worked with pharma industry to develop new treatments, three focused on influencing academic research, two specifically worked on influencing government policy for diagnosis and access to treatment, and all aimed to raise awareness of the disease.
5.3 THE RESEARCHER

As a researcher I experienced an irresistible pull towards researching the patient advocates. Approaching the topic cognitively, I had very good reasons. In my work in drug development and in regulatory decision-making, patient voice is becoming very important. So, figuring out how best to seek patient input to develop new treatments is seen vital. Then there are the emotional stories of individual patients that touch me and irritate at the same time. I could see the importance of that new treatment for that patient, and simultaneously I question how one person’s experience relates to, and even over ride, established scientific methodology used in decision-making on topics that impact many more patients globally. The resignations from the US regulator’s advisory panel in response to the approval of the Alzheimer’s drug came as no surprise to me.

The voice of patients driving decisions can easily be taken as a threat to science by some key influencers and by decision makers in regulatory bodies, governments, health care providers, and in businesses. I embraced this discomfort because I was curious about what the patient advocate role is really about. It is so common for new roles to emerge in organizations to solve a problem, and I always had this feeling that there was probably, more to the story, hiding within the larger system.

I have great interest in large scale system change. Studying the patient advocate role could provide an opportunity to gain insights about the larger health/social system. Then, as I interviewed the participants, a surprise occurred. I became aware of a wish that I had not been aware of when I committed to the topic.

As I interviewed the participants, and as their stories unfolded, I could not help but make parallels with the patient advocates and the EMC participants. From the start of the course I had been wondering what made us register to EMC, and what made us keep coming back module after module, despite the mess we were facing and working with, (EMC participants would know exactly what I mean). Studying the patient advocates, in a way, became akin to studying EMC participants during their transition to become “change agents”. Exploring patient advocates in their role as change agents, for me, was perhaps understanding myself and other EMC participants.
I believe that the awareness of this unconscious wish, that one may consider a helpful transference, balanced my focus in my research. I could better move from the individual to the social system and vice versa; applying a binocular vision (Biran, 2006). It also equipped me to explore it as an adaptive issue rather than a technical one. As I became more and more absorbed in the stories of patient advocates, it created openness in our interactions. It wasn’t about finding solutions, and it wasn’t about seeking known problems. It was mutual reflection and exploration of meaning.

I was also conscious of the political nature of the dynamics. My pharmacist training and employment history in pharmaceutical companies might have influenced who participated and who had not. I was conscious of potential conflict of interest for them. At the start of the interviews I emphasised that I was conducting the research as an INSEAD student, not as an employee of a pharmaceutical company or a healthcare professional. I believe that my openness and ability to actively listen without an agenda enabled participants to open up and to focus on their stories.

5.4 THE PROCEDURE

5.4.1 Interview Questions: Tapping into the unconscious

There were two parts to the interview questions. The first part concentrated on the stories of each patient advocate, their individual lived experience of the disease diagnosis, and critical life events before and after they stepped into the patient advocate role. The second part focused on what function the role might be serving at system level through exploration of the role-in-the-mind, their interactions in the role, and how that might be shaped by the context of the role.

I used these questions as a guide during the interviews ensuring I asked at least three questions from each part of the questionnaire. This enabled flexibility to dive deeper into the life events they consider as critical in relation to their roles. The questions also aimed to create openness for participants to share life events from other parts of their lives. The questionnaire is included in the APPENDIX: The questionnaire.
In order to access the associative unconscious (Long & Herney, 2013), I asked participants to draw themselves in the patient advocate role and listened to their reflections on their drawings. In relation to the role, I asked them to rename the role, and to identify their three most important responsibilities if they were to write a job description for it. These questions allowed exploration of anxieties in their subjective experience of being in the role. Each participant’s subjective experience was a piece of the puzzle that I, as the researcher, was working towards to discover their “reality”. Using socioanalytic methods there is the “recognition that each person is but a small part of a much broader system with a limited perspective of the whole tells us that a broader social and external reality is far more complex than can be grasped from isolated individual fleeting experiences” (Bain, 2013, p. 310).

I conducted all interviews on-line due to travel restrictions during the pandemic which also enabled participation from so many countries. With their permissions, I recorded and transcribed the interviews for analysis. The discussions I held with the exploratory group members, and feedback from the faculty and members of Wave 32 helped me shape the questionnaire in line with the objectives of the research.

5.4.2 Data Sources and Collection

The 60-90 minute semi-structured interviews with the seven patient advocate participants formed the basis of the IPA. As I interviewed the 6th participant, I felt I had reached the saturation point. Despite the differences in disease, age, country, duration in role, and different focus in their tasks, a pattern in each participant’s story was emerging.

In my inquiry, the conversations with the exploratory group were extremely helpful. The members of this group witnessed the patient advocates in their role, supported them to take their role in the broader system, or they had taken the role themselves. It is important to note that four of the exploratory group members asked for a detailed research proposal or a “protocol” before considering putting me in touch with their patient advocate contacts. Some specifically sought exactly what problem the research would solve, and whether it was a problem that resonated with them. Exploration of the lived experiences in the role was far from solving a problem, it was about uncovering what was beneath the
surface that we don’t know how to solve with our existing know-how. I consider their reactions valuable data which may be symptomatic in a system that has tendencies towards solving challenges with primarily a technical approach.

5.4.3 Data Analysis

For the data analysis, I listened all the seven interviews, highlighted significant statements and tabulated them. I re-read the notes I took during and after each interview, and noted repeating, or contradictory statements from both the participants and the exploratory group. From this, I derived four themes. The four themes and theme clusters that emerged are presented below:

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As an EMC student experiencing and learning about adaptive change over the last two years, I was able to make some sense of the transformation the patient advocates were going through individually. I could relate to and empathise what it takes to go through that change. There was a possibility that I was idealizing the participant advocates for their courage. For me, this might have served to contain feelings of pity for what they went through, and admiration for how they came out of it. It is also possible that, as a healthcare professional, I was projecting my wish that they create a change in a system that is in need of change and is very difficult to change. I suspect I am not alone here.

In relation to the data sources, there was value in focusing on the diverse all-comers. As a foundational research this diversity revealed different pieces of the puzzle.

6. FINDINGS AND DISCUSSION

The essence of an individual taking a patient advocate role followed a common pattern in all participants. They first emerged as a perfect patient and then transformed to a perfect(ing) patient while being grounded in reality. The interviews in this research revealed a collective story of a patient advocate which goes like this:

A person becomes ill. The diagnosis of the disease is followed by treatment. Something goes wrong for the person: the disease can’t be diagnosed, there is no treatment, they can’t access treatment, or they are offered a treatment option they are uncomfortable with. The person, on one hand, deals with the situation and all subsequent events in their lives emotionally, evaluating their past, present and future trajectories. On the other hand, they confront a highly technical “system” driven by norms and facts which attempt to simplify the complexity by categorisation and reliance on facts and numbers. The person finds that it is almost impossible to question or break those norms. They find solace from other patients. Eventually the person overcomes the adversities. They learn to live with the losses they endured. They share what they know with other patients. There is sort of a positive learning which becomes the start of the next thing.
Then someone asks the person to share their experience broadly. The person first speaks for themselves, writes their story, and very quickly they start voicing the collective experiences and wishes of other patients and their families so those that come after them can have a better experience. They encourage other patients to question the norms. Other patients ask them to speak up, to break the judgement and stigma. Then they speak more. They get better at it. They identify as a patient advocate. They had not planned or wished for this. In their new and evolving role, they build on a lot of the skills they had before their diagnosis. They didn’t want to be a patient advocate to start with, but now that they became one, they would not have it in any other way.

They give hope, they open up new possibilities for other patients, medical profession, policy-makers and companies. They talk about what is not discussable. At times is becomes too much. They realise they need to protect themselves. They put a healthy distance to other patients. They select where they speak, and what they speak about. They also ground themselves in reality. Their experience is one of many. Even if they represent the patients, they understand it may not be applicable to all. They also realise that the changes they advocate for are fundamental changes and that the successes may only make a tiny dent in the larger system. But they give it a go anyway, because they are needed.

This collective story revealed four themes in my analysis. Of the four themes, the first two relate to the “inside out” domain of inquiry about personal growth and evolution of identity and role(s) starting from when participants first experienced the disease. These two themes tell the story of how they become the “perfect” patient. The perfect patient who is not helpless, who is questioning, and who is powerful to decide for themselves.

The latter two themes are a result of “outside in” domain of inquiry. In particular, the tasks they perform in the context of the broader system as change agents and how the system might influence their activities as a collective expression of the needed
development of the system. These latter two themes tell the story of the “perfecting” patient. The patient who engages with contradictions and rigidity in the system, who creates a dialogue on topics that cannot be solved with our current know-how, and who helps bring adaptive change.

In the following sections I will discuss each theme.

6.1 THEME ONE: ADULT DEVELOPMENT

From encountering the disease, and taking the patient advocate role, individuals are exposed to a continuum of optimal inner conflict that increases their capacity to hold contradictions and take personal authority independent from external expectations.

After the diagnosis of the disease, individuals went through a series of development phases. For all participants, the disease diagnosis brought immense uncertainty to their lives. The uncertainties included death that could be imminent or much closer than they ever imagined. There was a substantial loss of quality of life, for example, due to not being able to move, talk, and not knowing whether or not they will regain these functions ever again in their lives. Others had gone through long-term treatment that took a toll on the body which also offered similar uncertainties in relation to whether or how they can continue to take care of their children, go to work, be a partner, and generally be part of society. I will explore this in three ways. The first is taking an existentialist stance (Yalom & Yalom, 1998), the second is through the lens of psychosocial development (Erikson, 1985) and the third is mental development in adulthood (Kegan & Lahey, 2009).

6.1.1 Confronting Mortality

Firstly, existentialist psychologists argue that death is lurking beneath the surface at all times, and as we grow up, we develop defences against death through denial. Yalom (1998) states that “learning to live well is to learn to die well; and conversely, learning to die well is to learn to live well” (p. 185). In his work with terminally ill cancer patients he witnessed patients reporting startling shifts and inner changes that can be characterized in
no other way than personal growth (Yalom & Yalom, 1998). All the participants in my research reported that they went through a fundamental learning experience that resulted in personal growth: as a consequence of the diagnosis, they learned to die well and live well simultaneously. As one participant put it, “I felt that with the diagnosis [of cancer]… it was kind of like a big warning to make sure that I appreciate my life more.” She talked about how she re-evaluated her relationships, her work, and the roles she was taking in her life as a mother, partner, employee, and she made changes in all these areas over time. Another participant talked about how she had become more compassionate, more than before. Another said of her diagnosis that “it’s been transformational in a good way. I don’t regret having got what I’ve got, I think it’s made me a better person.” All the participants experienced substantial personal growth over a relatively short time, for example soon after initiation of their treatment, regaining a level of mobility, or coming to terms with loss. It also gradually pulled them towards taking the advocacy role.

I propose that facing mortality through their experience of the disease, ultimately shifted the participants to a more “authentic” and free existence that was critical in taking the patient advocacy role.

6.1.2 Developing Strengths: from Hope to Wisdom

Secondly, the radical helplessness and dependency on others brought on by the disease represented regression to Erikson’s first stage of psychosocial development (Erikson, 1985). It is as if they regressed to become “babies” again, and then promptly progressed through all stages of development, except that they didn’t take a lifetime to go through the stages, and that they “time-travelled” to their past, as well as to their future to “older ages” and resolved the psychosocial crises associated with each stage. As they progressed through the stages they developed the strengths associated with that developmental stage. For example, radical helplessness confronted them with the psychosocial crisis of trust vs mistrust. Could they trust the doctors, nurses and other caregivers for stability, for bringing certainty? They learned about, and understood their treatment options, how they can get it, and implications of each of them. They evaluated how their choice would match their purpose and values in life. Successful resolution of this crisis meant that they
could integrate hope as a strength into their lives which then equipped them to give hope to others in the patient advocacy role. Table 1 includes their key focus and how each stage is associated with the extent they stepped into the role:

**Table 1: Psychosocial Development from Disease Diagnosis to Becoming a Patient advocate adopted from Erikson (Erikson, 1985)**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Psychosocial Crisis</th>
<th>Basic Strength</th>
<th>Key Focus</th>
<th>Taking Patient Advocate Role*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Trust vs. Mistrust</td>
<td>Hope</td>
<td>Disease diagnosis and deciding on the treatment plan</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Autonomy vs. Shame</td>
<td>Will</td>
<td>Taking control of the treatment decision</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Initiative vs. Guilt</td>
<td>Purpose</td>
<td>Reaching out to other patients to gather info</td>
<td>+</td>
</tr>
<tr>
<td>4.</td>
<td>Industry vs. Inferiority</td>
<td>Competency</td>
<td>Sharing their experience</td>
<td>++</td>
</tr>
<tr>
<td>5.</td>
<td>Identity vs. Role Confusion</td>
<td>Fidelity</td>
<td>Separation of patient identity and patient advocate role</td>
<td>+++</td>
</tr>
<tr>
<td>6.</td>
<td>Intimacy vs. Isolation</td>
<td>Love</td>
<td>Committing to make it better for other patients &amp; families</td>
<td>++++</td>
</tr>
<tr>
<td>7.</td>
<td>Generativity vs. Stagnation</td>
<td>Care</td>
<td>Organizing other patients to make a difference for others</td>
<td>+++++</td>
</tr>
<tr>
<td>8.</td>
<td>Ego Integrity vs. Despair</td>
<td>Wisdom</td>
<td>Accomplishments that make a difference, and facing death without fear</td>
<td>++</td>
</tr>
</tbody>
</table>

* My subjective assessment regarding the degree the participants stepped in to take patient advocate role.

The table illustrates the individuals’ fast pace development from regression to stage 1 with the disease diagnosis, and how they expanded their reach in the role and evolved it as they progressed to further stages of development. There is no time line associated with their pace of development, other than to note that it did not take a whole life time.

I propose that the individuals sufficiently resolved conflicts and developed necessary basic strengths from hope, will, purpose, competency, fidelity, love, care, and wisdom that equipped them for progression in the role.
6.1.3 **Personal authority and Mental Development**

Thirdly, the participants demonstrated increased mental complexity as they experienced the disease in their lives, and as they took the patient advocacy role. Participants shared many anecdotes about having a thick skin, thinking for themselves, not worrying what others think of them, reflecting on why previously they allowed others to undermine them, and how they did not have confidence before. Multiple times they indicated that they could not just receive their treatment, get over the losses and continue with their lives. There was something else for them to do for which they needed to take responsibility. They all reported that they started living their lives not based on others’ expectations but based on their own compass. In all cases, they aim to make it better for others: others could be diagnosed earlier, get access to [new/different] treatments, learn to question and make their own decisions, receive support when they feel lonely and lost, be treated as a human and not as a category. In Kegan and Mahey (2009)’s terms, the individuals taking patient advocate role demonstrate greater mind complexity as if they “are getting behind the wheel in order to drive” (self-authorised mind) as opposed to “getting themselves included in the car so they can be driven” (socialized mind) (p. 19). As patients, once they dealt with the impact of their disease with some success, and started expressing the voice of the patients, the advocacy role offered them the context for the next developmental step. They could tolerate many contradictions and conflicting views.

They experienced a life changing disease, and despite that they had an amazing life beyond what they could have imagined. They welcome a fact-driven rational health system, and at the same time utilize their intuition and emotions to decide what is best for themselves and to assist other individuals in the same position. They advocate for policies and guidelines to ensure global access to treatments, as well as personalisation of healthcare and the freedom for patients to choose. They expect medical professionals to ‘know’ so that they can diagnose, treat and care for patients, and they are OK to see that these experts also ‘don’t know’ (and use the internet as a resource just like them as one participant explained). In fact, the role of “patient advocate” itself integrates contradictions: helplessness of a patient and the power of an advocate. They balance hope
(success stories) with reality (happy endings are not going to be for everyone). The ability to hold these contradictions gives a hint about self-transforming mind complexity (Kegan & Lahey, 2009, p. 19). The participants’ development towards a self-transforming mind was facilitated by conditions that were common for all the participants. They all experienced what is called an “optimal inner conflict” (Kegan & Lahey, 2009, p. 54).

The stories of every participant revealed the components of optimal inner conflict that supported them in their inside out transformation. First, they all experienced persistent personal problems and frustrations with their diagnosis, treatment or care. Something went wrong for them. Secondly, it pushed them to the limits of their way of knowing. They were no medical experts, they had to make life and death choices. Life, as they knew it, had changed irreversibly. Old ways of knowing could not possibly help them in this new setting. Thirdly, they cared about making it better for others who will confront similar challenges in the future. And fourthly they digested the shock of the change in their lives and distanced themselves sufficiently from their disease to change themselves and the system. Instead of using the patient advocacy role as a reparation to digest the changes in their lives, all patient advocates had allowed time after diagnosis before they decided to step into a patient advocacy role. In fact, one participant stated that she had no energy for two years to set up the charitable organization that she had been considering, even though she knew that is what she would eventually do. For her, those two years were about coming to terms with the life changing outcome of losing her partner. It was only then that she was ready to pursue taking on the patient advocate role.

I propose that the patient advocates were able to step into the role after going through “accelerated” personal development following diagnosis of disease that continued when they were in the role.

6.1.4 Critical Evaluation of Theme one: human development

Analysis showed a connection between development of individuals and how it influenced how they took the patient advocate role. The further they advanced in their personal development, the more they committed to the role and the broader influence they had.
This research didn’t assess how each psychosocial development stage or mental complexity was integrated in each individual’s life prior to the disease diagnosis. Since there was no “baseline” assessment, influence of individuals’ development until disease diagnosis remains unexplored. This could provide another dimension to the results.

The research did not formally assess mental complexity of the patient advocate participants, although their descriptions provide reasonable indicators of increasing mental complexity. Did they step into the patient advocate role because they already had mental capacity for it or did the disease and the role provided them with the means to develop as adults? This question remains unanswered in this research.

6.2 THEME TWO: IDENTITY AND ROLE

The values of individuals act as a driver to step into the patient advocate role, and they demonstrate the ability to self-care by setting suitable boundaries between their [patient] identity and the role.

6.2.1 Personal Life-time Values

The participants all reported they were surprised and not surprised seeing themselves living this new fulfilling life. Surprise was about how good their lives turned out to be despite the life changing disease they encountered. They could tolerate ambivalence about having to embrace an undesirable disruptive disease to have fulfilment in their lives as a patient advocate. Values such as equality, taking responsibility, standing up for what is right, working hard and believing in yourself featured in their descriptions of their lived experiences. Every participant stated that their values guided them in their lives and previous roles. One participant, referencing his teenage years, said that he grew up in a community which required fighting for civil rights and that this is no different to being a patient advocate. Another highlighted that if she sees something is not right, she cannot walk away and instead do something about it so others won’t be harmed.

I propose that the activation of their long-term values in the context of the disease experience act as a driver for the individuals to step into the role as a patient advocate.
6.2.2  **Patient Identity and Advocacy Role Integration**

Participants reported that their patient identity is considered as a prerequisite to take on the role because being a patient gives them credibility. One participant posed the question: “How can people be patient advocates when they don't have any direct experience of what they're advocating for?” In the exploratory calls, those who were not patients or their relatives/carers also indicated their limitations in advocating for patients. This rigidity is worth exploring. Take an environmental advocate, or animal’s right advocate. Do they all have direct experience of or are implicated from the issues they are advocating for? One of the exploratory group members states multiple times: “We are all patients!” It is as if she wants her colleagues to face that they can be or have been patients instead of externalising patients to be “out there”.

Being ill is an undesirable state for humans that creates anxiety. No one wants to be a patient or experience disease. In order to cope with this anxiety, we externalise patients. That means only those unfortunate ones who cannot deny having the lived experience of a patient are “allowed” to step into the patient advocacy role. They get the task of speaking about what others are not authorised to say. For the patient advocates, this means they need to do the work to integrate their patient (or patient’s relative) identity with the role. The image of the patient identity they convey is one that overcomes helplessness and at the same time one that is deeply connected with it without any denial. Through their own experience, they also convey hope for others. With their hero stories of facing mortality, become worthwhile voices to represent other patients.

The patient advocate role serves as a means to connect with helplessness without being overwhelmed by it and without overwhelming their audiences.

6.2.3  **Self-care in role**

Containing such polarised emotions carries significant risk for their wellbeing when they take the role. Both patient advocates themselves and the exploratory group indicated that burn-out is a common occurrence amongst patient advocates. Admittedly, there are some rational reasons for this. For example, they conduct advocacy work on a volunteer basis in addition to their daily commitments. They are mostly unpaid for this work that made
them question if they are valued at all. They are being asked to do too many things by, and for, many different people. It is hard to say “no” when one is there to help others and they feel they are able to do so. While these reasons make sense rationally, the impact of having to contain polarised emotions in the role that is also connected with a very difficult part of their lives poses far reaching risks. The analysis showed that participants developed elegant strategies to tackle these risks.

The main risk minimising strategy they tend to employ is, ironically, distancing themselves from other patients, especially as they advance in their advocacy role. As one participant put it, “I am not too much involved with too many patients that are newly diagnosed”. Another states that “sometimes she doesn’t want to be a patient” (so she takes a “break”). It is also telling that all participants talked about patients in third person as if they were separate from the patients. Another, being a dietician, brought her dietician identity that created a safe distance from being a patient and gave her more authority.

I propose that for the patient advocates to take on the role, they first transform their patient identity. When they take the role, they are no longer “the patient”, but instead they become a “person with a disease”. In other words, the disease becomes the object in order for them to take the role.

6.2.4 Critical Evaluation of Theme two

Approaching it from an inside out domain of inquiry, it is plausible that the self-protection strategies work for the patient advocates. Their personal development, as discussed in theme one, also provides the foundation for them to say “no”, or give them the resilience to cope with contradictions. This may be insufficient for all in the longer term because there are greater risks from outside in perspective. How they are perceived by the individuals they interact with and represent, how threatening they are to the experts and what they are really called upon to do, are all factors that may impact the durability of their resilience. It is, therefore, important to consider the influences from outside in domain as discussed in the subsequent two themes.
6.3 THEME THREE: RISING AS A CHANGE AGENT

As a change agent, they engage with both the emotional and the technical aspects of the health system to enable adaptive change.

6.3.1 Appealing to the head, heart and guts

When first diagnosed with the disease, besides facing mortality, redefining their future trajectories and dealing with the emotions relating to these, the participants actively engaged with the scientific facts relating to their disease. They read scientific papers proposing differing opinions to make their choices. Further in time, in the role, they continued to follow scientific progress relating to the disease. They were able to engage their heads, their rationality, to make their own analytical assessments of choices available to them, and also to help other patients understand choices open to them. This was initially a way to regain power over their situation which deepened as they step into the role. Some of the available training programmes targeting patient advocates who are patients/relatives themselves (The European Patients’ Academy on Therapeutic Innovation (EUPATI)) introduce the complex technical aspects so that they can be effective in their role. These include information about medicines development, regulations and health technology assessments.

One participant elegantly describes how her choice not to take the standard treatment indeed was a plausible scientific option. In discussing her choice to go against the scientific norms, she quotes evidence from multiple studies to explain the rationality of her choice. However, she doesn’t stop there. She also tunes to her intuition as she describes how she “knew” the standard treatment was not for her. She couples this with statements about patients having the right to be empowered to take decisions for themselves and also her anger about how she had to stand strong to negotiate with the medical profession about her choice as she was going against the norms.

Another participant conveyed herself as a bridge between the patients and the medical staff as well as the pharmaceutical industry. One of the participants highlights the responsibility of patient advocates to spread accurate information. Another participant, an engineer and a “rare disease” patient, says “they asked me to speak for patients because I
understand the facts, so I can speak their language, and explain them to others”. He then goes on about explaining how disappointing it is to have delays in accessing treatment which could result in patients dying, because they do not fit into existing categories of diseases. Another says “Rather than just accepting and grieving, for me it was more about moving forward, empowerment, giving the tools that we need to face the situation.” A third one indicates he is doing what he does to help people embrace change.

I propose that, as change agents, the patient advocates demonstrate the ability to engage with the heads, hearts and guts simultaneously.

6.3.2 Emotional Containment

In their role, they integrate the emotions of the patients they represent with the rational and technical side of the rigid system they confront. It is not only the patients’ emotions they contain. Those who lean to facts cannot free themselves from emotions either. As one participant puts it “[medical profession] talk about educating about telling [the patients] what this drug is for, how to take them. But there is a lot more. And for me, there's something that is a lot more important which is helping [patients] believe in themselves, and helping them understand that they lead their life. So, they should have the power, without giving it to someone else, like a doctor, or like a pharma company or a family member. It's about us as patients to decide.” Unfortunately helping patients believe in themselves, that they lead their life are not a priority for the medical profession. If you asked any medical staff, they would not own it as their responsibility in their job although they would agree on its importance. Letting down the patients – who are humans like themselves- is a likely source of disappointment that may be subject to suppression by the members of the medical profession, institutions and companies.

Heifetz (2009) distinguishes technical challenges from adaptive challenges. “While technical challenges may be very complex, and critically important, they have known solutions that can be implemented by current know-how. They can be resolved through the organization’s current structures, procedures and ways of doing things. Adaptive challenges can only be addressed through people’s priorities, beliefs, habits and loyalties” (p. 19).
As change agents, the patient advocates surface much deeper questions that requires reconsidering the priorities, beliefs, habits and loyalties in the broader system. These highlight some adaptive challenges. For example, how are the patients viewed by themselves and by others? What powers do they hold? How are they treated as a whole human, a human that is mortal? How can health systems be designed to be patient-centred?

I propose that patient advocates demonstrate negative capability engaging with the emotional aspects as well as the technical aspects. They contain emotions projected from both patients and non-patients which places the patient advocates to succeed in engaging all parties for a dialogue about the adaptive change regarding empowerment of patients.

6.3.3 Critical Evaluation of Theme three

Although patient empowerment featured in this research, there are many other adaptive changes that the patient advocates are associated with, in particular as a result of the advancements in science and technology. How can decisions be made based on impact at large scale be balanced with its impact on individual? How can patients have access to drugs that are approved by the regulators but not reimbursed by healthcare providers due to their high cost? How can artificial intelligence can be utilized in healthcare? How does the current specialization in medicine need to be adapted? What adaptations are needed for personalised healthcare to materialise? These questions all feature adaptive challenges that the patient advocates relate to and each could be a topic of a research project.

Health systems operate within the boundaries of countries so each country may experience different adaptive challenge influenced by their culture. Take the leading scale of the culture map that puts different countries in a scale between egalitarian and hierarchical (Meyer, 2014). One may expect that patient empowerment would be demanded by patients and enabled by non-patients more in egalitarian cultures than in hierarchical cultures, hence would feature differently in priority in their respective health systems. The research participants were mainly from countries that are mapped towards egalitarian in the scale. The adaptive challenge for a health system in a hierarchical culture likely will be different than patient empowerment.
6.4 THEME FOUR: HEALTH SYSTEM DEVELOPMENT

In their role, patient advocates serve the function to help the development of the health system by engaging with the anxieties triggered as a result of the tension between scientific rationality and social aspects.

6.4.1 Science and Emotions as Tension

In the research, it became evident that it was not just the participants who stepped into the role. They were also invited by different parties in the system. The transition from perfect patient to perfecting patient started when patient advocates were asked to share their experience, or give their opinions for decision-making. “I didn’t plan to become a patient advocate. I was invited to speak because I can talk and others understand.” one participant says. Another provides a detailed account of how she was asked to share her experience with the top neurologists of her country at a national scientific conference that lead to her being invited to other conferences. The more she talked the better she became at it, and the better she became at it the more she was asked to speak. For all the seven participants, they get asked more and more to share their experiences, and opinions so gradually patient advocacy started taking majority of their time. Eventually patient advocacy had become a full time endeavour for four of the seven participants in this research. Practicalities indeed played a part for their choice, such as physical limitations of how much they could work as they live with the disease or demanding treatment schedules. They then let go of their past career paths that no longer matched their developed selves. Likely there is more to this. It is, therefore, worthwhile to explore what other tasks were being asked of them unconsciously by the parties in the system. Let’s start with how exploratory group members viewed patient advocates.

Some exploratory group members renamed patient advocates as “professional patient” or “expert patient”. It is indeed an established concept. Cordier (2014) defines the experiential and academic skills of expert patients concluding that “Empathic and skilful expert patients are evidently necessary to the future of the healthcare system” (p. 856). The phrase “expert” mirrors the health system’s norms: in order to have a voice you need to be an expert so the patients also need to be “decorated” with expert title to be heard in
the system. Expertise in this context refers to both academic and experiential skills. One may substitute this with multiple pairs that patient advocates embody:

<table>
<thead>
<tr>
<th>Technical</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic skills + Experiential Skills</td>
<td></td>
</tr>
<tr>
<td>Disease + Illness</td>
<td></td>
</tr>
<tr>
<td>Rational + Irrational (on the surface)</td>
<td></td>
</tr>
</tbody>
</table>

Patient advocates, through the integration of these pairs, make it safe for the parties in the system who are intrinsically driven by rationality to experience the social and irrational aspects. In an influential study of how scientific facts are constructed, Latour (1979) discusses how scientists aim to remove social factors once a fact is established that gives solidity and credibility to their scientific work (p. 24). This tendency in the conduct of science naturally gives more weight to the technical aspects. Consequently, it becomes difficult to reach a balance between the social (e.g. establishing relationships that empower patients) and technical systems (e.g. creating policies, regulations and scientific guidelines to treat diseases). Social and technical systems are interdependent, “their core interface consists of the relations between a nonhuman system and a human system” (Trist, 1981, p. 11). There is also the layer of the psychosocial system that is concerned with “the cultural values and norms, the power and the position of the interest groups, or the social structure itself” (Trist, 1981, p. 12). Addressing adaptive challenges in healthcare requires engaging with both the psychosocial and sociotechnical system simultaneously. It means working with the social structures within this system and this generates anxiety in a fact driven system that intrinsically supresses the social aspects.

I suggest that, as the parties in the health system construct scientific facts relating to disease, having to engage with the social aspects relating to illness creates anxiety for which patient advocates are tasked to help unconsciously. They are safe bodies to contain the emotions, while relating to the rational tasks as expert patients.
6.4.2 Complexity of the system and categorization as a simplifier

In interacting with non-patients, patient advocates show empathy for the medical profession, and are aware of the complexity of research, drug development, and policy. One participant expressed that “a lot of the doctors kind of hit a wall themselves where they didn't know what to do.” Another participant states that one thing she realised that, “for example my [doctor] started her studies, there were maybe like, 12 types of this disease. Now there are more than 200. She cannot be specialised in everything. Things are moving so fast.” The system traditionally deals with complexity through categorisation which is currently being challenged. As one participant says “if you don’t fit into a category, they don't know what to do with you”. According to Menzies (1960) “efficient performance of the primary task and the types of technology available to do this sets limits to possible organizations” (p. 101). The picture that is shaping hints that as a result of these limits, the old ways of knowing is no longer working and it is difficult to face it. This leads to socially structured defence mechanisms, for example by promoting a new role, called patient advocates, to project the anxiety of not being good enough.

Many of the participants also added that they aim to generate dialogue. One participant said “I don't like to fight, and win and lose when it comes to [disease]…you need advocacy in order to talk to each other”. Another stated “You start to have these growing fights between the science and what a patient wants and needs, to build a bridge, if it's a fight I don't want to be part of the fight.” Patient advocates aim to humanise a system that categorises people and sets protocols to deal consistently with diseases (that people have). The inability to materialise patient-centricity and empowerment creates an anxiety also in the broader system.

I propose that the patient advocacy role emerged as a social defence due to the inability of scientific practice to deal with both the social and technical aspects of rapidly evolving health system.

6.4.3 Critical Evaluation of Theme four

The potential social defence identified in theme four relates to a deeply rooted aspect in the practice of science that shakes the norms of science. It is an adaptive change. It would
be a fantasy to expect it can be solely resolved by patient advocates. It is important to acknowledge many other valuable efforts by non-patients (as evidenced by the research on this topic) that aim to bring patient-centricity and empowerment systematically in the practice of medicine, policy making and drug research, development and access.

7. CONCLUSION, IMPLICATIONS AND FUTURE RESEARCH

The lived experiences of patient advocates who participated in this research revealed a journey involving intense and rapid personal growth, identity transition, and role evolution. The disruption of disease on their lives is followed by personal growth that eventually led to fulfilment in many aspect of their lives. Their identities transitioned from: a healthy person, then to a patient, and then to a person with a disease. Simultaneously, their role evolved from helpless patient to “perfect” patient and then to “perfecting” person with experience of the disease. The tasks they engaged with also evolved from understanding, coming to terms with and regaining control over their own situation, followed by helping other patients to understand, come to terms with and regain control over theirs, and then to creating system changes that enhanced the experience of other patients and also of non-patients. The personal growth and the transition in their identities were prerequisite to them taking a change agent role and the subsequent evolution of the role. The tasks these change agents engaged with is an expression of changes that the broader health system and involved parties are wishing to bring. In this sense, the emergence of the role can be considered a social defence.

The use of the terms “perfect” and “perfecting” patient must not be understood as a divergence from “good enough”. Every person I spoke to in this research was explicit about their limitations, including their mortality. My choice of the term was influenced by the source of their motivation. It appeared that their not-good-enough experience motivated them to take the role. In this sense the terms “perfect” or “perfecting” correlates with not-good-enough experiences of participants. It is also linked with the task of healthcare. In a nutshell, the primary task of healthcare is about delaying death or making it more tolerable. Settling on a “good-enough” approach to this topic is a slippery slope, so I chose to use the words “perfect” and “perfecting” instead.
The anxiety of being in the “can’t-be-good-enough” system triggers social defences. The research gave hints that the role might have emerged as a social defence as a product of anxieties of patients and non-patients. Social defences can serve as distraction. For example, the parties in the system, be it members of medical profession, healthcare institutions, companies, policy-making bodies, may develop dependency to patient advocates in their activities. Current debate and efforts of organizations and institutions to define exactly when, how and on what questions to obtain input from patient advocates maybe considered as an off-task activity. It may be considered as addressing an adaptive challenge through mainly technical means because it is using existing structures, procedures and ways of doing things to solve problems and challenges (Heifetz, Linsky, & Grashow, 2009b).

The overall adaptive change we face is about the development of healthcare system to care for the humans as a whole and in the face of rapid developments in science and technology. It requires shifts in people’s priorities, beliefs, habits and loyalties that goes beyond the current know-how. While it is necessary to implement technical changes to integrate patient input, it is equally important to consider what the emergence of this role means and what task it is serving. What does it say about the health system? What changes in priorities, beliefs, and habits are needed? Is this role an escape from doing the adaptive work, or is it a catalyst for the adaptive work to develop the health system? In the case of the Alzheimer’s drug, the patients and the expert neurologists had opposing views on the meaning of the scientific data for the patients, representing the polarity between social and technical aspects that is hard to integrate in scientific endeavour. It unearthed the need to reconsider priorities, beliefs and habits for all parties to work together.

As a foundational study I explored all disease types. There was a common pattern in their lived experiences of how they take the role. In line with the research objectives, the interviews were not designed to surface differences based on disease experience. There may even be different adaptive challenges for different disease types that influences the primary task of patient advocates in different cultures that future research can explore. For example, how might the health systems and the culture in different countries impact
the patient advocate role? What is the influence of a genetic disease that has been passed on from previous generations and could be passed onto future generations? How is the changing nature of cancer from a terminal disease to a potentially chronic disease is experienced? What is the lived experience of having a rare disease that is not understood? What about neurodegenerative diseases like Alzheimer’s, or Parkinson’s where disease onset is slow? These are likely questions for further research.

In this research I have not focused on the tangible tasks of patient advocates, or the outcomes they achieve. The importance of the role is not because of the tangible tasks they perform but because of a collective task they share. In this sense, the exploratory group members equally play an important role towards this collective task. They all perform the task of keeping the system in the productive zone of disequilibrium (Heifetz, Linsky, & Grashow, 2009b) for the adaptive change to emerge. The work they do is important not only for patients, but for all of us.

Insights from this research are applicable to broader contexts. Firstly, individuals' development and integration of their values and purpose are necessary for them to be enablers of any social change. Zooming out to accompanying social defences would support identifying tasks that make difficult but lasting change possible. Secondly, it can provide important insights to see beyond the tangible tasks of roles. In organizations, as new roles are created, it is valuable to consider the social purpose of these new roles. This awareness would allow asking questions that one doesn’t know how to answer and would lead to more successful development of institutions.
8. **APPENDIX: THE QUESTIONNAIRE**

**Intro** (confidentiality, permission to record etc)

**Can you tell me what made you become an advocate for XXX patients?** (aims to talk about the story of his/her illness, information about the past, disease/emotions/encounters with medical institutions or actors/memory, etc.)

**Can you please draw yourself as a patient advocate?** Who do you believe can ideally advocate for patients? (creates safe reflection space, mutual exploration of the drawing to explore the symbols and the associative unconscious, informs the rest of the questions)

**In what ways do you think, your way of experiencing the disease contributes to you to become an advocate?** (explores the link between disease and the role)

**What was the main feeling behind your wish to be an advocate?** (explores what they might be trying to resolve)

**In what ways the advocate status is making you mad, sad and glad? Who are those people that make you mad, sad and glad?** (explores their interactions with other roles/systems and their relationships with them)

**What factors do you feel uneasy regarding your advocate position?** How do the disease, or the country you live in or the people you interact with effect your activities? Other factors? (explores role and task links, influence of the disease, culture, people on their tasks)

**Can you share life events that comes to your mind at different stages of your life, for example from childhood, as a teenager or as a young adult that might have contributed to you taking this role?** Any memory from your childhood about disease? Any memory regarding hospital/doctors? Regarding a hard time you or your family had, in which you/your family gave a struggle to achieve sth.? (Probes their life history and identity potentially before the disease that may have led to them stepping up to become pt advocate) (etc). (Q5,6,7 probes about identity transition as a result of the disease, and
identity transition to the advocate role, how they dealt with these transitions, what they might be trying to resolve, eg grief)

**Role:**

**In your view how did the patient advocate role start?** (explores the perceived need for the role, and collects hints about their ambitions in taking the role)

**If we were to rename the “patient advocate” role, what would we call it? What comes to your mind?** (aims to bring dreams, fantasies, fears and disappointments connecting with the associative unconscious)

**Who especially needs patient advocates? For what do they need them?** (explores the interface with the broader system, potential basic assumption groups?)

**If there was a job description for patient advocates, what would be the top 3 responsibilities?** (what do they actually do? Are there frustrations? Any contradictions with what they said before?)

**In actual fact, you do fulfil an unwritten job description. Who has written the script of the role?** (note to self: test this question and rephrase to explore authority, who they believe they are serving)

**What else comes to your mind that is important for you? Were you surprised about anything that came up in this conversation?**
9. **BIBLIOGRAPHY**


Menzies, I. E. P. (1960). *A case-study in the functioning of social systems as a defence against anxiety*


