CASE REPORT

Family as the primary caregiver: palliative care in the Golan Heights

Elon Richman,¹ Amit Ringel,¹ Jonah Susser Kreniske,¹ Wajdi Safadi^{2,3}

¹Medical School for International Health, Ben Gurion University of the Negev, Beer Sheva, Israel

²Department of Surgery, Ziv Hospital, Galilee, Israel

³Golan Polyclinic, Golan Heights, Israel

Correspondence to

Dr Elon Richman,
richmane@post.bgu.ac.il

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SUMMARY

Palliative care is recognised by the WHO as an essential component of care for the seriously ill. Geographically isolated and historically underserved communities, particularly from ethnic minority groups, face obstacles in obtaining adequate palliative care. This case involves the care of a 26-year-old Druze man suffering from a terminal cancer in his Golan Heights village. Local physicians were able to train the patient's father in a palliative care capacity. In the effort of capacity building, the physician and palliative care team also aided the aggrieved family in the process of coping. Robust support networks, both at state and community levels, facilitated the care provided. In showcasing the role of the national and local safety net in activating and building community resources to address a dearth of palliative care services in disadvantaged regions, this case models a potentially effective community-based approach to palliative care for patients from underserved populations.

CASE PRESENTATION

The patient was born into a Druze family in the Golan Heights in 1987. The region had been annexed by Israel 6 years earlier. He was the second of four children, three brothers and one sister, the oldest of whom died in a tractor accident at age 15. The patient experienced early delays in intellectual development, which his family attributes to his having fallen off a mattress at 3 days of age. By the age of 12, the patient began attending separate classes in school to accommodate his learning disability. At 20, the patient developed episodic syncope, causing him to lose consciousness at moments of intense stress. At 21, he developed epileptic seizures. Four years later, the 25-year-old patient was diagnosed with a malignant astrocytoma. The prognosis of recovery from the brain tumour was poor. Physicians at the Israeli teaching hospital responsible for the diagnosis informed the family that the patient had 18 months to live. Far from home and in an alien cultural environment, the patient's father had misgivings about leaving his son to spend his last months in the hospital. His concerns included that his already frail son might suffer from hospital-acquired infections, or experience some other form of neglect. Confident in his determination to provide for his son until the end, the patient's father decided to return home to the Golan Heights with the patient.

Given the complex and serious nature of the patient's condition, the capacity to provide palliative care extended beyond the capabilities the

father possessed at the time. In order to facilitate care in the isolated Golan Heights village where the family home was located, two local Druze physicians set about supporting the father by training him in the variety of practices he would need to provide the services his son would require. Medical decision-making was left to the presiding physicians, but technical administration of care was the domain of the primary caregiver, in this case the father of the patient. The physicians provided training in techniques ranging from placing intravenous lines and administering oxygen, to proper suction technique and bathing. The focus, however, was on five major tenets of the patient's comfort: pain control, control of emesis, constipation, seizure prevention and the avoidance of bedsores.

For the patient's pain, the physicians trained the father to administer appropriate doses of oxycodone, fentanyl patches and opalgin drops. To relieve his son's constipation, the father was taught to deliver the liquid laxative avilac. The father also received instruction on how to periodically change the patient's position to avoid bedsores, and on the anticonvulsant pharmaceutical regimen required to keep the patient's seizure condition under control. Additionally, the father meticulously bathed his incapacitated son on a daily basis.

The patient's Israeli medical insurance covered the cost of necessary medical supplies (including palliative medication and oxygen canisters), as well as weekly home visits by the two doctors. During these visits, the physicians would check the patient's condition, measure oxygen saturation, pulse and blood pressure and make necessary adjustments to care, in order to assure the patient's continued comfort. The physicians were also available for contact at any time, in case of emergency.

To monitor the quality of care being delivered by the family, a palliative care nurse visited twice weekly. The nurse observed the father's technique, and the level of services being provided in the home. While the father was deemed highly capable, the physicians describe adjustments being made by themselves and the nurse about once each month. The more technically challenging aspects of care were effectively delivering suction, proper cleaning of instruments and keeping the urinary catheter sterile, as well as dosage alterations required to maintain the efficacy of the pharmaceutical treatment plan.

While the physicians involved in the case emphasise that the primary caregiver was an especially fast learner, the training period spanned the length of 4 weeks. All parties involved in the treatment

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team, including the physicians and the nurse, provided psychological support for the family. In particular, the presiding physicians and nurses set time aside during their visits to discuss the emotional well-being of the family. Additionally, a social worker was available to the family to aid with non-medical and bureaucratic issues. This robust support network was a crucial supplement to the technical side of care.

During the course of the care, the patient's father ceased to work his land in order to stay by his son's side for the entire 10 months. Sleeping beside the patient, the father took great care to attend to his son's physical and spiritual needs. In addition to providing palliative care, the father constructed a four-walled bed to ensure that his son's seizures would not lead to an accidental fall. In this time, understood to be the end of his son's life, the father took to wearing traditional Druze religious garb at the bedside. He also dressed his son in the cloth of the faith. The presiding physicians describe this ritual within the home as a fundamentally important aspect of the family and the community coming to terms with the impending death of one of their own. Indeed, in this practice, the physicians note an aspect of care not replicable in the hospital setting. Father and son, draped in the Druze black robe and white headdress, were a presence in the community, remembered by those present as powerfully cathartic.

Throughout this period, the patient's paternal uncles supported the family financially. The preparation of meals and tasks of daily living were taken care of by the patient's mother and sister. Indeed, as described by one of the physicians involved in the case, the roles played by the mother and sister were critically important. According to the physician, during this period the father was working to the point of exhaustion, and it was the mother and sister who were a constant presence providing both the necessities of household maintenance and a reliable avenue of emotional stability. Additionally, the women of the house would observe the patient when the father took time to rest. One particularly challenging aspect of this time was caring for both the terminally ill older son, as well as the developmentally challenged younger son. In this capacity as well, the contributions of the mother and daughter were essential.

After 10 months, the patient died. Within the hour, the family and neighbours had arrived to pay their respects. Within 3 days, most of the town, as well as many neighbouring villages, had come to mourn. This extended support network was described by both the physicians and the father as a hallmark of the Golan Druze community, and both cite this cohesion as a source of the psychological strength which carried the family through the care and mourning periods.

The interwoven nature of the Golan Druze society and the familial bonds described in this case formed the safety net, which made the kind of devotion demonstrated by the patient's father a feasible endeavour. Indeed, when the patient's father was asked if he would be able to continue this kind of treatment for an indefinite amount of time, his response was an unequivocal yes.

The father described taking comfort in his Druze faith, and in knowing he had provided the care that made his son's ordeal a less painful one. In a discussion of the relationship between the faith and the care provided, the presiding physician emphasised this profound spiritual commitment to the community as a cornerstone of the Druze religion. Manifest in this case, that commitment was a part of what brought the father to the bedside, and the village to his side. In delivering palliative care within the community, the family was able to provide comfort to their son, and to begin emotional healing of the family and

the village in a way that could not have been accomplished far from home, in the halls of the closest hospital.

Today, the father cares for his third and only living son, who suffers from a severe developmental disability. Currently, the younger son requires assistance in feeding, bathing and dressing. While the demands of care are not as involved, the father emphasises that his capacity to care for his surviving son derives directly from his experience learning to provide comfort in the final months of his elder son's life.

LITERATURE REVIEW

Druze culture

Members of the monotheistic, Arabic-speaking Druze community reside across the northern Levant, with particularly large communities in Lebanon and Syria. Within Israel and the Golan Heights, the Druze population is estimated at 132 000.^{1 2} A faith closed to converts since the 11th century, the Druze follow the seven pillars of Islam while also incorporating various non-Muslim Levantine and Classical elements.³

Among those beliefs most relevant to the case presently described are an emphasis on a satisfied acceptance of fate pre-ordained by God, and a foundational belief in mutual aid manifest as "protection and aid to brethren in faith."⁴ Previous reports on the Golan Heights Druze communities have emphasised the role of strong community ties based on the principle of mutual aid and religious faith in a predetermined destiny as important for patients and families coping with challenging medical circumstances.⁵

Particularly in regard to death, the Druze faith revolves around a concept of transmigration of the soul. This belief constitutes the idea that the soul travels from one human form to another at the moment of physical death. In this manner, the human spirit is capable of migrating through many permutations of opportunity and experience, facing in each body a choice between right and wrong.⁴ According to discussions with members of the Druze faith in the Golan, this concept of transmigration contributes to a sense of spiritual existence which allows for a transcendence of the distinction between the individual and the community.

The Druze of the Golan have traditionally relied on both subsistence and varying degrees of commercial agriculture as a primary economic foundation.² Recently, Druze communities have experienced some attrition as an increasing number of individuals leave the village setting to pursue employment in urban centers and within the Israeli military.^{6 7} Apple farming, however, remains a vital financial and social motor for the Golan Druze society, as well as a compounding source of social cohesion.⁸

Medical background

The patient in this case suffered from a terminal astrocytoma. These brain tumours are a form of glioma defined by proliferation of astrocyte glial cells or de-differentiated forms of astrocytes.⁹ Seizures occur in 25–60% of high-grade glioma patients, and are commonly the presenting symptom (as was the case with the patient discussed in this case study).¹⁰ Other indications of tumour swelling may appear on brain imaging, including hydrocephaly and cerebral oedema (both observed in this case study on CT imaging of the patient). Additional focal symptoms may include speech impairment, interference with motor coordination, and loss of sensation in various parts of the body (the patient in this case study experienced loss of sensation on his left side).¹¹

Treatment options for patients with an astrocytoma depend on the type, location and progression of the cancer, and may include surgery, radiation therapy and chemotherapy.¹² While patients with low-grade gliomas may survive for years and initially maintain a relatively high quality of life,¹³ patients with high-grade gliomas often have a life expectancy of less than 1 year.¹⁴ In cases where there is a poor prognosis and limited treatment options (as with the patient discussed in this case study), a palliative care strategy may be sought to maximise the patient's comfort and quality of life as the disease progresses, and to ease the psychosocial burden of the disease on the patient's relatives.¹⁵

Palliative care

Palliative care is defined by the WHO as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹⁶

Palliative care can be provided in-hospital, at a hospice or at home.¹⁷ The site of care depends on the logistical and financial accessibility of these services, and the personal preferences of the patient and their family. Although all citizens of Israel have national health insurance provided by one of four Health Maintenance Organizations (HMOs), availability of palliative care services varied greatly between the HMOs and between different regions of the country until fairly recently.¹⁸ In 2005, Israel's parliament passed the Dying Patient Law, which provides a legal framework for end-of-life care options and decisions.¹⁹ In 2009, the Israeli Ministry of Health issued a directive regarding palliative care mandating that all HMOs must provide comprehensive palliative care at their facilities by 2013.²⁰ As a result of these developments, any terminally ill Israeli citizen is now entitled to receive government-funded palliative care at home, regardless of geographical location. To meet the demand for coverage throughout the country, many of the HMOs have outsourced home palliative care to third party service providers specialising in such care. Under national insurance coverage, these home palliative services are able to provide medical equipment such as intravenous lines, oxygen supplies and mouth suction devices, and have teams on call for 24 h support. The home palliative care teams provide education and training for the family caregivers of the patient, administer drugs and therapies that cannot be administered by the family, and provide psychological help, social work and other forms of support for the patient and family. Home palliative care is dependent on the availability of a family member or other responsible adult to serve as the main caregiver of the patient while at home. Care may be transferred to a hospital or hospice at the patient's behest at any point. Currently, there are numerous services providing modern palliative care around the country,^{21 22} and many hospitals now have multidisciplinary palliative care teams that include physicians, nurses, psychologists, physical therapists, occupational therapists and social workers.²³ Awareness of palliative care options and availability of the full range of services remain challenges, especially in more geographically remote regions.

GLOBAL HEALTH PROBLEM LIST

- Accessibility of palliative care
- Availability of a primary caregiver in the home
- Overcoming the financial burden of home palliative care

- Support and training of family caregivers during home palliative care

GLOBAL HEALTH PROBLEM ANALYSIS

The distance from the patient's home to the site of care can prove to be a major logistical obstacle to the provision of palliative care.²⁴ This is especially the case in less densely populated areas, such as the Golan. Travel time from the patient's town to Ziv hospital (the nearest major hospital) is approximately 1 h by car, or over 2 h using public transportation. Given the prolonged nature of palliative care treatment, travel can become a considerable limitation to families who want to be involved in the care of their loved ones.²⁵ The accessibility of culturally competent care was an enormous benefit in this case. Accessibility of local physicians who are aware of traditional norms and expectations is especially important in the sensitive and emotionally charged realm of palliative care. Home palliative care is able to alleviate the travel burden on families, thereby increasing the amount of time they can spend with the patient in a comfortable environment. Additionally, for close-knit communities like the one described in this case, the process of dying and grieving within the village context may be a vitally important shared experience. While the cost of palliative care delivered in the home pales in comparison to hospital services, it still requires serious public investment in order to be practised effectively. Evidence suggests that home provision of palliative care is a more cost-effective alternative to centralised delivery of services.¹⁷ Further research is needed to establish this benefit in diverse settings, and to elucidate and address the unique challenges faced by caregivers in the home.^{26–28}

Indeed, home delivery of palliative care can be an enormous financial and social strain on a family.^{29–31} Beyond medications and treatment costs, home palliative care relies on the availability of medical instrumentation at the site of residence. Oxygen tanks/tubes, suction devices and intravenous lines are covered by Israeli insurance as part of home palliative care, and would otherwise be prohibitively expensive for the family to purchase.

The father-caregiver in this case study, a farmer, was not able to work during the 10 months he spent caring for his son. The family managed to endure this difficulty with the help of significant financial support from the father's brothers. Today, they continue to praise their brother's efforts in caring for his son during his final months. Both the physicians and the father emphasised that this dedication is particularly prized in the Druze community, which may have contributed to the willingness of the extended family to help shoulder the accompanying burdens.

Families that do not have such social and financial support, at the state or community level, may be forced to forgo the home care option. Centralised services also retain their own financial obstacles, including cost of travel and accommodation for families. Providing compensation for family caregivers to offset losses from missed work may alleviate some barriers to the delivery of palliative care in the home. Considering the substantial cost associated with long-term hospitalisation, it is likely that the model of home palliative care could provide relief to overextended health systems.¹⁷

In this case, home-based care allowed the family to remain immersed within the social fabric of the village. The mother and daughter, with the help of a social worker, were able to provide the scaffold of non-medical support, which was essential to the father's role as primary caregiver. Relatives, neighbours and friends of the family were able to visit regularly, and they also played an important role in helping the family

persevere through trying times. When the patient ultimately passed away, the family was surrounded by both the physicians, the local spiritual leaders and hundreds of villagers committed to sharing their condolences with the family. This support network was a crucial contributing factor towards the family and the community's ability to persevere and eventually come to terms with their loss.

Another key aspect of this case is that the physicians, who facilitated the relevant development of palliative skills in the primary caregiver, were themselves from the local Druze community. The cultural competency of the physicians in this case improved their capacity to serve as facilitators of care. Indeed, support from these local physicians was fundamental in enabling the patient to stay with his parents in the home for the duration of his care. As illustrated through this case, a solid network of community and familial cohesion, facilitated by a palliative care team, with the support of national and local safety nets may render possible the delivery of quality palliative care to rural and culturally distinct communities.

Learning points

- ▶ Family caregivers, with support from the professional medical establishment, can provide palliative care in a home setting that matches, and in certain aspects exceeds, the quality of care that can be provided at a hospice or hospital.
- ▶ When physicians are both medical professionals and members of the patient's community, medical support can be seamlessly integrated with other forms of community support.
- ▶ Financial and practical difficulties in home delivery of palliative care can be overcome with substantial social support at the community and state level.
- ▶ The practice of delivering care to a loved one towards the end-of-life can be a cathartic endeavour which ultimately may aid the primary caregiver and other family members in the coping process.
- ▶ Further research is required to confirm the potential economic and social benefits associated with increased public support for decentralised palliative care options, particularly in rural communities.

Contributors ER took responsibility of planning, conducting and reporting the work.

Competing interests None.

Patient consent Obtained.

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