Patient inclusion, shared decision making and individualized health care
- between ideals and reality -

Patient inclusion, share decision-making and individualized healthcare interventions yields higher patient satisfaction, better treatment outcomes and utilisation of resources in the healthcare system. The principals are particularly important when managing long-term conditions such as chronic pain.They also have broad public and political support.

Nonetheless, there are many barriers in order to realize ideals so the approach becomes an integrated part of healthcare and potentials are realized.

Meeting at Center for Patient Inclusion

Recently, a meeting with a round table discussion was held with professor Victor Montori by the Center for Patient Inclusion in the capital region of Denmark

A small group of professional caregivers and managing directors from various fields of healthcare participated. I partook as patient representative from FAKS The Association of chronic Pain Afflicted to both listen and contribute to the discussion. The event was titled "*Patient inclusion and more humanity in health care",* and it addressed the advantages and barriers for patient inclusion and share decision-making.

Even though Professor Victor Montori primarily has his experiences from the American culture and healthcare system, many of the issues and mechanisms presented was relevant to discuss as well in a European and Danish context.

Center for patient inclusion

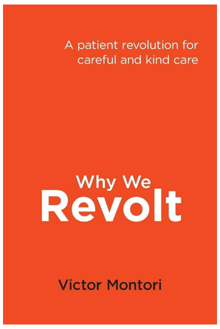
Center for patient inclusion - CPI in the capital of Denmark supports clinical practice with advice about patient inclusion. CPI also produce evaluations, user surveys and nationwide surveys of patient experiences -LUP.

Professor Victor Montori and The Patient Revolution

Professor Victor Montori is an international doctor and researcher with a special interest in patient and public involvement, clinical shared decision-making and minimally disruptive care. Victor works at The Knowledge and Evaluation Research Unit at Mayo Clinic in Minnesota USA. His research in healthcare services is frequently cited.

Concerning the potentials of improving patient satisfaction, outcomes and utilisation of resource Victor states: "It should not be as much about involving patients in decisions and in care but rather for clinician to involve themselves into the lived experience of patients, being curious and genuinely interested in the co-creating plans of care that fit. Otherwise, involvement alone would leave the patients to advocate and articulate their needs, which is easier for someone who is not that sick but very hard for someone who is alone, scared, and uninformed"

Victor Montori has written the book “Why We Revolt - A patient revolution for careful and kind care”. The book is available in English, Spanish and Italian but Victor wishes to have the book translated to other languages, so, please feel free to reach out to him.


A patient revolution for careful and kind care

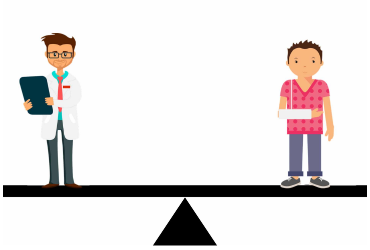
Why We Revolt

Victor Montori

Victor Montori is also one of the driving forces behind a global nonprofit organization - The patient revolution. This is a community of health care professionals, clinicians, patients and laypeople . The goal is to transform healthcare from a paternalistic relationship with an instrumental approach into a more even relationship and humanistic approach.

THE PATIENT REVOLUTION

Potential benefits of patient inclusion, shared decision making and individualized treatment



There are strong incentives for involving patients and individualizing healthcare, even though the documentation of the benefits are not always entirely clear. Healthcare professionals are experts in diseases and diagnoses. However, we as patients and our close family members and other informal caregivers are experts in our own lives with disease and functional disabilities. It is important to include these unique and personal experiences into healthcare.

> "Healthcare professionals are experts in diseases and diagnoses, we as patients are experts in our own lives”

Patient inclusion and SDM may also contribute to improve equality in healthcare. On average, certain demographic characteristics are associated with patients that are more vulnerable and resource-limited and subjected to poorer health and patient safety. If this group of people is met with the right understanding, communication and patience, they will likely be more able to navigate the healthcare system better and improve their self-care and health.

> “Patient inclusion and shared decision-making are particularly important when managing long-term chronic conditions and diseases”

Fostering patient inclusion, shared decision making and individualized healthcare are particularly important when managing long-term conditions such as chronic pain that cannot be cured and treated alone by a biomedical approach. As patients, we cannot simply remain passive and expect good outcomes from medicine and time restricted interventions alone. Therefore, it is essential to improve patients’ health efficacy and facilitate better self-management. Furthermore, better patient-doctor interaction and communication may be able to adjust some of the unconstructive consumer perception of the healthcare system. In addition, adjust the mismatch between patients’ expectations and the actual treatment options and outcomes. Patient inclusion and individualized health care also increase the likelihood of adhering to medical advice. Partly, this relates to interventions targeting people rather than surrogate outcomes such as biomarkers and picture screening findings that does not necessarily translate into value for the patients

The principles and methods of patient inclusion in individualized healthcare can also provide valuable insights into the backstory and bio-psycho-social elements that often interact in complex ways and influence symptoms, functionality and well-being. These elements include values and beliefs, bodily functions, social participation and not least the environment in which we live. The point of encounter in healthcare, however, is detached from the patient's natural settings. Therefore, it is essential for the clinician to gain a better understanding of life circumstances and to rise up to bird's eye view to understand the interwoven complexity of elements. This can be done e.g by means of patient reported outcomes - PRO that can focus the dialogue between clinicians and patients.

For the sake of clarity and remembrance, I have listed below some of the potential benefits of patient inclusion, shared decision-making and individualized healthcare:

- Strengthening patients' hope and confidence in their own abilities, decision-making and self-care.
- Providing patients with a broader bio-psycho-social understanding of the causes of symptoms and illness.
- Providing healthcare professionals with a more emotional understanding and a treatment approach that goes beyond a biomedical perspective and standard diagnostic categories.
- Reducing concerns and preventing unnecessary hospitalizations, screenings and treatments.
- Improving patient satisfaction with treatment by fostering more realistic expectations through a better understanding of the benefits and risks of treatment.
- Ensuring that the treatment goals pursued agrees with the patients' values and preferences.
- Ensuring continuity and coordination in treatment trajectories. When role distribution is unclear and there is a risk of falling between two chairs, patients are the first to notice and can sound the alarm.
- Ensuring greater health equity by reducing some of the unintended discrimination that happens against vulnerable and resource-limited patients and families.
- Increasing patients' adherence to medical recommendations and the patients' sense of ownership over treatment and health.
- Improving the work environment for healthcare professionals by reducing misunderstandings and conflicts and inspiring collaboration.

Barriers for patient inclusion and individualized healthcare

As the depicted in the previous chapter, there is a lot of good arguments for patient inclusion, shared decision making and individualized treatment. Nevertheless, this does not come without challenges.

Indeed Denmark has some of the best welfare in the world with a tax funded free healthcare system and a high level of equality and trust. Nevertheless, organizational structures and bureaucracy, inherently constitute a barrier to the implementation and sustainability of patient inclusion and shared decision making. The formal division of authorities and structures of power operate in silos.This hampers interdisciplinary and intersectional cooperation and innovation which is essential for an integrated and effective effort.

Too rigid adherence to clinical guidelines can also harm shared decision making and individualization. Guidelines are put into the world to help ensure evidence-based, effective treatments and prevent unnecessary or even harmful ones. However, applying them without individual consideration can result in pointless or detrimental interventions because patients do not need them or cannot implement them in their lives.

> "Evidently, it is more difficult to change the force of habit under stress and prioritize patient inclusion"

Visions and policies for patient inclusion and individualized healthcare are also hindered by the general lack of finances and personnel in the healthcare sector. With the demographic development of increasingly more elderly people and chronic diseases, healthcare personnel are already overwhelmed by tasks. In addition, they often need to spend time documenting their every step, distracting them from fully listening and understanding the patients. The ability to be fully present, empathy and authenticity are vital for interactions between humans and how conversations unfold. Evidently, it is more difficult to prioritize patient inclusion and change the force of habit under stress, but it also poses an imminent risk of a vicious cycle. As patients perceive stressed healthcare professionals as more emotional distant and dismissive they are likely to respond with uncommunicativeness or even hostility. This reaction places health care professionals in an even more invidious working environment which further exacerbates stress and burnout. As a result patient inclusion suffers even more.

Lack of proper education and training can also be one of the reasons why ideals and policies are not sufficiently realized. Therefore, it is crucial with training in tailoring both the content and the manner of conversation and interventions to the needs and abilities of the patients.

> "Evidence is not clear that the additional efforts and expenses are in keeping with the benefits of patient inclusion and shared decision-making"

Evidence is not clear that the additional efforts and expenses are in keeping with the benefits of patient inclusion and shared decision-making. The varying scientific documentation depends not only on outcomes but also on methodology, decision-support tools, clinical context and the patient groups being assessed. Fundamentally, the strongest evidence exists for patient perceived effects, while documentation for clinical and long-term effects is lacking.

Cost benefit analysis by healthcare management and administrators may therefore raise skepticism and reluctance. It is crucial as well for healthcare professionals in clinical practice to perceive their efforts as meaningful for them to put in an effort.

Nevertheless, it is likely that efforts and investments of patient inclusion will only show long-term results and also in settings and sectors other than those in which they were originally made. This requires incentive structures and systems that supports long-term goals.

Lastly, it is important to notice that Danish guidelines and policies for patient inclusions and shared decision are non-binding. Many efforts and projects are carried out locally by passionate healthcare professionals. As might be expected, this results in fairly large discrepancies between regions, hospitals, departments and clinics.

I have listed some of the mentioned barriers along with additional ones for the sake of clarity and remembrance:

- Lack of lessons on patient inclusion, shared decision-making and individualized treatment in healthcare curricula as well as ongoing training of healthcare professionals.
- Inadequate physical environment in terms of lack of privacy and quiet spaces can make it difficult to engage in intimate conversations and remember important information.
- Time pressure and constraints of human resources often lead to the de-prioritization of patient inclusion.
- High risk of stress and burnout among healthcare professionals as time pressure and rushed conversations leave them feeling unable to fulfill what they were trained for.
- Misunderstandings are prone to happen as both patients and healthcare professionals make assumptions about each other’s desires and motivations, which may not be accurate. Genuine interest, as well as the time and mental capacity for active listening and dialogue, are essential for aligning understanding and expectations.
- Patients’ situations change.Thus, patient inclusion and individualization requires a continual revision and modification .
- Ambiguous evidence shows that the extra efforts and costs spend on patient inclusion are justified by resulting benefits.
- Limited health literacy among patients and relatives can be a barrier to understanding and to engage in a meaningful way with their physician.
- Some patients are too stressed, depressed or simply do not have the capacity to express their needs and exert influence on their treatment. They require assistance in articulating values and needs through insightful questioning and support to carry them out.
- Some patients do not expect to be heard and consulted in their role as patients. As a result, they may misinterpret healthcare professionals’ questions and interest as uncertainty or a lack of knowledge.
- Conflicting wishes between patients and their relatives can put healthcare professionals in difficult situations.
- Shared decision making, and tailoring treatments to the individual often require healthcare professionals to have certain experience, confidence, and the mental capacity to deviate from standard guidelines, and protocols.

Momentum for patient inclusion and individualized healthcare but no easy solutions

Patient inclusion and individualized healthcare entail many opinions. Nevertheless, I am convinced that most people can support the fundamental principles behind. As mentioned, the arguments for are not only ethical such as reducing inequality across sociodemographic groups. Likely, the principles also contribute to a better patient-doctor relationships as well as patient experiences and clinical outcomes.

"The two-fold demographic pressure of increasing life expectancy and number of chronic diseases, necessitates greater self-management"

Furthermore, the two-fold demographic pressure of increasing life expectancy and number of chronic diseases, necessitates greater self-management and empowerment to reduce the strain on the healthcare system.

Consequently, there are many strong arguments for patient inclusion and individualized healthcare. As a matter of fact, the principles and policies have been a part of our healthcare system in Denmark for many years. Initially, patients' legal rights have been formally strengthened with informed consent along with more autonomy and influence on our own treatment and a less paternalistic doctor-patient relationship. Subsequently, patients and patient organizations have also gained influence on the healthcare system participating in decision-making on a higher organizational level.

Despite everything, there is still a lack of systematic patient inclusion and individualization across different clinical settings and situations. In addition, activities and actions that at first sight appear to be patient inclusion may turn out to be merely symbolic gestures and tokenism.

Simplified these limitations comes down to structural condition-based reasons, educational and personal ones. In addition, patient inclusion likely suffers from the absence of a unison definition of the concept.

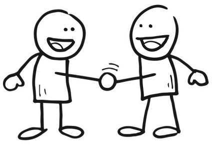
In conclusion good intentions and recommendations alone are inconsequential without the necessary framework conditions and professional expertise to carry them out. Consequently, there is a need to prioritize and allocate financial- and human resources to free up time and capacity for better patient inclusion and shared decision-making.

"It is essential that patient inclusion and individualized healthcare is regarded as a core service within the healthcare system"

It is essential that patient inclusion, shared decision-making and individualized healthcare are regarded as a core services within the healthcare system. Let alone that healthcare personal are willing to put in the time and effort to reflect and improve their skills in this field. Therefore, education on the subjects should be integrated into continuing professional training of healthcare personal and made a mandatory part of basic healthcare education.

An unfulfilled potential also lingers concerning health literacy among patients, relatives and public. Knowledge and reasoning should be regarded as a key asset when it comes to self management, making rational decisions about treatment and working effectively together patients and clinicians. Initiatives to improve this can include civic education, patient material, online resources and conversations with health care professionals regarding prevention, treatment, rehabilitation and help to navigate the healthcare system. The key lies in plain talking in a clear and comprehensible way.

To advance the field of patient involvement and individualized healthcare systematic efforts are needed to implement, monitor and share knowledge on national, regional and local levels. We all share a responsibility to maintain the positive momentum by working together as policymakers, health authorities, managing directors, healthcare professionals and patient organizations.



Bibliography and inspiration

There are various guidelines, principles, methods, and tools that can inspire and help operationalize patient involvement, shared decision-making and individualized treatment. Both in clinical settings, on an organizational level as well as in healthcare research. Below, you can find references to different organizations, articles and studies.

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About Lars Bye Moeller

Lars has has been living with chronic pain for over 25 years. 15 years he has been working voluntarily as a patient representative in the patient organization FAKS The Danish Association of chronic pain afflicted.

Together with his wife, Sanne Lydø, he runs a local department for people living with chronic pain with activities and support for self-help.

As a patient representative, Lars has participated in many pain research projects and work with national health authorities.
He spends much time advancing his knowledge in evidence-based medicine and research.

Health politically Lars works with various stakeholders to increase legislators's awareness of pain and change policies. This advocacy work is done both on a national as well as an international level via the multi-stakeholder platform SIP Societal Impact of Pain led by European Pain Federation -EFIC.
and Pain Alliance Europe – PAE