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PATIENTS AT THE CENTER OF THE HEALTH SYSTEM OR *PARACHUTE STUDY* PARADOX WE WANT TO PRESENT?

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In recent years, the emphasis on patient-centered care has gained significant traction within the global health community. This editorial seeks to highlight the critical importance of positioning patients at the core of healthcare systems, drawing on the paradox presented by the *Parachute Study* and other relevant literature. Our aim is to advocate for a healthcare paradigm that prioritizes patient needs, preferences, and outcomes over bureaucratic and economic constraints.

THE HEALTHCARE LANDSCAPE IN CEE COUNTRIES

Central and Eastern Europe(CEE) encompasses a diverse range of countries, each with its unique history, economic conditions, and healthcare systems. Despite these differences, common issues persist: healthcare systems in CEE countries face numerous challenges that can hinder the implementation of patient-centered care.

The challenges include economic constraints, political instability, and varying levels of healthcare infrastructure and technology. In many CEE countries, healthcare funding is limited, leading to shortages of medical staff, outdated equipment, insufficient facilities and disparities in healthcare access and quality. These limitations can result in long wait times for patients, inconsistent care quality, challenge in access to new drugs, clinical trials and significant out-of-pocket expenses, reduced access to specialized palliative care, and a general decline in the quality of healthcare services.

The fragmentation of services further complicates the patient journey, leading to discontinuities in care, lack of coordinated support and

Photo from Star Trek – an American science fiction media

out-of-pocket expenses for medications, treatments, and even basic healthcare services that can be prohibitively high. Disparities in healthcare access create significant challenges for patients in rural areas, who may need to travel long distances to access necessary medical services. This not only adds to the physical and financial burden on patients but also exacerbates health inequalities within the population.

Are we aware that all these componenets lead to worse health outcomes and increased long-term healthcare costs?

THE IMPERATIVE OF PATIENT-CENTERED CARE

The concept of patient-centered care is not new, but its implementation remains inconsistent across different healthcare systems, particularly in Central and Eastern Europe (CEE).

According to the Israel Journal of Health Policy Research – IJHPR (2021), patient-centered care is defined as care that respects and responds to individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions. This approach has been shown to improve health outcomes, patient satisfaction, and the overall efficiency of healthcare delivery.

Despite its proven benefits, many healthcare systems continue to struggle with integrating patient-centered care into practice. In the heart of Central and Eastern Europe (CEE), patients often find themselves in the epicenter of a healthcare mayham. It is a region where the Hippocratic Oath tangles with bureaucratic red tape, and the quest for effective treatment frequently feels like a journey in Kafka›s novel.

At many meetings and conferences with my colleagues, patient advocates, we often discuss the economic challenges facing CEE healthcare systems, where financial constraints often impede the adoption of patient-centered practices. They argue that a shift towards such a model requires not only additional funding but also a reorientation of healthcare priorities to focus on patient outcomes rather than purely economic efficiency.

As someone who has had the misfortune of being a *frequent flyer* in this system, but also a *patient advocate* for 16 years, let me paint a picture of what it's like being a patient carer in the middle of the healthcare system here.

THE WAITING SAGA – MASTERING THE ART OF PATIENCE

First, there's the waiting. In CEE countries, patients wait to get an appointment with a specialist, then for examination, diagnostics, surgery, and finally, if you get lucky to come so far, for the update of the reimbursement list, because not all new therapies are available in their healthcare systems.

Pamela Herd and Donald Moynihan, in *Health Care Administrative Burdens: Centering Patient Experiences*, highlight how excessive administrative burdens detract from patient care, advocating for streamlined processes to improve healthcare efficiency and responsiveness in the USA.

Additionally, a study on inequalities in access to healthcare in the EU by Rita Baeten, provides a detailed analysis of how the lack of healthcare professionals, healthcare services, and overall supply of healthcare, compounded by bureaucratic inefficiencies, negatively impacts healthcare systems.

In some cases, it appears that no matter where you live, excessive administrative burdens often take away time and resources that could otherwise be devoted to patient care. This can include lengthy waiting times, complex referral systems, and fragmented care coordination.

Ensuring that healthcare access is equitable requires addressing both administrative inefficiencies and shortages in healthcare resources. This can help bridge gaps in access and reduce disparities across different populations.

Streamlining processes and ensuring equitable access are key steps toward enhancing the effectiveness and responsiveness of healthcare systems to patient needs.

Putting all the patients who are waiting for services in one room creates a mini universe of society where each one of them shares a common enemy: time. Waiting becomes a bizarre game of endurance.

Do not forget: *The one who waits, time passes slowly*, especially when expecting to hear the most difficult diagnoses.

'Cancer?'

'No, thank you. I prefer waiting'

THE CONSULTATION CONUNDRUM – DOCTOR-PATIENT RELATION, THE ESSENCE OF PATIENT CENTERED CARE

Finally, the patient gets their appointment and is called by the healthcare provider. The doctor, burdened with too many patients and too little time, performs the delicate dance of an efficient but rushed consultation. The patient is expected to convey their complex medical history and symptoms in record time, often feeling like they are participating in a speed-dating event rather than a medical consultation.

Language barriers, outdated practices, and lack of resources lead to misunderstandings that could be straight out of a routine. Imagine a doctor prescribing a drug only available in a neighboring country, asking the patient to embark on a cross-border quest, akin to a medieval knight seeking the Holy Grail.

Patients often find themselves in the role of both detective and advocate, piecing together fragmented information to create a coherent treatment plan. Last decade has proven that as never before there are a huge efforts made by patient's groups and made a Patient Advocacy a highly value position that can deal and contribute with decision making processes.

Education, empowerment, and health literacy are crucial for patient advocates and can bring unique insights and practical wisdom that inform more holistic and effective care strategies. Incorporating these perspectives can bridge the gap between clinical evidence and real-world application.

'Any allergies?' the doctor asks, eyes already scanning the next patient's file.

'Just penicillin and bureaucracy', the patient quips, only to be met with a blank stare.

However, beneath the humor lies a serious call to action. And maybe, the most important: willingness for change. Patient-centered care is rooted in the principles of respect, compassion, and shared decision-making.

According to the Institute of Medicine (IOM), patient-centered care involves providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions.

This approach not only improves patient satisfaction but also enhances clinical outcomes by fostering better communication and collaboration between patients and healthcare providers.

BUREAUCRACY AND HEALTHCARE EFFICIENCY – THE POLITICAL WILL: MOVING BEYOND BUZZWORDS

The buzzword of the decade is *Patient-Centric Care*. Patients deserve timely, efficient care without the added stress of navigating a Kafkaesque maze. While we can chuckle at the paradoxes and ironies, we must also advocate for change.

The integration of modern practices, reduction of unnecessary bureaucracy, and prioritization of patient-centric care are essential steps toward a more humane system. Political will is crucial in driving the integration of modern practices, reducing unnecessary bureaucracy, and prioritizing patient-centric care.

A patient-centered approach necessitates that healthcare systems minimize bureaucratic hurdles and foster a culture of flexibility and responsiveness. This can be achieved by adopting policies that prioritize direct patient care activities and reduce unnecessary administrative tasks.

By doing so, healthcare providers can devote more time to understanding and addressing the unique needs of each patient.

EU MEMBERS VS. NON EU MEMBERS

The European Union (EU) has long been a beacon of progressive health standards and collaborative medical advancements. Membership in the EU offers numerous benefits that can significantly enhance a country's health system. This is particularly evident when comparing the progress of Croatia, an EU member since 2013, with North Macedonia, which remains outside the EU.

Croatia's integration into the EU has facilitated substantial improvements in its healthcare system. EU membership has provided Croatia with access to substantial funding through the European Structural and Investment Funds (ESIF). These funds have been crucial in modernizing healthcare infrastructure, improving the quality of medical facilities, and ensuring the availability of advanced medical technologies. Additionally, Croatia has benefited from the EU's commitment

to public health initiatives, including preventive care and disease management programs. The adoption of EU health policies and standards has also led to a more efficient and transparent healthcare system, ensuring better patient care and outcomes. Personalized centered care in Croatia has become a hallmark of these improvements, with significant strides in patient engagement and tailored treatment plans.

One of the most telling indicators of the disparity between EU and non-EU member states in terms of health services is the accessibility and quality of care. In contrast, North Macedonia, which has been a candidate for EU membership since 2005, still grapples with significant healthcare challenges. For instance, the reimbursement list for therapies in oncology and hematology has not been updated in over 15 years, leaving patients without access to new innovative drugs that could prolong or save lives. Meanwhile, in Croatia, nearly all new innovative therapies are available to patients within the public health insurance framework.

The alignment with EU health policies would enhance preventive measures, reduce health disparities, and improve public health outcomes in countries like North Macedonia. However, Croatia's experience also underscores a paradox within the EU healthcare system. Despite substantial investments and advancements, Croatia has the second-highest cancer mortality rate in the EU, 25% higher than the EU average. This is puzzling, considering Croatia spends more on cancer treatment than the EU average.

So, where did we go wrong?

The issue doesn't seem to be a lack of funding but rather how these resources are allocated and utilized. It raises critical questions about the effectiveness of healthcare strategies, the implementation of preventive measures, relocating resources, centralization and decentralization in various health services, the overall management of cancer treatment protocols and perhaps the societal and environmental factors contributing to health outcomes.

RURAL HEALTHCARE ACCESS AND DISPARITIES

It is important to know that the health culture, in one country very differs then other. So, their needs. As well as with the rural entities within one country.

Is this only a problem of the system or the society in general?

Efforts to reduce healthcare disparities should also have a focus on improving access to care in rural and underserved areas. Righi L (2022) in *General and vulnerable population's satisfaction with the healthcare system in urban and rural areas* explore the disparities in healthcare access in rural areas of Central Europe, emphasizing the need for equitable healthcare delivery. Rural populations often face significant barriers to accessing quality care, including limited healthcare infrastructure, workforce shortages, and geographical isolation.

These challenges underscore the importance of designing healthcare systems that are inclusive and capable of addressing the diverse needs of all patient populations.

One way to enhance patient-centered care is through the implementation of innovative solutions and health information technology (HIT) systems. Electronic health records (EHRs), telemedicine, mobile health units, and community-based healthcare initiatives can facilitate better communication between patients and healthcare providers, improve access to medical information, and enable more coordinated care, ensuring that all individuals receive timely and effective care regardless of their location.

These approaches can bridge the gap for rural between rural patients and healthcare services, ensuring that all individuals receive timely and effective care regardless of their location. But these technologies can also help reduce administrative burdens, allowing healthcare professionals to focus more on patient care within the health system in general.

THE *PARACHUTE STUDY* PARADOX

The *Parachute Study* by Smith (2003) provides a compelling analogy for understanding the limitations of evidence-based medicine when it comes to patient-centered care. The study humorously critiques the rigid application of evidence-based principles by pointing out that there is no randomized controlled trial (RCT) proving the efficacy of parachutes in preventing death from gravitational challenge (i.e., jumping out of an airplane). Yet, the benefit of parachutes is self-evident and does not require an RCT for validation.

This paradox highlights a critical issue in healthcare: the reliance on stringent evidence-based criteria can sometimes overlook the obvious needs and preferences of patients.

The punchline, of course, being that sometimes common sense must prevail over bureaucratic absurdities. In our healthcare saga, the *patient-centered care* claim shares a similar punchline – a noble ideal buried under layers of reality that are often farcical.

The insistence on paperwork and protocol, long waiting lists, and other real problems, modernly termed *challenges*, can sometimes override immediate patient needs, leading to a frustrating and sometimes dangerous delay in care.

In the context of patient-centered care, this means that healthcare providers must balance evidence-based guidelines with individual patient circumstances and preferences. The challenge is to ensure that the application of medical evidence enhances, rather than hinders, personalized patient care.

For patient advocates, the *Parachute Study* paradox serves as a call to action. It underscores the need for a more nuanced approach to evidence, one that values patient experiences and outcomes alongside rigorous scientific data. Patients often bring unique insights and practical wisdom that can inform more holistic and effective care strategies. Incorporating these perspectives can bridge the gap between clinical evidence and real-world application.

All known scenario: After all the lights of the conferences, meetings, and tribunes dim, and all the healthcare providers, experts, and *pre-election politicians with candy pink promises* and other relevant figures in healthcare policy-making, leave the room, the popular Patient-Centric paradigm resembles a tragicomedy if there is not a strategy to act for the change.

CONCLUSION: TOWARDS A PATIENT-CENTERED FUTURE

The journey towards a truly patient-centered healthcare system in Central and Eastern European (CEE) countries is ongoing. While significant progress has been made, substantial challenges remaining.

Transitioning to a patient-centered healthcare model is necessary goal, and not a one-day process. It is both a moral imperative and a pragmatic approach to improving health outcomes and patient satisfaction.

Addressing the economic, bureaucratic, and geographical barriers to patient-centered care requires a concerted effort from tripartite partnership and mutual cooperation: policymakers, healthcare providers and patient advocates.

The insights from the *Parachute Study* paradox remind us that while evidence-based medicine is crucial, it should not overshadow the practical and immediate needs of patients. Healthcare systems must strive to balance evidence with empathy, ensuring that patient preferences and values are at the forefront of clinical decision-making.

Placing patients at the center of the health system is not merely a theoretical ideal but a practical necessity. It requires a concerted effort to listen to and value patient voices, integrate their insights into clinical practice, and address the systemic barriers that hinder patient-centered care.

WILL THE PARACHUTE FINALLY OPEN?

Overall, Croatia is making significant strides towards implementing patient-centered cares but like many countries, it faces ongoing challenges that require continuous effort and adaptation.

By fostering a health culture that values patient input and prioritizes personalized care, we can create a more responsive and equitable healthcare system that truly places patients at its center. Only through collaborative efforts is it possible to create a healthcare environment where patients

are truly at the center of their care, leading to healthier, more satisfied populations and more resilient healthcare systems. In the end, we must remember that we are all patients.

'What's the most important thing I've done this year?'

'I survived.'

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KEYWORDS: *patient-centered care; parachute study paradox; healthcare systems; economic constraints; bureaucratic challenges; healthcare infrastructure; patient outcomes; access disparities; patient advocacy; efficiency improvement; political will; healthcare inequalities; collaboration*

Sažetak

PACIJENTI U SREDIŠTU ZDRAVSTVENOG SUSTAVA ILI PARADOKS *STUDIJE PADOBRANA (PARASHUTE STUDY)* KOJI ŽELIMO PREDSTAVITI?

B. Shrepfler

U posljednjih nekoliko godina naglasak na skrb usmjerenu prema pacijentu dobiva značajnu pozornost unutar globalne zdravstvene zajednice. Koncept skrbi usmjerene prema pacijentu postaje imperativ, posebno u zemljama Srednje i Istočne Europe (CEE), koje se suočavaju s brojnim izazovima uključujući ekonomska ograničenja, političku nestabilnost, različite razine zdravstvene infrastrukture i tehnologije.

Nedostatak financiranja dovodi do nedostatka medicinskog osoblja, zastarjele opreme i dugih lista čekanja za medicinske usluge, a i poteškoća u pristupu do nove inovativne terapije. Fragmentacija usluga dodatno komplicira put pacijenta, stvarajući diskontinuitet u skrbi i visoke troškove koji kompliciraju implementaciju ovog pristupa.

Ovaj članak koristi analogiju paradoksa "Parachute Study" kao slikovitu ilustraciju ograničenja stroge primjene medicinskih dokaza, sugerirajući da zdravstveni sustavi trebaju uravnotežiti znanost s očitim potrebama i željama pacijenata kako bi se postigli optimalni rezultati. Zahtjevi za skraćivanjem apsurdnih birokratskih prepreka i jačanjem političke volje za prioritiziranje potreba pacijenata naglašavaju se kao ključni koraci prema uspješnoj integraciji skrbi usmjerene prema pacijentu.

Autorica na suptilno satiričan način argumentira da zdravstveni sustavi trebaju uravnotežiti činjenice sa stvarnim potrebama i preferencijama pacijenata. Primjeri poput Hrvatske, koja je iskoristila EU fondove za modernizaciju infrastrukture i zdravstvenog sustava, pokazuju kako članstvo u EU može unaprijediti kvalitetu skrbi. Ali, izazovi poput dugih čekanja za specijalističke preglede i poteškoća u pristupu novim terapijama i tehnologijama, ističu potrebu za inkluzivnim pristupima koji mogu zadovoljiti različite potrebe pacijenata, uključujući i ruralne zajednice. Unatoč napretku, Hrvatska se

suočava s visokim stopama smrtnosti od raka, što ukazuje na potrebu za promjenama i učinkovitijeg upravljanja resursima kao i provedbe preventivnih mjera.

Skrb usmjerena prema pacijentu definira se kao skrb koja poštuje i odgovara na individualne želje, potrebe i vrijednosti pacijenata, osiguravajući da pacijentove vrijednosti vode sve kliničke odluke. Iako ovaj pristup pokazuje poboljšane zdravstvene ishode i zadovoljstvo pacijenata, njegova integracija u praksu zdravstveih sustava i dalje je izazovna za mnoge zdravstvene sustave, pa i one najrazvijenije.

Zaključno, autorica u članku poziva na tripartitno partnerstvo svih činilaca: donositelja zdravstvenih politika, pružatelja zdravstvenih usluga i zastupnika pacijenata (udruge pacijenata), kako bi zajedničkim naporima potsticali zdravstvenu kulturu kojoj je prioritet personalizirana skrb i na taj način prevladali sustavne prepreke i istinski smjestili pacijente u središte zdravstvenih sustava.

Na kraju, moramo zapamtiti da smo svi pacijenti.

KLJUČNE RIJEČI: *skrb usmjerena na pacijenta; paradoks studija padobrana; zdravstveni sustavi; ekonomska ograničenja; birokratski izazovi; zdravstvena infrastruktura; ishodi pacijenata; razlike u pristupu; zagovaranje pacijenata; poboljšanje učinkovitosti; zastupnik pacijenata; politička volja, nejednakosti u zdravstvu; suradnja*