CASE REPORT

Lifestyle changes of a family caring for a 25-year-old quadriplegic man after delayed spinal cord infarction

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SUMMARY

Worldwide, 110–190 million people over the age of 15 years are estimated to live with severe disability—a physical state of being defined by the WHO as “the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness.” Modes and qualities of disability care undoubtedly vary globally, dependent on income, health infrastructure and culture. Quadriplegia has a unique set of emotional and physical challenges that demand a great deal from care regimens and health systems. This case study examines a specific—and successful—configuration of quadriplegic care in a Druze village in the Golan and looks to the economic, geographic and sociocultural aspects of care.

CASE PRESENTATION

In 2008, a 20-year-old previously healthy man in a small mountainous Druze village in the Golan presented with non-traumatic C2 spinal infarction resulting in quadriplegia. The cause of infarction was never identified as anything besides a seemingly minor motor vehicle accident 8 months prior.

The patient spent 2 months at a tertiary level hospital and 1 month at a rehabilitation centre in a large city 2 h from his family's village. The family successfully advocated for their son's early release into home care against the will of the rehabilitation doctors. They remodelled their house in preparation for his return, making the bottom floor wheelchair accessible and building an enclosed breezeway to isolate the bottom floor from cold weather and microbes. They outfitted the living room of their house with a hospital bed, a suctioning machine hanging beside the bed, a percutaneous endoscopic gastrostomy tube, a ventilator and other necessary supplies for the patient. The family has backups of each machine as well as a generator in case of electrical outage. They also adapted their car to accommodate a wheelchair and a ventilator.

The family, since the infarction, has changed considerably in terms of time management, priority, caring roles and perspective. The parents, in addition to the local physician who trained them, are the primary care givers for their son and manage the ventilator, perform suction, physiotherapy, feeding, washing and hygiene. The patient's father, who travelled extensively around the world on work before his son's injury, quit his job to care full-time for his son. He now runs most of the family's daily errands outside of the house and is rarely away from home for more than a few hours. In the 6 years since his son's diagnosis, he has left Israel only once on a trip to the USA to meet with quadriplegic specialists.

Perhaps, though, it is his mother whose life has changed most in her son's care, sleeping by his bedside every night for the past 6 years, during which time she has not left their village once. Her everyday tasks around the house are nearly exclusively oriented towards the medical and social care of her son. Both parents acknowledge that they no longer give equal attention to all their children as they once did, but the entire family understands and accepts this.

The daily care regime is extensive. Approximately every 2 h, the patient is physically turned by both parents to prevent pressure sores and to ensure comfort. Bed linen is changed daily, a two-person process that takes at least 1 h. The patient's tracheostomy tube is suctioned according to need, on average twice an hour. Jevity food formula is administered via percutaneous endoscopic gastrostomy (PEG) tube during the day and the patient usually eats a solid food meal at night time. His mother also bathes the patient daily.

A rural village in the Golan, where the family lives, has dramatically changed since the introduction of electricity 50 years ago and the establishment of a large multipurpose clinic in the centre of the village within the last decade. The village's advancements have afforded the family the opportunity to care for the patient at home. The patient's nuclear family has provided 24 h care since the onset of paralysis. With technical healthcare training from the local clinic, emotional and financial support from the close-knit community, and incredible dedication, the family has helped the patient achieve excellent health outcomes over the past 6 years. Nevertheless, the patient is still struggling with the challenges he faces as a quadriplegic.

GLOBAL HEALTH PROBLEM LIST

- ▶ Financial burdens of quadriplegic care
- ▶ Family and community support for long-term care
- ▶ Availability of 24 h on-call medical care
- ▶ Long-term care and access to resources in settings of political instability
- ▶ Ability to provide at-home care
- ▶ Support and well-being of the family as caregivers
- ▶ Long-term outcomes in quadriplegia

GLOBAL HEALTH PROBLEM ANALYSIS

Worldwide, 110–190 million people over the age of 15 years are estimated to live with severe disability—a physical state of being defined by the WHO as “the equivalent of disability inferred for

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conditions such as quadriplegia, severe depression, or blindness.”¹

Quadriplegia is motor and sensory loss from the neck down. The inability to move, breathe by one's self and exert control over bowel and bladder function results in many complications. Lack of sensation and the inability to move makes pressure sores nearly inevitable. Continuous ventilation is associated with recurrent pneumonia. Quadriplegics regularly experience constipation and overflow diarrhoea. Long-term suprapubic catheters are associated with infection, haematuria and bladder stones.² The patient has suffered episodes of chest and urinary sepsis necessitating admission to the local clinic. Loss of sexual function accompanies quadriplegia and is difficult to come to terms with.³

Israel's 1995 Universal Health Care Law requires all citizens to have health insurance and provides the means for citizens to receive care via a progressive healthcare tax. Physical disability is covered by the subsidised national health provider *Betuach Leumit*. In accordance with this plan, a person more than 74% disabled—as determined by a 3-person health committee—is exempt from paying insurance contributions and receives 2299 NIS/month (approximately \$650/month) to cover health needs.⁴ In a national survey in 2013, Israelis rated ‘nursing care for the frail’ as one of their top two priorities to receive additional funding; Israel spends 0.5% of GDP annually on long-term in-home care, mainly for the elderly.⁵

Quadriplegic patients all over the world become depressed due to the abrupt change to a new and difficult life.⁶ As the WHO explains, a disability is not only a health concern, “It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.”⁷ One major change for quadriplegic patients is the challenge of maintaining a social life. A study in France concluded that patients' loss of independence negatively affected their lives due to the fact that it limited their sociability.⁸ It is not easy, or even possible in some cases, for a quadriplegic patient to travel or be outside of a medical institution. It has been shown that community participation is a statistically significant factor in predicting a spinal cord-injured patient's satisfaction with life; therefore, social exclusion due to a patient's physical state is very hard. The same study also showed that current health status and psychological issues are also significant determinants of one's perception of the patient's life.⁹ Physically disabled people adopt passive attitudes towards their caregivers as a result of the difficulty in expressing their fears and frustrations. Moreover, patients suffering from quadriplegia are entirely dependent on their caregivers and can develop a fear of losing them.¹⁰

Comparing patients from different cultures and communities gives us insight into how the context of a patient's life can affect their mental state and ultimate satisfaction with his/her life. In a comparison of Swedish and Japanese patients with spinal cord injury, life satisfaction of Swedish patients was higher than that of Japanese patients.¹¹ This was partially due to these patients' outlook on being in a relationship; the Japanese patients who did not have life partners were statistically unhappier with their lives than the Swedish patients without partners. This view on relationships is an example of how the influence of cultural norms can affect a patient's emotional well-being. Among British and Chinese quadriplegics with the same quality of life, the British group was more positive and satisfied.¹² In Chinese culture, disabilities can be seen as shameful and even as a punishment for sins, whereas the British culture does not share such ideologies. Perhaps these differences in cultural views affected the Chinese and British patients' perspectives on their own lives.

For this patient's family, increased medical and household costs combined with a reduced family income has been a financial burden addressed by health maintenance organisation (HMO) funding, community support and family giving. The family took three loans to fund the house remodelling and vehicle adaptations. With a rebate of \$1500/month from their health insurance as well as \$500/month of free food formula, the family is able to support their son ‘20 of the 30 days in the month’, according to the father. The remaining funds come from family members and personal assets. The community—inclusive of the family's 200 non-nuclear family members in the village—generally supports the family by cooking their meals. Indeed, their village's social connectedness as well as their unique kinship structure enables their particular configuration of care. One of the village's clinicians is on call to the family 24 h a day, 365 days a year, and changes the patient's tracheotomy tube monthly as well as the suprapubic catheter and gastrostomy tube every 3 months. Access to 24 h on-call high-quality medical care undoubtedly is a key aspect of the patient's good health outcomes.

The normalcy of the family's life has been disrupted by the need to provide round-the-clock-care for their son. Previous studies have shown that distress, hopelessness and financial stress generally lower caregivers' quality of life.¹³ Despite their resilience and dedication, these traits are still present in the family. Their village's unique location between two countries that are technically still at war as well as its isolation from Israel's cities prohibits access to useful services, and the possibility of further conflict remains a threat. As the patient's father explained, “If there were to be a war here, what would I do? How would we provide electricity, water and medicine for our son?” Aware of the risk, the family has a generator as well as 5 months worth of stored food, medicine and medical supplies.

The patient's family has gone to great lengths to give their son a life outside of medical facilities and to keep him at home. The family, one of the biggest in the village, feels very connected to their home and finds it necessary that their son be treated in their village. Studies have shown a positive correlation between social integration of patients' parents and their quality of life.¹³ This family has been able to cope and survive due largely to the community support they receive. Relatives in the area can visit both the patient and the family without having to travel outside the village. The patient and the parents have been able to maintain friendships, receive assistance, be it a cooked meal or a visit to the home, and find strength in the encouragement from members of their community.

Learning points

- ▶ Hopelessness that accompanies quadriplegia cannot be cured and can only be understood through lived experience.
- ▶ The presence of one's family and home care can help with the psychological issues that come with bed-ridden disability.
- ▶ Funding for in-home training and home modifications should be prioritised in long-term disability care.

Competing interests None declared.

Patient consent Obtained.

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