

Recommendations to Improve Palliative Care Provision for Marginalized Populations: Summary of a Roundtable Discussion

Claude Chidiac, MRes, MSc, RN, FHEA,^{1,*} Aline El Zakhem, MD,^{2,3,*}
Hibah Osman, MD, MPH,^{3,4} and Rana Yamout, MD^{3,5}

Abstract

Palliative care is increasingly recognized as fundamental to health and human dignity. However, a growing body of evidence highlights the variations in access to palliative care based on personal characteristics, belonging to a certain group, and socioeconomic background. Discriminatory attitudes and behaviors and lack of legal reform protecting the rights of marginalized populations are still common, particularly across Lebanon and the Middle East and North Africa region. This article presents a summary of a roundtable discussion organized by the Lebanese Medical Association for Sexual Health in collaboration with the Lebanese Center for Palliative Care-Balsam, focusing on improving palliative care provision for the following populations: prisoners; lesbian, gay, bisexual, and transgender people; refugees; migrant domestic workers; and people with substance use disorder. It also offers recommendations based on the key themes identified from the discussion, in the hope that they will guide the development of guidelines and policy to advance equity in palliative care provision for marginalized populations.

Keywords: disparities; health equity; marginalization; palliative care; stigma; underserved populations

Introduction

PALLIATIVE CARE is increasingly recognized as fundamental to health and human dignity. Both human rights and health care groups have been advocating to improve equity in service provision without discrimination.^{1,2} Despite this, a growing body of evidence highlights the variations in access to palliative care based on personal characteristics, belonging to a certain group, and socioeconomic background.³⁻⁶ While existing models of palliative care are currently focusing on early access to care,⁷ they have largely failed to meet the needs of vulnerable and marginalized populations.^{3,4} Vulnerable people who are able to access health care tend to receive suboptimal care, and as a result, many avoid or delay seeking care. In the case of stigmatized and vulnerable persons with advanced illness, many spend

their final days in settings that have limited resources, expertise, and support where preferences and wishes are often ignored, and death is unplanned.^{5,6,8,9}

Lebanon has witnessed recent developments in the area of palliative care with an increase in service providers and changes in legislation aimed at improving access to services and opioid analgesics.¹⁰ Despite this, significant challenges remain, which impede adequate access to palliative care. At a governance level, there is no palliative care national strategy that sets out a comprehensive framework aimed at promoting high-quality care and integrating palliative care within the wider health care system.¹¹ The Lebanese law in conjunction with cultural taboos, religious beliefs, and lack of public openness about death and dying allows health care professionals and families to conceal the truth from patients regarding their prognosis or diagnosis, regardless of patients'

¹Department of Palliative Care, Homerton University Hospital NHS Foundation Trust, London, United Kingdom.

²Department of Internal Medicine, ³Department of Anesthesiology, American University of Beirut Medical Center, Beirut, Lebanon.

³Lebanese Center for Palliative Care, Balsam, Beirut, Lebanon.

⁴Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts, USA.

*These authors contributed equally to this work.

[†]ORCID ID (<https://orcid.org/0000-0001-9769-8449>).

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wishes and preferences.^{11,12} At the financial level, palliative care services are still neither publicly funded nor covered by most private health care insurance plans.¹¹ This limits the availability of services, and as such, health care professionals are discouraged from specializing in palliative care. At the delivery level, lack of palliative education is a major issue. Specialized palliative care training programs are not available in Lebanon. There are two community palliative care services in the Beirut area, and a few hospitals provide palliative care consults; however, specialized palliative care services remain limited. In parallel, there has been increased advocacy spearheaded by nongovernmental organizations (NGOs) with increased media visibility, and some landmark legal rulings in support of certain marginalized groups such as Lesbian, gay, bisexual, and transgender (LGBT) people and people with substance use disorder (SUD).^{13–16} However, these sporadic initiatives have mainly focused on basic safety issues with limited efforts to improve palliative and end-of-life care for the marginalized person.

In an effort to address the palliative care needs of marginalized populations, the Lebanese Medical Association for Sexual Health (LebMASH) in collaboration with the Lebanese Center for Palliative Care—Balsam (Balsam) organized a roundtable discussion on improving equity in the provision of palliative care. This article is a summary of the roundtable discussion held in March 2019 as part of LebMASH's National LGBT Health Week. It offers recommendations based on the key themes identified from the meeting, in the hope that they will guide the development of guidelines and policy in this area in Lebanon, and the Middle East and North Africa (MENA) region.

Description of the Roundtable Discussion

Balsam is an NGO that was established in 2010 with the aim of advancing palliative care in Lebanon. LebMASH was established in 2012 as an NGO that aims at advancing the rights and health of LGBT people and other marginalized populations. Annually, LebMASH organizes a National LGBT Health Week, which includes several initiatives aimed at increasing public awareness and promoting the health and well-being of LGBT people, and other marginalized groups. As part of the annual LGBT Health Week, LebMASH and Balsam have been jointly working on initiatives to address the palliative care needs of marginalized communities within the wider health care system in Lebanon.¹⁷

After discussions with key stakeholders, including community partners, palliative care providers, and NGOs working with marginalized groups, it was decided that the roundtable discussion will focus on the following populations: prisoners; LGBT people; refugees; migrant workers; and people with SUD. Over 20 participants representing national and international organizations participated in the event (Table 1). Participants used the consensus-based definition of palliative care developed by the International Association for Hospice and Palliative Care¹⁸:

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

The issues relevant to each population were explained through opening statements by a facilitator. This was followed by a discussion among all participants, considering possible solutions and their implementation. Ideas and proposed solutions from all participants were synthesized into recommendations by the facilitators and presented back to participants. There were no disagreements or lack of consensus among participants and all recommendations were agreed upon unanimously. The following sections present a summary of the roundtable discussion.

Ending the Invisibility of LGBT People in Palliative Care

The risk of certain serious illnesses is higher among LGBT people compared to cisgender heterosexual people. LGBT people are less likely to attend routine screening and are more likely to engage in risky behaviors compared to their cisgender heterosexual counterpart due to stress from discrimination, homophobia, and transphobia. In Lebanon, LGBT people have been subjected to a long history of anti-LGBT bias, stigmatized identity, and discrimination where legal, social, and institutional support for the LGBT individual remains marginal. The Lebanese Penal Code Article 534 states that sexual intercourse opposing to nature will be punished by imprisonment, and it continues to be used to prosecute LGBT people.¹⁹ Many health care professionals still perceive LGBT people to be mentally ill and require treatment through conversion therapy. In a setting where religion plays an important role in daily life, LGBT people may face additional existential distress and inequity in religious and spiritual

TABLE 1. ROUNDTABLE DISCUSSION FACILITATORS

Name	Title	Organization
Dr. Asaad Kadhum	Chief of Health	United Nations High Commissioner for Refugees
Dr. Aline El Zakhem	Medical Director	Lebanese Center for Palliative Care—Balsam
Mr. Claude Chidiac	Executive Board Member	Lebanese Medical Association for Sexual Health
Dr. Ramzi Haddad	Co-Founder and Head of Treatment Program	Lebanese Addiction Center—Skoun
Mr. Karim Mrad	Captain and Inspector General	Human Rights Department, Lebanese Ministry of Interior
Ms. Elena Fassi	Case Worker	Anti-Racism Movement
Ms. Malani Kandearachchi	President	Sri Lanka Women Society

support, as many religions regard homosexuality as unnatural. The two largest religious groups in Lebanon are Islam followed by Christianity, and both condemn homosexuality. All these factors have led to distrust in public and health care services, and many LGBT people continue to lead a double life to avoid rejection by family, services, and society.

The issues and needs specific to palliative care include late or no access to care due to anticipated discrimination and previous negative experiences; fear of disclosing one's identity; negative attitudes of health care professionals; lack of knowledge and understanding of LGBT issues and needs among health care professionals; misconceptions about "family of choice" and next of kin; disenfranchised grief; and the social challenges that same-sex partners experience as caregivers.

Participants discussed how legal reform, public education, and collaboration between palliative care services, members of the LGBT community, and LGBT organizations are necessary to improve equity of care. They called for approaches to creating LGBT-affirmative care at individual and service levels. In the Lebanese context, this needs to include a clear nondiscrimination statement and policy based on sexual and gender identities; increased visibility of LGBT-friendly materials in palliative care services; use of inclusive language in the assessment process; and incorporating LGBT topics in palliative care curricula. LebMASH has developed LebGUIDE, an online directory, which lists LGBT-friendly health care providers, including palliative care providers, who have been screened for their attitude and behaviors toward LGBT people through a self-reported survey. Promotion of LebGUIDE was proposed as a means to proactively engage with the LGBT community. In addition, research related to the impact of sexual orientation and gender identity on palliative and end-of life care needs is needed to inform practice and service planning in the region.

Integrated Palliative Care Services for People with SUD

SUD-related deaths have been increasing globally. According to the Lebanese Addiction Center—Skoun, the number of people suffering from drug addiction in Lebanon was estimated at 10,000–15,000 in 2010. People with SUD are at increased risk of premature death, homelessness, mental health problems, and financial difficulties. They are often stigmatized as being violent, manipulative, and non-compliant with treatment, which can impact their access to health care and the quality of care they receive. This can result in increased health care costs and delayed care as people forego preventive therapies and defer care until they are seriously ill. The Lebanese Ministry of Public Health (MOPH) and Ministry of Social Affairs play an important but partial role in care provision due to limited capacity and alternative priorities, leaving the health and social care of this population primarily in the hands of local NGOs.

In the context of serious illness, patients with a history of SUD are at an increased risk of complications and ineffective pain management. There are currently no guidelines for pain management specific to people with SUD in Lebanon. There is also no coordination of care between treatment centers and prescribers of pain medications, and there is no centralized database of opioid prescriptions to monitor dispensed medications. Opioid misuse, diversion, and drug interactions are

more common in this population, and patients in recovery are at increased risk of relapse. As a result, patients with a history of SUD often do not receive adequate pain management.

Participants discussed how care coordination between palliative care services and SUD treatment centers is essential. Training of providers about the specific needs and issues of people with SUD and explicit inclusion of people with SUD in policies related to pain management are important steps to meet the needs of this vulnerable population.

Palliative Care for Migrant Domestic Workers

The International Labor Organization estimates that there are 11.5 million migrant domestic workers around the world, of which 19% are working in Arab countries. Lebanon hosts over 250,000 migrant domestic workers from Asia and Africa with limited access to health care. The Lebanese labor law requires workers to be linked to a Lebanese citizen through the Kafala or sponsorship system. The employer is mandated to provide their worker with basic health insurance, which only covers a very limited set of medical services. Laboratory tests, preventive care, management of chronic illnesses, and palliative care are generally not covered. Workers with no sponsorship have no legal status or health insurance coverage and are at risk of deportation if they attempt to access care.

Under the sponsorship system, migrant domestic workers have limited rights and are socially and financially vulnerable. Many are subject to racism and are at the mercy of their employer. For those who develop serious illness and are able to access emergency care, cultural and language barriers tend to be ignored. Health care providers are more likely to refer to the employer as the decision-maker, leaving the worker with little autonomy over their care. Migrant domestic workers who develop a serious illness may receive basic medical treatment in Lebanon and return to their country to receive further care. However, even returning to their country of origin may be problematic as it is subject to the will of the employer, who may or may not facilitate the process.

Participants discussed the efforts by activist groups that aim to eliminate the sponsorship system and provide workers with adequate rights. Improvement of insurance coverage is essential to increase access to health care. Cultural sensitivity and identifying communication needs should become core elements of training and development programs. In addition, advocates and interpreters should become an essential part of care delivery for people with limited social network, with language and cultural barriers, and/or who cannot make decisions on their own.

Palliative Care in Prisons

It is estimated that there are 110 prisoners per 100,000 people in the MENA region with 7000 prisoners in Lebanon distributed among 23 prisons. Health services in prisons are limited. The central prison in Roumieh is the only prison with a medical unit on-site, which provides acute care to inmates. Male prisoners undergo mental health screening on prison entry. However, the prison system does not provide any other preventive health services. Inmates requiring hospitalization are transferred to government hospitals affiliated with the MOPH.

The prison population tends to be older due to stringent sentencing, which results in long periods of incarceration.

This increases the likelihood that an inmate will be diagnosed with a serious illness at some point during the prison sentence. Inmates diagnosed with a terminal illness may be transferred to less crowded areas of the prison, and their family members may be granted exceptional permission for more frequent visitation. In 2002, the penal code was amended by a judiciary Sanctions Reductions Committee to allow for early release and death at home.

Challenges to the care of prisoners include budgetary constraints, lack of availability of pain medications, lack of a referral mechanism to specialists, administrative complexities, security issues, and lack of skilled support. There is a strong interest in increasing access to health care in the Lebanese prison system in general, and the notion of providing palliative care to patients with serious illness was welcomed.

Recommendations by the panel focused on providing palliative care training to health care professionals at the prison medical unit as well as establishing affiliations between the prison system and hospitals that provide palliative care services. Representation of palliative care on the Sanctions Reductions Committee was also suggested as a means for identification of people with palliative care needs. Defining of eligibility criteria and collecting data on the number of inmates who could benefit from palliative care would be helpful to assess needs and plan future developments. Involvement of inmates as volunteers to offer psychosocial support was proposed as part of the initiative. All efforts should be in coordination with the Internal Security Forces (ISF), MOPH, medical unit in Roumieh central prison, and the Human Rights Office in the prison system.

Palliative Care for Refugees

With conflicts forcing displacement of large populations in the region, Lebanon has become home to hundreds of thousands of refugees. In 2017, the United Nations High Commissioner for Refugees (UNHCR) estimated that one in six people living in Lebanon are refugees or asylum seekers. It is estimated that 14% of refugees have chronic illness in Lebanon, and almost one third (29%) of this population report challenges in accessing care. The UNHCR provides coverage of secondary health care to refugees with ~80,000 referrals to 40 hospitals every year. Refugees receive the same basic package of care and services regardless of nationality. The UNHCR provides ~75% of the costs of life-threatening situations, and refugees are expected to cover the remainder. When patients require hospital care, UNHCR subsidizes the cost of care. In cases of serious illness, the ceiling of cost coverage is usually exceeded in the very early phases of treatment, and as treatment continues, the refugee accumulates debt.

An Exceptional Care Committee (ECC) meets every two weeks to assess complex cases and provide evidence-based recommendations, allowing UNHCR to prioritize resources for life-saving conditions. Lack of clear guidelines and standards of practice endorsed by the MOPH, regulations limiting access to opioid analgesics, geographic distribution of refugees, and lack of data on refugees who could benefit from palliative care create challenges in developing a system that meets the needs of this population.

Introducing palliative care services to the refugee population could help decrease the burden of unnecessary treat-

ment, decrease health care costs, and improve quality of life. Proposed interventions included a call on for the government to adopt the recommendations published by the World Health Organization (2018) on integrating palliative care and symptom relief into the response to humanitarian emergencies and crises.²⁰ This includes the development of guidelines, regulations, and referral networks to integrate palliative care services in the care of refugees. Provision of training and information sessions to personnel in affiliated hospitals, as well as members of the ECC, would also be helpful. In addition, a palliative care specialist could serve on the ECC or provide consultation services on patients admitted to hospitals upon the request of UNHCR.

Discussion

To our knowledge, this roundtable discussion was the first initiative which sought to explore strategies to improve equity in palliative care provision for marginalized people in Lebanon and the MENA region. It identified barriers and facilitators to accessing care and offered recommendations at multiple levels, including individual, organizational, educational, policy, and research levels (Table 2). While some of the palliative care needs of marginalized populations are similar to the rest of the population, there are additional clinical considerations that need to be identified. Marginalized people living with advanced illness face additional stressors due to their stigmatized identity, limited social and family support network, and legal concerns. While all people facing advanced illness are vulnerable as they near the end of life, certain groups are made more vulnerable.²¹ This occurs when hidden assumptions about certain communities influence care practices and policies. These assumptions can lead to differential treatment and exclude people from standard care practices,²² resulting in additional stress at a time of increased vulnerability.

In recent years, there have been significant policy recommendations to improve health care access for marginalized communities.^{23–25} Despite this, discrimination, marginalization, and inadequate care remain a reality for many people. While legal reform protecting the rights of vulnerable people has been implemented in western countries,^{26,27} this has not occurred globally and particularly across Lebanon and the MENA region. This ultimately delays access to care, resulting in unrecognized needs and avoidable suffering.

Living with a life-limiting illness or bereavement can create psychosocial and spiritual challenges,²⁸ and marginalized people living with a stigmatized identity face additional stressors.²⁹ Public health approaches in the form of partnerships between health care organizations and NGOs, health promotion programs, public education, and engagement with members of the marginalized communities are needed. Such approaches can positively influence attitudes related to marginalized communities and the psychosocial and emotional morbidity associated with bereavement or living with advanced illness.^{28,30}

In addition to public health approaches, embedding palliative care education into existing health care curricula is an important step toward providing patient-centered dignified and humane care. Introducing providers to the palliative care approach and identification of patients who could benefit from specialist input are crucial. To meet the needs of a diverse

TABLE 2. RECOMMENDATIONS TO IMPROVE CARE FOR MARGINALIZED POPULATIONS WITH ADVANCED ILLNESS

Individual	Avoid value-laden assumptions or questions Demonstrate cultural sensitivity and reflective practice Promote and respect autonomy and preferences of individuals Explicitly involve the individual and those important to them in their care
Organizational	Increase visibility of marginalized populations Initiate collaborations and engagement with members of marginalized populations Initiate collaborations between health services and NGOs that work with marginalized populations Include content related to marginalized populations in professional development and induction programs Initiate advocacy programs and assign advocates for people with limited social network, who are vulnerable, or who are not able to make decisions about their own health Initiate routine data collection and monitoring Ensure palliative care is represented in service planning and development
Policy	Develop nondiscrimination policies Include marginalized populations in relevant policies Ensure palliative care is represented in decision-making bodies and health-related strategies
Educational	Incorporate palliative care education in existing health and social care curricula Include content related to marginalized populations in palliative care education programs Include communication skills and cultural competence training as core components in health care curricula and professional development programs
Societal	Promote public education Include marginalized populations in health promotion programs Increase visibility of marginalized populations in the media and other public initiatives
Research	Set palliative care research priorities for the region Involve and consult with members of marginalized populations in research planning Conduct research with marginalized populations Conduct research on person-centered outcomes and communication needs

NGOs, nongovernmental organizations.

population, a culturally responsive approach to palliative care is needed. Therefore, cultural competence in palliative and end-of-life care communication should become an essential component of training and development for all health care professionals and those working with marginalized people with advanced illness. Health care education and professional development programs need to promote self-reflection and encourage health care professionals to develop awareness of own beliefs, attitudes, behaviors, biases, and prejudices. Simple changes in practice can significantly improve the care experience of marginalized people, such as avoiding value-laden assumptions or questions, and explicitly involving those important to the person in their care. Moreover, palliative care providers should be integrated into decision-making bodies and serve as advisors or expert consultants to provide input on policies, service planning, and relevant cases.

There is lack of routine collection of data and research with marginalized communities. Routine collection of data and interdisciplinary health care research in collaboration with marginalized communities are needed. Research focusing on person-centered outcomes and communication needs are specifically lacking in Lebanon and the MENA region. Such research is needed to inform service planning and development, improve the care experience of marginalized people, and support health care professionals to be able to identify those with acute needs, and inform education programs.

The dissemination of the recommendations from this roundtable discussion has occurred through a variety of channels. A mass media campaign led by LebMASH resulted in the recommendations and issues pertaining to marginalized groups being discussed on several national television shows to raise public awareness. In addition, several articles and blogs were

published about the event and its outcomes in national newspapers and magazines.^{31,32} The participants in the roundtable discussion have played a crucial role in sharing the recommendations with policymakers, as the majority assume key leadership roles within government and international agencies, and relevant NGOs. Therefore, forging partnerships with the participants and their organizations is a key step forward toward advancing palliative care for marginalized groups in Lebanon. Despite the dissemination efforts, there remain significant challenges in translating the recommendations into practice, especially with the current situation in Lebanon. The Covid-19 pandemic has created an unprecedented tragedy around the world. In Lebanon, this was accompanied by severe political and economic unrest. In addition, the dire health and humanitarian crises were made worse by the devastating explosion in Beirut on August 4, 2020.³³

Although the participants in the roundtable discussion included members of the LGBT community and a representative of the migrant domestic workers, we acknowledge that the voices of prisoners, people with SUD, and refugees were not represented. This warrants follow-up collaborative efforts with all direct stakeholders in the near future to ensure that the recommendations are produced by and for all involved. It is challenging to address the detailed issues and needs of all the groups and the diversity among and between the different groups in a one roundtable discussion. However, this roundtable discussion broke new ground and started a dialogue about a topic that has never been previously addressed in Lebanon. It sought to address a gap in palliative care service delivery and to function as catalyst for advancing equity in palliative care provision for marginalized communities in Lebanon and the MENA region.

Conclusion

Lack of access to palliative care due to personal characteristics, belonging to a certain group, or socioeconomic background is unjust and at odds with palliative care principles. Focused efforts at individual, organizational, societal, policy, and research levels are needed to improve the care experience and address issues related to accessing care for marginalized populations. This roundtable discussion initiated a dialogue about improving equity in palliative care provision for marginalized populations in Lebanon and the MENA region. It offers recommendations that can guide policy development in the region and beyond. The eagerness and commitment from participants were striking and warrant continued collaborative efforts toward further developments.

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Address correspondence to:

Rana Yamout, MD, MPH

Department of Anesthesiology

American University of Beirut Medical Center

Maamari Street, PO Box 11-0236, Riad El Solh

Beirut 1107 2020

Lebanon

E-mail: ry30@aub.edu.lb