

Saudi Palliative Guidelines Development

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Background

Palliative care is required for a wide range of diseases. Worldwide, there is a major population of adults in need of palliative care who have chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, AIDS and diabetes. Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Today, Saudi Arabia has a total population over 32,552,336 million, the majority are Saudis based on 2017 statistics, with a life expectancy at birth of 76 years (WHO, 2017) [1]. The burden of disease in 2012 was attributable to communicable diseases 12.6%, non-communicable diseases 78.0% and injuries 9.4%. The health workforce density is 26.5 physicians and 53.73 nurses and midwives per 10 000 population (WHO, 2014).

In 2012, the total deaths was over 90,000; non-communicable diseases accounted for 78% of these deaths. This population can benefit tremendously if they were managed by palliative care services when access is guaranteed for them before death (WHO, 2014). The country is going through a tremendous change and transformation in the healthcare sector and developed a new model of care in which palliative and end of life care is one of its dimensions. Due to different preparation and training of palliative care healthcare professionals who received their training in multiple countries overseas; there is a lack in the utilization and consistency of palliative care guidelines. As a result, there is a move to develop Saudi palliative care guidelines.

The purpose of the Saudi Palliative Care Guidelines is to provide in a readily usable format, practical, evidence-based or best-practice guidance on a range of common clinical issues [2]. These will be of benefit to both generalist and specialist providers of palliative care. Development of these guidelines provides a practical guide to standardize practice among healthcare professional to deliver best quality care for palliative patients and their families. They are based on and adapted from recognized palliative care resources and institutions. Adherence to guidelines recommendations will not ensure a successful outcome in every case. It is the responsibility of all professionals to exercise clinical judgment in the management of individual patients.

Methodology

Scope and target population

The Saudi Palliative Care Guidelines are a compilation of evidence of best practices in the management of adult patients with life limiting illnesses [3]. They are designed for use by healthcare professionals in any care setting who are involved in supporting people with a palliative life limiting condition.

The guidelines have been developed by a multidisciplinary group of professionals working in the community, hospitals, and specialist palliative care services throughout Saudi Arabia. The guidelines have been developed in accordance with AGREE Criteria and as per request and support from the National Cancer Center at the Saudi Health Council. This guideline was developed for primary and specialty healthcare professionals caring for adult patients with life-limiting, life-threatening or chronic, progressive illnesses. Also, for patients seeking

curative or life-prolonging treatments; or patients who are best served by active end-of-life management.

Process

Phase 0: In preparation for Saudi Palliative Care Guidelines development; National Cancer Center (NCC) at the Saudi Health Council (SHC) did several meetings to assess the current situation and put the best suitable plan for the guideline's development [4]. Meetings to develop and finalize the plan was conducted from May until August.

Phase 1: In August 2017 a central team from the National Cancer Center at the Saudi Health Council, Riyadh was developed to formulate a committee of Palliative care experts which consisted of 14 members from across the country, with two administrative staff for support and logistics.

The selection of members was based on the following criteria:

- I. Senior Palliative Care consultant.
- II. Have academic or research interest.
- III. From different health care provider.
- IV. Geographical distribution.
- V. Multidisciplinary team represented

The selected members were informed about the systemized process for the guideline's development, and tasks for each team members was assigned in accordance with EBM framework [5].

Phase 2: A process to develop and review 22 palliative care clinical guidelines by all committee members utilizing a systemized process was completed by November 2017. Each guideline was reviewed by each member, with agreement that all guidelines would follow the following sequence: Introduction; General Guidelines; Assessment; Management/ Procedures; References; and Appendix

Phase 3: by December 2017, a final draft of guidelines was developed and is awaiting approval from the respective scientific committees.

Phase 4: After Approval, a 3-year implementation plan will begin. The implementation plan will include a briefing of all Palliative Care Department Directors by the respective national guidelines teams. Also, Specialty specific workshops to be conducted. Develop centralized resources by having a Web page under the National Cancer Center at the Saudi Health Council with these guidelines [6].

Result

Guidelines were completed and awaiting approval within the set time frame. No pre-existing national guideline in palliative care was available before. Flexibility within a defined framework was given. The committee members dedicated their own time to work on guidelines. About 4-5 meetings were conducted with 3-10 major revisions to come up with the final results. Different approaches for different specialty practices was used. Copyright and permissions were needed and obtained as appropriate. Time frame for the project was 4 months to 6 months.

Conclusion and Overall Reflection

It was a challenging but vital project. The process of developing guidelines is as important as the outcome. There was an organizational learning. Repository of good practices from various PC specialties practice and better understanding of their needs.

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