

## Developing Palliative Care Services for Terminally Ill Patients in Saudi Arabia

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Palliative Care is an accepted specialty of medicine and nursing which concentrates on the total care of patients suffering from any form of terminal illness. Its development as part of the health care services is a recognition that dying is a normal consequence of living and that the support of health professionals and the use of modern medical technology can relieve much of the distress normally associated with dying of illnesses such as cancer. This article looks at the experience of King Faisal Specialist Hospital and Research Centre in developing a palliative care service for the terminally ill since 1989 in the hope that other institutions in the Kingdom will be encouraged to do likewise. *Ann Saudi Med 1995;15(4)*:

Cancer patients suffering from a terminal illness require special care and support. This care may be provided entirely by family and friends but often needs to be given, at least in part, by the health care services. In many countries, this care is now formalized in a palliative care program which can be described as: "a centralized program of palliative and support services to patients with a terminal illness and to their family in the form of physical, social, and emotional care provided by an interdisciplinary team of professionals who are available at home and in an inpatient setting".

Care provided during a cancer patient's final illness may be the most important care they receive in their entire life. The unrelieved pain and distress caused by advanced cancer has been the motivation for developing palliative care programs. With modern medical methods and skilled nursing, most symptoms can be relieved to some degree.

A palliative care program (PCP) would concentrate on two things:

- 1) Provide specialized care for those 70% or so of all cancer patients who inevitably die of their illness. In Western countries, 45% to 50% of cancer patients may expect to be cured. In Saudi Arabia, where over 70% of adult and 80% of pediatric patients present with advanced cancer (stages 3 and 4),<sup>1</sup> cure rates will be less and a 30% cure rate may be more realistic. (This may be higher in children). The majority of treatment given by cancer services in the Kingdom is, in the end, palliative. Palliation

involves treating both the disease process (palliative treatment) and the patient as a whole (palliative care). Surgery, chemotherapy, and radiotherapy are all used extensively for palliative treatment as well as for cure. In general, any reduction in tumor load by achieving a remission relieves tumor symptoms.

However, reduction of tumor load and symptom relief are not always synonymous and in advanced cancer there are other valuable methods of relieving symptoms.<sup>2</sup> In palliative care, the center of concern shifts from the pathological process to the person<sup>3</sup> and the emphasis is on controlling the patient's symptoms.

The goal of both cancer treatment and palliative care services is similar; only the methods are different. Both attempt to relieve symptoms, prevent impending problems, improve the quality of life and extend survival if possible. Figure 1 illustrates how these two methods of treatment overlap when considering the end-points of cancer therapy.

Palliative care services are now considered an important adjunct to cancer therapy services but they also apply to other patients with a terminal illness which can cause persisting distress, such as AIDS, cardiomyopathy, and chronic obstructive lung disease (COLD).

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FIGURE 1. End-points for cancer treatment.

FIGURE 2. Combination of active and palliative treatment. "From Palliative Care Services Guidelines, Health Canada, 1989. Reproduced with permission of the Minister of Supply and Services Canada 1994."

2) Provide educational programs which should focus on teaching health care professionals how to provide better symptom control, psychological support, and a coordinated delivery of services to the patient. It should teach them to consider more carefully how the illness changes the patient's whole lifestyle and expectations and how much the health service can help modify their progressive disablement and distress.

Figure 2 illustrates how supportive and "holistic" care (the care of the whole patient) should be provided from the time of diagnosis, so that the improved quality of life from initial treatment can be maintained as far as possible until death.

The World Health Organization's definition of Palliative Care is: "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment."<sup>4</sup>

This definition does not limit palliative care to cancer patients but in practice, 90% to 95% of the patients involved in a palliative care program have cancer.

### The Principles

What are the essential characteristics of a palliative care program? 1) The coordination of care for patients with a terminal illness, at home or in hospital, by a distinct service; 2) the unit of care is the patient and their family, who have the right to make choices and decisions based on an understanding of their illness and to have those decisions respected; 3) care is provided by an interdisciplinary team; 4) the care is coordinated and delivered by specifically selected and trained nurses; 5) the service is directed by a

physician; 6) the emphasis is on control of symptoms, be they physical, social, or emotional; 7) the services are available on a 24-hour a day/7-day a week/on-call basis; 8) the program must be sensitive to differences in faith and culture and incorporate the patient's beliefs into decisions on their care; 9) following the death of a patient, the program should ensure that grief support is available for the family. This may be provided by the program itself or by other community services; 10) there is a system of structured staff support and communication; 11) the program is integrated and coordinated with other services and continuity of care for the patient is provided; 12) there must be regular evaluation of the program and its services. This evaluation may extend into the area of research;

13) the program will provide education for its own staff, other health care providers and the public. The program must evolve to provide formal academic training in palliative care for other health care professionals in the Kingdom.

The above characteristics are internationally recognized basics of a palliative care program.<sup>5,6</sup>

### The Problems

#### 1) Referrals

At King Faisal Specialist Hospital and Research Centre, there was evidence that poor communication with referring doctors and prolonged follow-up of patients who came long distances from outside Riyadh, when this tertiary hospital had little specific to offer, was hurting the hospital's reputation for patient care.<sup>7</sup> Patients developed unrealistic expectations that their progressive symptoms from advanced cancer would somehow be managed and relieved only at this Institution, when the reality was that they were often sent home, but with no involved local medical or nursing service who knew their problem. Previous reports have commented on this loss or compromise of benefits of high quality medical care once the patient with a chronic illness returns home.<sup>8</sup>

The corollary is that many referring doctors do not recognize the need to continue looking after dying cancer patients in their own region. This may be due to their lack of confidence and skills in this area.

Ill patients require a planned and orderly discharge to either home or their local hospitals. This applies particularly to cancer patients, where fear and uncertainty about the future makes care at a tertiary hospital the easiest decision for the patient, their family, and their referring doctors.

Currently the Kingdom lacks a well-developed system of primary health care services with their network of family doctors and community nurses, whose job is to know and understand the patient and their problems.<sup>9</sup> It is important to ensure that patients with a terminal illness have their

needs transferred to another health care facility and that continuing care will be provided. A palliative care program aims to stabilize the patient's symptoms prior to discharge to their home or local hospital with specific recommendations for care.

The emphasis for cancer patients in Saudi Arabia is on "curative" treatment and it is not always recognized by clinicians that the patient may be more appropriate for palliative care. This "interface" between cancer treatment and palliative care will only improve when clinicians see the benefits of an established palliative care program and what it can achieve for their patients.

## 2) *Inpatient Unit*

Studies have shown that during a terminal illness, 80% of cancer patients will require at least one admission for symptom control during their last year of life. The average duration of stay is short and 60% to 70% of patients can be discharged home again.<sup>6,7</sup> The remainder may die during admission or have no care givers at home to return to. The latter reason, however, would be unusual in the Kingdom, with its strong family life.

The emphasis in palliative care is to allow the patient to die in dignity and comfort in their own home, involving their family and friends as care givers, supplemented as necessary by the health services. Such home care for the dying shortens the period of bereavement, giving satisfaction to the family that they were present and participated in the care of the patient, and leaving them with a feeling of worth. It ensures that they are involved in decision-making and allows them to prepare in their own way for the patient's death. The Kingdom has the advantages of a strong traditional family life and religious faith for this purpose.<sup>1</sup>

Some patients have overwhelming symptoms, e.g., pain, shortness of breath, and vomiting, which simply cannot be controlled at home and the patient has a while yet to live. For this reason, the PCP must have an inpatient unit. Such a unit also serves as a base for development as a center of excellence, a place for knowledge and skills to be developed and disseminated. An inpatient unit provides the framework of personal and professional support to cope with staff stress, as this area of work presents both great rewards and great strains. Palliative care is not only a program, but must also be a "place" that people can relate to.<sup>10</sup>

Each program should have a small number of beds designated for palliative care staffed by doctors and nurses who are motivated and trained for this type of work.

## 3) *Siting an Inpatient Unit*

There are two possibilities for siting an inpatient unit: (a) within a general hospital. Although the emphasis on palliative care is to avoid invasive procedures and toxic

therapies, they are sometimes needed. Insertion of Denver shunts for ascites, the occasional use of tracheostomies or gastrostomies, or insertion of intraesophageal tubes all need to be available if required. As well, there are the advantages of a patient returning to a hospital they already know and trust. The major advantage, however, is an educational one, of siting the unit within a major institution to spread the principles of palliative care to other health professionals; (b) a stand-alone unit. Many PCPs elsewhere in the world are complete stand-alone units called "Hospices". Usually they are developed by, and accountable to, private charities rather than government funded, but remain as a public rather than a private service. This is mainly because of a lack of government funds in many countries to develop new services. Larger hospices, however, develop close links to major hospitals, both for the specialist services of a general hospital when required, and the opportunity for educational programs.

Stand-alone hospices often provide day care services which allow the patients to attend one to two days per week when their needs can be assessed and their care givers can be relieved for a few hours. A stand-alone unit has the advantage of being specifically designed and built for the purpose but if not careful, can suffer isolation from the mainstream of medicine.<sup>10</sup> There is also the problem of how Saudi patients would react to being treated in a separate institution dedicated to the terminally ill. Would this be culturally acceptable?

There are definite advantages to siting an inpatient unit within a general hospital closely linked to community nursing, oncology and surgical services and pain clinics.

## 4) *A Consultative Team*

Both an inpatient and community nursing unit can provide skilled staff to form a consultative team within the hospital. This team should consist of a doctor, a nurse, and a social worker specifically identified for the task. Many patients develop strong links with their hospital specialists and ward nurses and wish to continue in their care. A consultative service would provide the extra skills and knowledge for the usual care givers to continue providing for the patient's needs. It would also help plan their discharge and explain the services to be provided when they go home.

A consultative service can be an alternative to an inpatient unit. In Western countries, the care of the dying is now seen as a specialist medical and nursing service, with its own standards and training programs.<sup>11</sup> Palliative care inpatient units have been described as intensive care units for the dying, with "aggressive" palliation required to control multiple symptoms. The constant supervision of the patient and the detailed adjustments to their medications is an intensive, skilled, and time-consuming process. Coordinating a similar standard of care for seriously ill

patients in other wards geared to different tasks and with different skills is not so easy. A consultative team ideally should be an outreach of the inpatient palliative care unit in order to provide a flexible service that fits the needs of both the patient and their normal care givers.

##### 5) *Integration and Coordination*

Palliative care is part of the mainstream of medicine and should not be regarded as peripheral to other parts of the health service. A palliative care program is a specialist medical and nursing service based on a community nursing program and an inpatient unit. A community nursing service strengthens and extends the primary health care services, which are underdeveloped in the Kingdom. It may elect to look after the chronically ill as well as the terminally ill. A PCP should not reduplicate already existing services but should develop good communications and collaboration with other services. Coordination with oncology services, surgical services and pain clinics are essential. Many fields and disciplines are involved in palliative care which can be coordinated by a PCP.

##### 6) *The Role of Clinical Pharmacology*

A palliative care physician should have a knowledge of cancer medicine and be a good clinical pharmacologist. At present, one of the major impediments to the use of modern methods of palliative care in the Kingdom is the lack of appreciation of modern methods of both delivery and use of pharmaceuticals. Examples are:

a) morphine - the mainstay of pain relief. There is a general lack of knowledge of how and when to use morphine effectively. The use of long-acting morphine tablets has revolutionized pain relief in a terminal illness.<sup>12</sup> This medicine is simply not available in most parts of the Kingdom. There is a general reluctance to use morphine of any kind and this is compounded when it is not used effectively, when the patient may only suffer from side effects such as constipation without obtaining the benefits of effective pain relief. Its use in an injectable form by nurses outside the hospital is restricted, which limits the ability to deliver effective pain relief for seriously ill patients at home. Eighty percent of dying cancer patients will suffer pain and in sixty percent it will be severe and require strong analgesics such as morphine. This involves many thousands of patients a year in the Kingdom who, at present, cannot get access to adequate pain relief during a terminal illness.

There is an unreasonable fear of morphine addiction among patients and their families in the Kingdom but addiction is never a problem in treating patients with a terminal illness. Studies have conclusively shown that there is no significant association between morphine usage for pain relief and social drug abuse.<sup>13,14</sup>

b) alternative routes of medication. Sometimes patients are unable to tolerate oral medication, either because of

weakness or vomiting, and yet they require a constant infusion of medicine to control symptoms. The two major alternative methods of drug delivery in a terminal illness are rectally or by subcutaneous infusion. A variety of medications can be given rectally, including some oral preparations such as long-acting morphine tablets which can be used as a suppository twice daily.<sup>15</sup> A subcutaneous infusion uses small, relatively inexpensive pumps which can be safely used in the hospital or at home and are easily supervised. They give continuous and precise delivery of analgesics, antiemetics, anxiolytics and corticosteroids. The subcutaneous site is reliable and reduces the risk of infection over the intravenous route, which is far more expensive in both time and resources, requires more expensive pumps, has a higher complication rate, and limits the patient's ability to move between hospital and home. A subcutaneous route can also be used to administer fluids; it is possible to give up to one liter of normal saline per day this way.<sup>16,17</sup>

##### 7) *Cultural Aspects*

Foreign health professionals are constantly impressed by the strength of family life in the Kingdom. The family unit is the structural foundation of Saudi society and the impression is that patients here cope better with a terminal illness at home than happens elsewhere. This is probably because of the close family involvement and their strong Islamic faith which allows them to accept death as an expression of God's will. It is a religious duty to provide for parents in case of need and to help make their lives as comfortable as possible.<sup>18</sup> Another reason may be because modern medicine is a relatively recent development and people are more used to enduring physical hardship. This is all the more reason to ensure that their distress is not ignored.

For the foreseeable future, care will be provided by foreign nurses and for a while longer by foreign doctors, who must be educated in the social and cultural life of the Kingdom. Their task, however, is aided by the ritual of hospitality which is such an important part of Saudi life.

There is an impression that palliative care in the Kingdom is confused with euthanasia.<sup>19</sup> The two are opposites. Palliative care is the moral and ethical alternative to euthanasia. The motive for euthanasia is life without hope. Good palliative care, by relieving the patient's symptoms, providing support and knowledge, restores hope. Hope is the patient's personal possession; it should not be destroyed. Life is impossible without hope, but day by day our hopes change as our condition changes, so that hope can and does become based on reality.<sup>20,21</sup>

Another misunderstanding is that using morphine can be a form of euthanasia by shortening life. There is no evidence that the proper use of morphine shortens life in a

terminal illness. On the contrary, morphine quite commonly extends life; by relieving unbearable pain (which itself can radically shorten life), patients become comfortable, can interact with their surroundings and regain the will to continue living.

Then there is the question of "withholding treatment" in a terminal illness. It would be unethical for a doctor or a nurse to withhold a known and effective treatment from any patient. It has, however, also been considered unethical to use a known ineffective treatment on a patient, whether terminal or not. While generally these ethical guidelines are applied to "unorthodox" (or unproven) methods of treatment, it has wider connotations. The resuscitation of a terminally ill patient with CPR is generally considered ineffective and is not indicated. No physician in America has ever been sued for not resuscitating a terminally ill patient. Inappropriate surgery, the use of ineffective chemotherapy or radiotherapy, the use of intensive care or artificial respiration in a terminal illness, are all examples of treatment from which the patient may reasonably be dissuaded if they are considered ineffective at that stage. The art of medicine is to decide when life sustainment is futile and, therefore, when to allow death to occur without further impediment.<sup>3</sup> However, the approach should always be flexible to the needs of the individual patient and where there is doubt, the doctor should consult with medical colleagues.

#### 8) *How the Public Perceives Cancer*

Bedikian and Saleh interviewed 100 Saudi patients with cancer and reported that 92% had an adverse reaction to the diagnosis, with a median duration of symptoms from three to five months. None received professional assistance for these problems and the authors recommended psychosocial support be available to patients as part of their total management.<sup>22</sup>

Bedikian, in a further study, interviewed 250 healthy Saudis on their attitudes and knowledge of cancer, which revealed a considerable degree of fear and anxiety about this disease.<sup>23</sup>

Similarly, Ibrahim et al. interviewed 600 adults on their knowledge and attitudes toward cancer and confirmed the high level of fear and misperceptions about the disease. Both groups of authors called for more comprehensive health education and awareness of cancer as a treatable disease.<sup>24</sup>

However, two editorials on the treatment and control of cancer published in the *Annals of Saudi Medicine* in 1986 and 1990 failed to mention palliative care as an essential part of the spectrum of cancer management.<sup>25,26</sup>

The relationship between the doctor and the patient in Saudi Arabia is different from that in Western countries. In the West, health care systems are based on the individual where patients are treated as autonomous agents capable of

receiving information on which they make decisions about their own future. In Saudi Arabia, the predominant principle is one of "beneficence" where the patient is viewed as one member of the larger family and the family is responsible for the patient. The consent for the patient's treatment is usually a substitute consent by the family, whose purpose is to avoid disturbing the patient emotionally. In this way, the family considers they are protecting the patient from harm by making efforts to secure their well-being and ensuring that the patient is treated in an ethical manner (beneficence). If patients are told the truth, then they need to understand the situation and act accordingly. In Saudi Arabia, it is assumed that an ill person will not adapt to the true situation of a terminal illness, resulting in a loss of hope, which may lead to an earlier death than might otherwise occur. This policy of beneficence also relies on health professionals being authority figures who can be trusted to do what is best for the patient.

This concept of denying the patient information on their illness is shared by other countries<sup>27</sup> and similar attitudes prevailed in Western countries until only 20 years ago. The introduction of modern medical technology, however, has also changed the relationship between patient and doctor. Such technology has "costs" to the patient in terms of toxicity, as well as major benefits. Increasingly, doctors dealing with cancer or other major illnesses insist that the patient is fully informed and able to give consent before starting treatment which will have side effects. Already, many patients in this country are well informed about their illness and have some idea of their prognosis and this trend will steadily increase.

Any problems that occur are usually those of communication and understanding. The aims of a good health service should be - "to provide treatment that will restore patients to as near normal or usual a quality of life as possible under the circumstances" or - more simply, "to maximize the patient's well-being".<sup>28</sup> It is the job of health professionals to explain not only the benefits but also the limits of treatment in ways the patient understands.

### **The Response**

What is required in the Kingdom of Saudi Arabia to provide a palliative care service? The following is a description of how this problem was tackled at King Faisal Specialist Hospital and Research Centre (KFSH & RC). In 1989, at an informal meeting, a group of nurses discussed the possibility of establishing a home health care program for seriously ill patients in the Riyadh area. A proposal was formulated and accepted by the hospital administration, who established a task force to design and implement a pilot study to assess its feasibility. Four questionnaires were developed and sent to patients, families, nurses and

physicians to survey their attitudes towards such a concept. The results of the survey were encouraging. Two areas of concern were the language barrier and a possible negative response from Saudi families to the idea of non-Saudi females entering their homes to care for family members. However, the survey indicated that a home health care program was feasible.

A pilot study was approved in February 1990 and implemented over a four-month period, surveying 12 patients who had to meet predetermined criteria: they were in the terminal stages of cancer with a life expectancy of less than three months; they were to be referred by a consultant at KFSH & RC; they were not to be receiving any form of curative treatment; and their residence was to be within 50 km of the hospital.

Each patient was visited one to three times a week as their needs dictated. Education of the patient and family was a vital component of the visits. Increasing the caregiver's knowledge helped them to feel more comfortable in their role of caring for the patient and increased their confidence in performing procedures and decision-making. The nurses communicated with the referring physician on a regular basis. Pain management, nutrition counseling, skin care, catheter care, respiratory care and emotional support were the major foci of nursing care. Any necessary durable medical equipment, such as wheelchairs and bedside commodes, were loaned to the patient and medications and medical supplies were delivered to the home of those families who were unable to collect them. The service was available 24 hours a day, seven days a week. This was essential, especially when patients were close to death and families needed additional support and assistance.

Of the 12 patients, nine died at home and three in hospitals other than KFSH & RC.

The results of the pilot study indicated that patients and their families benefited from the nursing care and psychosocial support. The study demonstrated that such a program reduced the need for hospital admissions, clinic and emergency visits, and thereby contributed to the judicious use of hospital resources and staff time. It also enhanced the hospital's public relations.

The study demonstrated that patients and their families were very receptive to the advice and care given by the nurse and welcomed her into their homes with friendship, respect and hospitality. This acceptance helped break down the communication barrier.

In May 1991, approval was given to implement a home health care program under the supervision of a committee to oversee its ongoing planning and implementation. The program was established under the direction of a medical director and a head nurse and consisted of four staff nurses, four interpreters/drivers who were Saudi males, a social worker, a secretary and a messenger. Nursing requirements included having experience in community nursing, a

working knowledge of Arabic, and a sensitive, caring and nonjudgmental approach to patient care in a different cultural setting.

The only major deviation from the pilot program was the extension of the service to care for the chronically ill as well as the terminally ill. Currently about 75% of the unit's work is for the terminally ill.

Since it began, a total of 710 patients have been referred and currently 82 patients are being managed by the program.

The involvement of Saudi men as drivers and interpreters in a home health care program has proved very successful in allowing foreign professionals to become involved in family life for the purpose of caring for patients at home. The impression is that the service is greatly appreciated by patients and their families, particularly for the higher level of communication that occurs.<sup>7,29</sup>

In 1991 Dr. Derek Doyle, Medical Director of St. Columba's Hospice, Edinburgh and a world authority on palliative care, was invited to visit the Kingdom and advise on palliative care services at KFSH & RC. His report<sup>7</sup> critically evaluated the problems and made specific recommendations on the further development of the home health care service, the appointment of a specialist in palliative care, the development of a consultative team, a palliative care inpatient unit and particularly the need for an educational program which would create awareness and heighten skills generally. He recommended the preparation of guidelines on ethical issues as they relate to information for patients and their families and the need to educate expatriate staff on Islamic and Arabic culture as they relate to dying, death, and grief, so that patients and relatives be accorded the most sensitive care possible. His recommendations are gradually being implemented at KFSH & RC and require broader acceptance throughout the Kingdom.

Currently the home health care service has five nurses, four translator/drivers, two physicians and a support staff. Four inpatient beds dedicated to palliative care and under the direction of an experienced nurse clinician have been opened.

## Discussion

The problems of palliative care in Saudi Arabia can be summarized as follows: 1) the strong emphasis on "cure" even when this is no longer possible; 2) the lack of physicians with an interest in palliative care; 3) the fact that patients generally are not told their diagnosis of cancer and have no idea of their prognosis; 4) the lack of a family health service, integrated with secondary and tertiary care, to provide continuity of care in the community; 5) the lack of adequate methods of pain relief; 6) the unwillingness to discuss issues of death and dying.

Many other developed countries have identical problems.<sup>13,14,27</sup> The Kingdom, however, has the advantage of a centrally organized government-supported health service to help plan and implement such services on a national level.<sup>9</sup>

The delivery of palliative care has not yet properly begun in the Kingdom and yet the case for a palliative care program is compelling: - on humanitarian grounds - to ease human suffering; - on cost - inpatient cost is generally considered to be more expensive than other hospital care, and home care reduces inpatient use (it should not be forgotten, however, that while palliative care may be cheaper medicine, its real importance lies in the fact that it is better medicine); on completing the social contract - for provision of health care by a government to its people by demonstrating that the care of the patient comes first and that "failure" of curative therapies does not leave the patient dependent on their own devices. "No cure" should not be used as an excuse for "no care". Incurable patients still need doctors and nurses, even though they feel they cannot do as much for the patient as they would like.<sup>30</sup> In the Kingdom, this problem is heightened by the lack of primary care services in the community which would otherwise know the patient and take over their care.

Cancer is one of the most treatable of all chronic illnesses. While our ability to improve survival is still limited, the ability to control symptoms and improve quality of life has continually improved. Dr. Neill McDonald, a Canadian expert, recently wrote that he considers palliative care to be one of the four major advances in the clinical management of cancer patients in the last decade.<sup>3</sup> He lists these as: - adjuvant chemotherapy of some cancers, the control of nausea and vomiting, palliative care, and progress in bone marrow transplantation.

In the final analysis, palliative care is simply good medicine and there is no one group that has a unique hold on the humane management of pain and psychosocial issues. The philosophy of palliative care is best integrated within a health system where it can permeate and influence the care of cancer (and other) patients at all stages of their illness. Developing palliative care programs throughout the Kingdom now would speed up that process.<sup>31</sup>

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