



Case Report

# Role of Respite Palliative Care in Understanding and Managing Complex Palliative Care Situation – A Case Report

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## ABSTRACT

**Introduction:** The concept of total pain encompasses a person's physical, psychological, social, spiritual, and practical struggles. Effective pain and symptom management are the core elements of palliative care which aims at reducing suffering and improving quality of life (QOL) throughout the course of illness and need to be addressed with multidisciplinary coordinated approach in a timely manner. It may be challenging for palliative care providers to address all these distressing issues during short out-patient consultations. Hence, Respite Palliative Care Unit (RPCU) is an appropriate place to provide holistic patient care.

**Case Description:** A 59-year-old widow, from Muslim community, was following up with Palliative Medicine out-patient department for management of progressively increasing chest pain with frequent exacerbations. She remained unsatisfied with the pain management and reported moderate to severe intensity of pain despite maximal pain management using multimodal approaches. We planned to systematically explore and address the issues leading to uncontrolled pain and distress. The patient was admitted to RPCU for holistic pain management and continuity of care. We explored and addressed the complex psycho-socio-spiritual aspects contributing to the total pain experience to achieve better symptom control and improve her overall well-being.

**Conclusion:** This case report emphasizes the role of RPCU in effective and holistic management of psychosocial, spiritual issues, difficult communication, and advanced care planning. This model of palliative care can be a valuable addition to various health-care set-ups in the developing countries for improvement of patient care.

**Keywords:** Cancer, Palliative care, Respite care, Complex symptoms

## INTRODUCTION

Palliative care is a holistic approach of patient care that provides support to patients and their families addressing physical, psychosocial, spiritual, financial, practical, informational, anticipatory, and decision-making needs.<sup>[1-3]</sup> Patients with life limiting illnesses often have complex care issues. Often such patients go through rapid transitions in life because of the uncertain course of illness. This not only affects patients but also impacts the well-being of their families.<sup>[4-6]</sup> It accounts for increased distress and exacerbates the experience of physical symptoms. It may be challenging for palliative care providers to address all these distressing issues during short out-patient consultations and

often changing health-care professionals (HCP) leading to variability in healthcare team inputs.<sup>[7]</sup>

Such complex situations may require a comprehensive care plan including adequate pharmacological management, building up trusted HCP-patient relationship, having a safe and reassuring environment for the patient care, continued psychological support, and multiple focused discussions with the patient and family to resolve the conflicts and issues around care planning. Admission to Respite Palliative Care Unit (RPCU) can provide opportunities for such comprehensive care which can improve overall quality of life (QOL) of patients.<sup>[8]</sup>

We present the case of a 59-year-old lady who was admitted to the RPCU with severe unrelieved pain. Her admission to

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RPCU unfolded underlying sources of psycho-socio-spiritual stressors influencing her overall suffering.

## PATIENT INFORMATION

### Clinical details and timeline

Mrs. N (name and other possible person identifying characteristics have been altered slightly to ensure confidentiality), a 59-year-old Muslim widow, case of metastatic carcinoma of cervix, was diagnosed and treated for cervical cancer 12 years ago. On follow-up she developed cancer treatment related chronic complications such as chronic cystitis and urethral stricture, which was treated. She developed local and distant recurrence of disease 11 years post-treatment in form of right lung mass extending to pleura and eroding 8<sup>th</sup> rib posteriorly. She received multiple cycles of chemotherapy and palliative radiotherapy for recurrent cancer and lung mass, but the disease progressed, and she was referred to palliative medicine unit for continuation of best supportive care.

The patient regularly followed up in palliative medicine out-patient department (OPD) alone for management of progressively increasing right chest wall pain with frequent exacerbations. Mrs. N reported inadequate pain relief at every follow-up visit to the OPD. She had moderate to severe intensity of pain despite maximal pain management using multimodal approaches such as nerve block, anti-inflammatory drugs, morphine, and neuropathic pain adjuvants.

### Psychosocial-spiritual profile

Mrs. N, a mother of six (three sons and three daughters), was the sole bread-earner, after she lost her husband 7 years after her cancer diagnosis. She has been a very positive-minded and practical person, lived life as it came and an extremely protective mother. Her two elder sons were married and lived separately while she lived with her 3 unmarried daughters and youngest son. All her children had to abandon education after their father died. Mrs. N worked as a housemaid and her income could barely meet the basic daily needs of her family. She was the sole decision maker and never involved anybody from her family in the discussions about her illness. She attended her religious and community practices as she was doing before her diagnosis, which helped her cope with her stressors. Despite repeated requests from health care team, she continued to hide her illness from her loved ones as she feared stigma and social ostracization.

With progressively increasing cancer, Mrs. N had become sicker, often causing missed workdays which affected the family income. She borrowed money from friends and relatives to sustain her family. She was also worried about the future of her children. Due to inadequate funds, she defaulted on medications and instead diverted that money to meet needs of her family. She was aware of her progressive

illness and hoped that her children will be able to move-on after her death in the same way as she did after her husband's death.

Evaluation during the OPD visits, we ensured consistency in the HCPs attending the patient. Acknowledging her distress with empathy helped in developing a trusted doctor-patient relationship. With rapid disease progression the HCP team emphasized the need to have a family member of patient's choice to be a part of future discussions about her illness and care planning. Due to the perseverance and empathy, the patient eventually relented to involve her eldest daughter to accompany her to the OPD. During this visit, palliative medicine physician introduced the diagnosis and the anticipated disease trajectory to the patient's daughter. However, in view of the complex care needs envisaged by the PC team, it was important that Mrs. N and her daughter received consistent and undivided attention. While such a holistic care structure appeared challenging during routine OPD consults, we admitted her to RPCU for further management. We intended to systematically explore and address the issues leading to uncontrolled pain and distress. The treating palliative medicine physician introduced the patient and her daughter to the RPCU team during her OPD consultation. This ensured non-abandonment and a seamless transfer of patient from OPD to RPCU.

## Management

### Physical pain

Pain medications were reviewed, regularized, and monitored closely. She had mixed nociceptive- neuropathic and bone pain due to the lung mass infiltrating paraspinal space, chest-wall and ribs. She was put on round the clock and breakthrough doses of morphine, with addition of etoricoxib and pregabalin to cover the inflammatory and neuropathic pain. A small dose of methadone was added as co-analgesic after adequate titration of all pain medications. The importance of compliance with dose and schedule was emphasized to both patient and her daughter. There was a notable improvement in the pain score after titrating the analgesics and she was able to perform her activities of daily living without any assistance.

### Psychological pain

Mrs. N's fears were mainly related to the future of her children, managing finances, getting her daughters married and settled. She was also afraid that her children will not be able to cope with the news about her illness. Among all her children, she shared an extremely close bond with her youngest son and was extremely protective about him. She was scared to confront about her illness to him. She was worried about losing control over her life, physical dependence and thus not being able to fulfill her role as a mother.

Exploring on previously unaddressed and distressing psychological issues surrounding Mrs. N was one of the significant aspects in addressing her total pain. The continuity of care and consistency among the HCPs helped building up trust and rapport with the patient at RPCU. We had more time to explore about the hopes and fears.

Involving patient's daughter in the discussions unburdened the patient of the long-standing collusion and her fears. This provided a sense of relief to the patient and ensured a safe environment to vent-out her emotions. She also eventually involved patient's youngest son in the discussions. He understood the situation, was extremely hopeful about the patient's improvement in her disposition. The active involvement of her children in caregiving, strengthened their familial bond, helped to explore further support systems for the patient and gave a sense of relief to all. The team at RPCU coordinated the entire process. We noted a significant decrease in pain score of the patient after addressing the collusion. This also improved her self-care, compliance, and overall well-being.

### ***Spiritual pain***

Mrs. N was a follower of Islam, and her life was driven by a strong sense of religiosity. Her journey with cancer diagnosis, treatment, recurrence, and progression triggered deep existential questions towards profound suffering and distress. Unfortunately, she also lost her husband, who was her strongest support and companion, during this difficult journey. Her source of strength and coping was centered around her faith in *Allah*. Her inadequately controlled pain caused difficulty in performing "*Namaz*" (a daily religious prayer done by Muslims in standing and kneeling or sitting position). She perceived this as a sense of spiritual distancing, which increased her spiritual distress. Not addressing the spiritual distress, adequately as per the patient, was resulting in a vicious cycle of lack of trust in health-care system, poor treatment compliance, inadequate pain control, and difficult coping.

She was given analgesics for movement related incident pain which helped her to engage in the prayers. Discussing about her faith, having spiritual group therapy sessions, encouraging her to recite the verses from Qur'an (religious text of Islam), and seek religious support were some of the measures that seemed fulfilling to the patient. Exploring and addressing patient's spiritual needs further strengthened her trust in HC system. This also consolidated her inner strength to fight the death anxiety, improved her coping and led to better symptom control. It helped to regain her lost meaning and willingness to seek support from her family in caregiving process and improved QOL.

### ***Social pain***

Mrs. N's beliefs were highly influenced by the sociocultural groups that she was part of. She strongly believed that her

cancer diagnosis would be a serious impediment for her and her family's social and religious roles and that they would be ostracized from their community. She was worried about social stigmatization and her negative self-perceptions about illness led to secondary stigmatization. These issues dissuaded her from seeking adequate medical, social, psychological and rehabilitative support in terms of hospital visits for symptom and disease management, homecare visits, counseling support, using rehabilitation devices, etc. Her catastrophizing of the social issues surrounding the illness was a source of heightened anxiety, which added to poor symptom control, behavioral issues, disturbed interpersonal relationships and poor treatment compliance. It severely impacted her social interaction and basic activities of daily living as the patient lived in a chawl, with a public toilet system. She found it difficult to use the public toilets due to increased pain during squatting and fear of revealing her cancer diagnosis to her neighbors.

We conducted psychoeducational sessions for the patient clarifying her myths and providing her with practical information and resources about cancer management. This helped in better management of her anxieties and fears about cancer. It also helped her to accept the support extended by the health-care team and social support groups, thus leading to better rehabilitation of both patient and family. The patient could use a commode chair arranged by the medical social worker. She was able to seek assistance from her daughter for her basic activities of daily living. Her daughter, who had left her studies, was able to enroll for a course in nursing education with the help of some financial assistance. We managed to engage patient's family for discussions about diagnosis and prognosis of the patient and planning for further care. The patient and her children felt more confident their social roles and were able to regain their community participation. Patient's daughter was empowered for caregiving at home.

### **RPCU team challenges in this case management**

Even though we tried to achieve reasonable pain control, working with a patient having multiple complex issues surrounding her pain-perception was a lengthy process. It involved continuous inputs from the health-care team, multiple sessions of counseling with patient and family.

As patient was obstinate, it was very challenging for nursing staff to maintain and teach medicine compliance to the patient and caregiver. Continuous complains of uncontrolled pain by patient and her daughter, sometimes demoralized nursing staff. We conducted team meetings to keep the healthcare staff motivated for patient care.

It was challenging to conduct a family meeting with patient's son and daughter, as patient was adamant on non-disclosure of diagnosis and prognosis to her children. However, with continuous persuading she agreed to involve her children in the process of care and decision making.

## DISCUSSION

The concept of “respite services” in context of palliative care is not described uniformly in different sociocultural and socioeconomic set-ups globally.<sup>[8,9]</sup> In the developing countries, respite services serve mainly as a step-down facility from over-burdened in-patient units. The respite model of palliative care developed in our set-up, was envisaged to have a multi-disciplinary team of HCP including palliative care physicians, nurses, psychologists, social workers, rehabilitation therapists and volunteers to provide a holistic patient care, patient and family education and empowerment along with some respite from caregiving burden for the caregivers.<sup>[10]</sup>

With this case we explored some more roles of RPCU in patient management. First, instead of using it as a step-down facility, the RPCU team was introduced in person to the patient and involved in caregiving during the OPD consultation. This meant that the RPCU team ran parallel with the hospital based palliative care services, which gives sense of involvement to both RPCU team and the primary care team. This led to seamless patient transfer and kept the channels open for discussion between the HCPs.

Second, we could provide more time to the patient and caregivers, a safe, confidential, and friendly environment for them to feel comfortable in discussing about their fears and vulnerabilities as compared to busy outpatient or in-patient units in hospital. The team members remained constant, as compared to shift duties in hospital set-ups was particularly advantageous in ensuring the continuum of care provided to the patient. This ensured building up a trusted relationship between the healthcare team and patient. It also helps in working with patients and families to develop a meaningful and realistic care plan for future.

Third, RPCU is a small unit, with few patients and families admitted in it. This environment creates an informal support group for the patient and their caregivers suffering from the consequences of an incurable life-limiting illness. Sharing their experiences, challenges, and triumphs during the difficult journey, provides a sense that they are not alone. This can be very encouraging and can help in coping for patients and caregivers.

## CONCLUSION

We conclude that RPCU is a versatile palliative care model that can be utilized to manage complex palliative care issues. The flexibility of processes and indications for RPCU admissions allows us to customize the services according to the needs of individual patients. Apart from the medical and

nursing issues, it allows for effective and holistic management of otherwise neglected psychosocial, spiritual, difficult communication, and advanced care planning related issues. This model of palliative care can be a valuable addition to various health-care set-ups in the developing countries for improvement of patient care.

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## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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## Conflicts of interest

AG and JKD are part of editorial team at IJPC.

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