CASE REPORT

Social considerations of inflammatory bowel disease in Southern Israel

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SUMMARY

Chronic diseases pose unique social challenges beyond traditional health considerations that require specific attention. In this report, we examine the case of a middle-aged woman with ulcerative colitis, living in Southern Israel. Trust between the patient and physician is shown to positively influence a variety of therapeutic outcomes and should be considered a fundamental component of successful care. In context of the military conflict between Israel and Gaza, the needs of patients with chronic diseases cannot be forgotten. The work environment is also identified as an area of particular concern, as a supportive work environment is essential in order to maintain satisfaction in the workplace and sustain a high quality of life. Out-of-pocket costs for medications are confirmed to be a significant barrier to adherence. Better understanding of patients' financial capabilities, along with affordable therapeutic interventions, will alleviate healthcare-related financial burdens and improve health outcomes.

BACKGROUND

Chronic diseases pose unique social challenges beyond traditional health considerations that require specific attention. In this report, we examine the case of a middle-aged woman with ulcerative colitis (UC), living in Southern Israel. Trust between the patient and physician is shown to positively influence a variety of therapeutic outcomes and should be considered a fundamental component of successful care. In context of the military conflict between Israel and Gaza, the needs of patients with chronic diseases cannot be forgotten. The work environment is also identified as an area of particular concern, as a supportive work environment is essential in order to maintain satisfaction in the workplace and sustain a high quality of life. Out-of-pocket costs for medications are confirmed to be a significant barrier to adherence. Better understanding of patients' financial capabilities, along with affordable therapeutic interventions, will alleviate healthcare-related financial burdens and improve health outcomes.

CASE PRESENTATION

The patient is a 52-year-old woman who was diagnosed with UC in 1999. She was born in Azerbaijan, Former Soviet Union (FSU). Married for 32 years, she has two children, a son and a daughter. She has an extended family in many different parts of the world. Her family is Jewish and immigrated with

a group of Russians to Israel in 1990. They originally settled in northern Israel, but in 1994 moved to Sderot, a city in southern Israel close to the Gaza Strip and have been living there comfortably ever since. Sderot absorbed a large number of Russian immigrants in the 1990s, and there is a sizeable Russian community in place. She speaks fluent Hebrew. The patient is a supervisor in a large Osem factory, which is a large food manufacturer and distributor in Israel. She enjoys her job and has been working there for 15 years. She was consistently healthy in the FSU and did not have any major medical concerns. In those years, their family had a 'big house' and was economically comfortable.

The patient's disease symptoms arose in 1999. She was diagnosed in 2006 with UC. UC is a chronic and relapsing inflammatory bowel disease (IBD) that produces bloody diarrhoea and severe abdominal pain.¹ Despite multiple consultations, no doctor was able to successfully diagnose her, treat her symptoms and help her manage her disease until her current gastroenterologist (henceforth called Dr E or her physician), who was successfully able to treat her disease and has remained her specialist since 2006. The patient has a very strong connection with Dr E, and she gives her physician full credit for improving her health and quality of life. She believes that no one else can help her and has full confidence in Dr E's medical skills. For her part, Dr E attributes these statements and feelings to the comprehensive care for the patient that she offers and to her availability. She makes a specific point in her clinical practice of spending more time with patients and making herself more easily accessible to patients with IBD at the beginning of their diagnoses. Medical appointments in Israel can be difficult to schedule, especially for specialists. While the average person in the south of the country might wait months to see a specialist,² Dr E tries to see her patients within a week of being informed they need her.

Israel's healthcare system has recently been comprehensively described by Clarfield and colleagues.³ All legal residents of Israel receive universal coverage of health services through a legally defined 'basket' of medications, medical services and technologies that are determined annually by law to be covered by the state. These health services are administered under the responsibility of the government and are provided by four not-for-profit health plan service providers. There are also low out-of-pocket copayments, mainly for medications, visits to specialist physicians and

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some diagnostic tests such as sophisticated imaging studies. Each health plan also offers supplementary insurance that citizens can add on top of their initial coverage.

The gastrointestinal community clinic is very accessible to the patient, who lives only a 7-min bus ride away. The clinic is operated by Clalit, the largest of the four health plan services in Israel³ and is now in a new, updated facility, which is significantly improved from the previous building. The patient sees the clinic as a much more pleasant location to receive healthcare. She considers herself a 'strong woman' and always attends her appointments alone. She also has a very effective family support system and speaks about her family frequently. She reports that her employer is very understanding and flexible in regards to her needs related to her condition. She has a flexible work schedule and can take sick days whenever necessary. Despite her UC, the patient is overweight and developed type 2 diabetes as a side effect of steroid treatments for UC. As a result of the side effects of her disease, she became non-compliant with her medications. Subsequently, her disease flared up and symptoms worsened. After a significant amount of time, her physician was finally able to successfully treat her symptoms. She is currently taking multiple drugs, including infliximab. Some of her drugs are not fully covered by national health insurance, and she is required to pay for some medications out of pocket. Infliximab is the most expensive of these drugs, and while it is partially subsidised by Clalit, it costs her 800 NIS (approximately \$200) for every infusion she receives. These costs are significant to her and her family.

In the summer of 2014, her disease flared up again during a military conflict between Israel and Gaza. Her current major medical concerns are diarrhoea and a frequent need to defecate. She is convinced that the aetiology of her disease is connected to the stress of living in Israel. She repeatedly stated that she had no significant health concerns back in the FSU. Since 2000, as the Second Intifada began and the Israel-Palestinian conflict entered a period of heightened intensity and violence, the city of Sderot has been under sporadic and sometimes heavy rocket fire from militant organisations in Gaza. In this context, the patient has 15 s to seek shelter on hearing a warning siren. The patient has undergone multiple stressful and traumatic experiences; she has a vivid, tragic memory from 2004, when she witnessed a rocket landing close to her house and killing two children. The sirens, explosions and the stress of living under a constant threat have caused psychological distress. The patient emphasises the constant stress of living under rocket fire. She has particularly strong memories of trying to get her children and infant grandchildren into bomb shelters with very little warning and of being forced to constantly think about the presence of shelters vis-a-vis the locations of people she cares about. The rockets make it difficult to sleep and exercise outside. She becomes frightened and stressed, and when sirens sound she often has the urge to defecate. Rocket-induced-stress causes her to have frequent bowel movements, and shelters do not have restrooms available. These symptoms, closely related to stress and anxiety, may be more consistent with irritable bowel syndrome than IBD, but irrespectively they cause even more complications, stress and anxiety.

GLOBAL HEALTH PROBLEM LIST

- ▶ Having a strong physician-patient relationship and trust in one's doctor
- ▶ Chronic health and military conflict
- ▶ UC and challenges in the work environment
- ▶ Out-of-pocket cost of medications

GLOBAL HEALTH PROBLEM ANALYSIS

Patient rapport

The patient was quick to express her adoration, trust and appreciation for her physician. She explained in depth how she considered Dr E to be the most amazing physician, and in the patient's view, Dr E is the only person she could imagine successfully treating her health issues. She believes that her physician cares about her and is fully invested in improving her health and quality of life. In contrast, she did not feel trust or confidence in her previous physicians, and for years, the doctors she visited failed to treat her symptoms and manage her disease. While evidence shows that the majority of patients trust physicians to act in their best interest,⁴ the literature is filled with concerns over the undermining of trust in this relationship.

Focus on the physician-patient relationship has increased dramatically over the past 20 years.⁵ While trust is a defining element in any relationship, it is understood to be particularly fundamental in doctor-patient interactions. Trust in one's physician encompasses an overarching set of expectations that the patient has from the doctor and the healthcare system. It can be understood as the patient's willingness to embrace a vulnerable situation, with the belief that the physician will care for the patient's interests and will do what is best for the patient.⁶ These expectations include making the appropriate diagnosis, choosing the correct treatment, acting ethically, having genuine interest in the patient's well being, confidentiality, availability and transparent disclosure of information.⁷ Increased trust has been repeatedly shown to positively influence a variety of health outcomes. Patients with a high degree of trust in their healthcare providers have improved chronic disease management.⁸⁻⁹ This benefit is especially relevant to IBDs such as UC, which is a chronic, relapsing disease with significant impact on quality of life.¹⁰ Multiple studies have demonstrated that increased trust correlates positively with self-reported symptom and health improvement.⁸⁻¹¹ Increased trust in one's physician has also been directly associated with fewer physical limitations in patients with cancer.¹² Repeated studies across multiple chronic diseases, including IBD, diabetes and hypertension, have shown that a healthy patient-physician relationship improves patient adherence to treatment.⁵⁻¹⁰⁻¹³ Self-reported non-adherence to medical therapy among patients with IBD ranges from 40% to 60%.¹⁰⁻¹⁴ This must be an area of significant concern to physicians, as adherence to medical therapy directly decreases the risk of disease recurrence, particularly in UC.¹⁰ Better trust also increases the likelihood that patients will reveal sensitive information to their physician, which may be necessary for proper medical care.¹⁵ Similarly, trust has been demonstrated to correlate with patient acceptance of therapeutic recommendations, satisfaction with those recommendations, satisfaction with medical care, decreased patient disenrollment and increased use of preventative services.¹³⁻¹⁶⁻¹⁸

Thus, it seems obvious that efforts should be made to build trust in the patient-provider relationship to enhance patient outcomes. Three core components of patient-physician trust have been identified in the literature: interpersonal and technical competence, moral comportment and vigilance.¹⁹ These aspects could serve as targets for interventions aimed at modifying the behaviours of healthcare providers, so that trust can be improved. Many broad mechanisms for achieving increased trust have been proposed. Some have suggested that medical education increasingly integrate psychosocial aspects of interaction and training into medical curriculums as well as placing an increased emphasis on teaching medical students to offer

effective emotional and informational support.²⁰ Other research has suggested that communication training of licensed physicians, integrative health coaching, physician disclosure of financial incentives and the ability to spend more time with patients may increase patients' trust in their primary care providers.^{21–23} The experiences of our patient suggest that demonstrating genuine care for the patient's health, increasing physician availability and making physician appointments more easily accessible might increase patients' trust in their physician and improve health outcomes and patient satisfaction.

Armed conflict

For the past 20 years, the patient has lived in Sderot, a city in southern Israel located 1 km from the Gaza Strip. This city has been under intermittent and sometimes heavy rocket fire from rockets launched by militant organisations in Gaza.²⁴ Rockets have claimed the lives of nine residents of Sderot.²⁵ Over 90% of residents in this city have experienced an explosion from a rocket at some point, whether in a neighbourhood, school, business or other residential setting.²⁶ There is a sophisticated radar system or 'red alert alarm' in southern Israel to alert citizens to possible incoming rockets. Once the siren sounds, Sderot residents have 15 s to seek shelter.

It would also be remiss to examine the impact of armed conflict on health in southern Israel without briefly acknowledging the profound impacts armed conflict has had on the neighbouring Palestinian population in Gaza. The Gaza Strip is a narrow area located on the Eastern coast of the Mediterranean Sea, bordering southern Israel on the north and east. The aftermath of the war between Israel and Gaza Strip in 2014 serves as a tragic example to illustrate the horrific consequences of conflict on health. Using a most basic analysis, approximately 2200 Palestinians were killed during the 50-day conflict, 501 of whom were children.²⁷ A further 11 100 Palestinians are estimated to have been wounded and 25% of the population were internally displaced.²⁸ Furthermore, damage to critical healthcare infrastructure, along with an unreliable supply of clean water and inconsistent electricity, dramatically impaired treatment for both acute and chronic conditions, both during and following the surge in armed conflict.^{29–31} Additionally, heightened periods of armed conflict invariably lead to the restriction of travel across the border with Israel, limiting medical assistance, referrals and replenishment of medical supplies.³² Finally, as a result of conflict, the flow of patients who cross the borders from the Gaza Strip to receive care in Israeli hospitals decreased. In essence, armed conflict has made healthcare unsustainable for the suffering Palestinian population.

Despite the considerable health consequences of armed conflict, this field has not received the same degree of attention from public health research and policy as many other causes of death and disability.³² From a social science viewpoint, political scientists have long studied the causes of war but have focused primarily on the decisions to go to war and not on the health consequences of those decisions. Civilian populations can be affected either as collateral damage or as deliberate targets. However, negative health consequences are also realised from the decrease in resource allocation towards healthcare, the displacement of populations and the breakdown or interruption of health, social services and civil society during conflict. Resource allocation involves the distribution of resources among competing programs.³³ Conflict reduces the pool of available resources for expenditures on the healthcare system. Understandably, defence, national security and military sectors compete for

financial resources that in the absence of conflict would be spent on healthcare.³⁴ War also reduces rates of productive economic growth, thus decreasing the tax revenues that governments can use to finance healthcare.³⁵ A weak economy also decreases the resources that companies can devote to employee health as well as straining the resources that individuals can use to pay out-of-pocket health expenses.³⁶

Similarly, states involved in violent conflict are often unable to meet the public health needs of their societies as their healthcare infrastructure may be damaged. Essential facilities may be damaged or destroyed, such as clinics, hospitals, laboratories and healthcare centres as well as water treatment and electrical systems. Repairing infrastructure also leads to decreased healthcare spending, as funds must now be appropriated to fix what was previously functioning. Missile attacks in southern Israel have a significant effect on the healthcare system and on appropriate facilities. This has resulted in the development of both a missile proof hospital in Ashdod and a missile-protected blood bank in central Israel.^{37–39} Many facilities have been damaged, and a significant number of clinics are still not properly physically protected against rocket attacks. In Gaza, during the 2014 escalation, 17 of the 32 hospitals in the Strip suffered damage, and 6 were forced to close or relocate. Furthermore, over half of the community clinics in Gaza were damaged, ranging in extent from broken windows to complete destruction.⁴⁰ At the Sderot Gastrointestinal Community Clinic, where the patient in this case report receives healthcare, there is no protection on the top floor of the building. As such, this space must remain unused during military escalations. During these incidences, healthcare appointments take place in bomb shelters, which are limited in number. Physicians and patients must rush into reinforced rooms when the siren sounds, reducing the standard of care given within these facilities and causing psychological stress to both patients and caregivers.

Armed conflict between Israel and Gaza also limits patient access to care. Our patient reports being afraid to go outside for fear of being trapped when the siren goes off with no secure place to seek shelter. These concerns prevent people from leaving their homes and seeking necessary healthcare. Dr E reports that paradoxically, despite increased need, the clinic was much quieter than usual during Operation Protective Edge. Similarly, healthcare professionals are affected by the threat of rockets and terror attacks, whether consciously or not. Multiple studies have revealed physicians and nurses to be at moderately increased risk for PTSD and depression after exposure to war stress.^{41–43} Healthcare professionals may also resist fulfilling their duties or attending the clinic out of fear and anxiety. Dr E confirmed this from her experiences, as she explained that many healthcare workers were either uncomfortable or not willing to attend the clinic she practised in during the 2014 war between Israel and Gaza.

Healthcare accessibility during armed conflict is an issue with multiple dimensions. Much of the health research has focused on PTSD, but many experience the anxiety of rocket attacks through bodily symptoms.⁴⁴ And while many healthy people develop anxiety-related symptoms and psychosomatic stress in response to missile and security threats, those with chronic diseases are a particularly vulnerable population that requires special attention during armed conflict. This is especially true for patients suffering from IBD, for which stress and anxiety are significant risk factors for disease onset, relapse and higher disease activity.⁴⁵ Many studies have drawn connections between stress, disease relapse and symptom exacerbation of UC.^{45–48} From a qualitative perspective based on clinical experience,

most of Dr E's patients with IBD experienced disease flares over the summer during the latest war with Gaza. Our patient is convinced that the aetiology of her disease is connected to the stress of living in southern Israel. This connection makes sense to her because her symptoms arose near the beginning of the Second Intifada in the early 2000s, a period of heightened tensions in this conflict.

A significant area of concern for patients with IBDs is frequent bowel movements.⁴⁹ The anxiety induced in our patient from rocket sirens immediately worsens disease symptoms and induces the urgent need to defecate. Thus, care and resources in times of conflict should be directed towards those suffering from trauma or post-traumatic stress also towards those with chronic diseases and unique needs. In conflict prone areas, policy makers and public health officials need to pay specific attention to maintaining safe healthcare facilities and ensuring that high standards of care and access to care for citizens and healthcare professionals is sustained, even in times of conflict.

Challenges in the work environment

Estimates of IBD prevalence range from 6.3 cases per 100 000 persons in Asia and the Middle East to 24 per 100 000 in USA.⁵⁰ As many as 1.4 million people in USA and 2.2 million in Europe suffer from Crohn's disease (CD) or UC.⁵¹ It is most commonly diagnosed in people between 15 and 35 years of age,⁵¹ which corresponds with a time when people are likely to be concerned about employment prospects and conditions. Most people with IBD are still able to work successfully, as unemployment statistics and labour force participation rates have been found to be similar in patients with IBD compared with controls.⁵² However, patients with IBD have reported significant disease-related anxiety in the workforce. One survey found that a quarter of employees with IBD reported concern about being discriminated against in the workplace and one-third described fear of losing their jobs because of IBD.⁵³

Employment surveys conducted with patients with IBD have revealed that one of the most significant fears for such people is having an 'accident' at work. UC is characterised by diarrhoea and patients suffer from urgent needs to defecate. The urgency and frequency of needing a toilet directly affects patients' lives. Dr E reports that some of her patients admit to skipping meals and eating less in order to avoid using restroom facilities outside of their homes. Patients also report significant concern about embarrassing smells and sounds.⁵³ Many workplace toilets lack sufficient ventilation and/or have cubicles that are open above and below partitions, which do not offer sufficient privacy. Having access to properly designed toilet facilities close to their place of work is extremely important. Patients' anxiety and quality of life would improve if there were separate, individual restroom facilities or if there were specific toilets for disabled persons.⁵³ Due to frequency and urgency, patients may also find it difficult to take public transport and may prefer to drive to their place of work. Most people feel uncomfortable talking about bowel movements, especially to employers and thus awareness and a supportive social environment at work are crucial. Wyke *et al* conducted a 6-year study of working patients with IBD and found that most patients (80%) felt that their coworkers were 'generally helpful'.⁵⁴

Having the flexibility to access the toilet at work whenever the patient requires is essential. Allowing time off for medical appointments and treatments is also critical. A large study showed that patients with IBD had more sick days because of IBD symptoms.⁵⁵ Newer treatments for UC require extended

periods at hospitals or healthcare centres. Following operations for IBD, patients take a median of 6 months off from work.⁵⁵

A supportive work environment such as the patient of this case report describes is essential for patients with IBD to maintain satisfaction and performance in the workplace. Many adjustments needed are often inexpensive and cause little disruption. The medical community, employers and coworkers need to be more aware of the daily effects of IBD on employment and the workplace environment.

Medication cost

In chronic diseases, the cost of treatment is often a significant factor affecting multidimensional aspects of patient care. Out-of-pocket expenses have been identified as a sizeable barrier to treatment adherence. In a more patient-centred model of medicine, it is increasingly important to consider the out-of-pocket costs to the patient and keep cost and affordability in mind, in addition to outcomes and side effects. The patient of this case report lists the cost of her treatments as a significant financial burden. For many patients, this cost becomes more than a burden, and given the financial pressure, it becomes an unrealistic treatment option.

Cost as a modifiable barrier to adherence has been well described in the literature.^{56–61} There is extensive documentation that costs of medication and treatment are directly associated with poor adherence. In 2013, one study in America found that nearly half of patients reported skipping treatments or not appropriately filling cancer-related prescriptions due to high costs.⁶² Another study found that 1 in 10 Canadians who receive a prescription report cost-related non-adherence.⁶³ Costs associated with UC are among the highest of the many chronic diseases. Infliximab and adalimumab, two monoclonal antibody treatments for UC, are recognised as the most expensive therapeutic choices. A 100 mg phial of infliximab costs in the range of \$2000–\$4000 for the average adult (wholesale price).⁶⁴ Annual medical expenses of insured patients with IBD in USA, where medical costs and prices are particularly high, have been estimated at \$18 963 for patients with CD and \$15 020 for UC.⁶⁵ Total annual costs for patients outside USA are somewhat lower, but are still approximated at \$5000.⁶⁵ The patient of this case reports pays 800 NIS (\$200 approximately) out of pocket per infliximab infusion and states that while she continues to receive the significant health benefits from this treatment, it still constitutes a financial burden for her and her family. Dr E qualitatively reports instances in which she has recommended Infliximab to patients with UC, but they were unable to pay and thus did not receive the medication. In response, Dr E prescribes alternative medications such as steroids, which can be less effective and carry more side effects.⁶⁶ In UC as well as in other chronic diseases, non-adherence to treatment is associated with disease flares, exacerbation of symptoms and poor health outcomes.¹⁰ This has a significant effect on patient quality of life, rate of hospitalisation and healthcare utilisation.^{67–69} Medication-related costs can lead to high levels of psychological distress for patients and their families, as patients come to fear the costs of their next hospital visit because they cannot afford more medical debt. Patients in USA have reported coping with medical costs by reducing spending on leisure activities, decreasing spending on food and clothing and using savings to pay for treatment-related expenses.⁷⁰

Non-adherence is a significant societal burden and results in exorbitant healthcare costs. One study calculated that in USA, the annual cost to the healthcare system caused by non-adherence

approached 300 billion US dollars.^{71 72} In addition to relieving patients of financial burdens, increased treatment adherence as a result of less expensive medication is cost-effective and will alleviate some of the pressures on the healthcare system. In accordance with the current push towards cost-effective treatments, lowering the costs of UC management and increasing patient compliance is crucial. A recent study showed that patients with IBD taking infliximab who were 80% adherent or greater were associated with lower total healthcare costs.⁷³ This supports a societal incentive to identify factors affecting adherence and implement policies that promote it. In order to improve patient adherence, physicians must be prepared and willing to discuss costs with patients. Discussing affordability, especially in health systems where drug costs are not fully covered, should be a regular part of the patient interview. Both the American Society of Clinical Oncology and the Institute of Medicine have recently listed patient–physician discussions of the cost of cancer care as a critical component of high-quality, patient-oriented care.⁷⁰ Research shows that patients and physicians express desires to discuss costs, but these discussions rarely take place.^{74–76} The responsibility for improving adherence has generally been placed on the patient and the healthcare provider. Physicians are often unfamiliar with the specific costs of medications and procedures, and they feel inadequately equipped to supply financial information about treatments.⁷⁷ However, if non-adherence is to be effectively addressed and improved, other components of healthcare and pharmaceutical industries must also take responsibility. Decreasing the costs of medications and procedures that have been shown to be effective must become a priority. Given the reductions in health outcomes, psychological distress and quality of life connected to cost-related non-adherence, cost-associated topics should be addressed in medical training alongside the specific pharmacology. The costs of adherence promotion

far outweigh the cost savings to the entire system after improved adherence. With cheaper medications, less out-of-pocket costs and greater physician awareness of drug prices and patient capabilities, the patient adherence, health outcomes and quality of life will improve and national expenditures on chronic conditions will decrease.

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Learning points

- Increased trust in one's physician has been shown to be a critical factor influencing a variety of important therapeutic processes that lead to better health outcomes and patient satisfaction.
- Medical education should integrate knowledge about psychosocial aspects of doctor–patient interaction to provide effective emotional and informational support, with the goal of establishing and maintaining patient trust.
- Care and resources in times of conflict should be directed towards those suffering from trauma or post-traumatic stress and also towards those with chronic diseases, whose unique health needs must be taken into consideration.
- Allowing time off for medical reasons, offering flexible working hours, unlimited toilet breaks and creating a comfortable restroom environment are all significant factors that would improve quality of life and workplace satisfaction of patients with inflammatory bowel disease (IBD). The medical community needs to be more aware of the daily effects of IBD on employment and the workplace environment.
- Increased efforts should be made to decrease the costs of medications, reduce out-of-pocket health-related expenses and increase physician awareness of drug prices and patients' financial capabilities to increase adherence to treatment, alleviate healthcare-related financial burdens and improve health outcomes.

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