

PALLIATIVE MEDICINE AND HOSPICE CARE

Open Journal 

February, 2015 • Volume 1, Issue 1

Editor-in-Chief : Michael Silbermann, PhD

Associate Editors : Nathania Bush, DNP, APRN, BC

Karis Kin-Fong Cheng, RN, PhD, FHKAN

John Weru, MB, CHB, MPC



TABLE OF CONTENTS

Opinion

1. Importance of Psychological Research in Palliative Care: Barriers in its Development 1-3
– Joaquín T. Limonero* and Francisco Gil-Moncayo

Opinion

2. The Fight against the “Human Disaster” of Cancer in the Middle Eastern Countries 4-7
– Manal Al-Zadjali and Michael Silbermann*

Review

3. Spirituality and Religiosity during the Perioperative Period for Cancer Patients and their Family: An Integrative Systematic Review 8-15
– Joann B. Hunsberger*, M. Jennifer Cheng and Rebecca A. Aslakson

Review

4. Palliative Care for Nephropathic Patients 16-23
– Gianluca Villa*, Sara Samoni, Paola Di Maggio, Alessandra Spinelli, Silvia De Rosa, Fabio O. Tartaglia, Iacopo Lanini, Claudio Ronco and A. Raffaele De Gaudio

Case report

5. The Challenge of Allocating Scarce Medical Resources during a Disaster in a Low Income Country: A Case Study from the 2010 Haitian Earthquake 24-29
– Annekathryn Goodman* and Lynn Black

Opinion

*Corresponding author

Joaquín T. Limonero, PhD

Stress and Health Research Group
Faculty of Psychology

Universitat Autònoma de Barcelona
Campus Universitari s/n 08193

Bellaterra (Cerdanyola del Vallès)
Barcelona, Spain

Tel. +34 93 581 31 76

Fax: +34 93 581 33 29

E-mail: joaquin.limonero@uab.cat

Volume 1 : Issue 1

Article Ref. #: 1000PMHCOJ1101

Article History

Received: March 19th, 2014

Accepted: April 22nd, 2014

Published: April 23rd, 2014

Citation

Limonero JT, Gil-Moncayo F. Importance of Psychological Research in Palliative Care: Barriers in its Development. *Palliat Med Hosp Care Open J*. 2014; 1(1): 1-3. doi: [10.17140/PMHCOJ-1-101](https://doi.org/10.17140/PMHCOJ-1-101)

Copyright

©2014 Limonero JT. This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Importance of Psychological Research in Palliative Care: Barriers in its Development

Joaquín T. Limonero^{1*} and Francisco Gil-Moncayo²

¹*Stress and Health Research Group, Faculty of Psychology, Universitat Autònoma de Barcelona, Spain*

²*Psycho-Oncology Unit, Hospital Duran i Reynals, Institut Català d'Oncologia (ICO), L'Hospitalet de Llobregat, Spain*

Diseases in general, and particularly those that threaten the continuation of life, may affect the person in diverse manners causing suffering or emotional distress. At the end of life, suffering may be caused by different dimensions (physical, psychological, social & spiritual), and these dimensions can contribute separately or in an accumulative way to the experience of suffering. Consequently, the problems related to one dimension can cause or increase others leading to total suffering (in patients and their families).¹

In palliative care the unit of care is the whole person, both the patient and significant others, with the well-being as the goal. To get this aim a multidisciplinary palliative health care team embraces the principles of holistic care with inclusion of psychosocial care as well as physical care.²

Taking in mind the interactive effects of the integrated dimensions of suffering, research on the psychosocial aspects in palliative care (emotional reactions, interactive emotions, coping strategies, spirituality...) is a basic task for later apply this knowledge in the care of the patient and his family to provide comfort or diminish suffering.³

The analysis of the psychosocial aspects in patients with advanced illness or at end of life has a number of characteristics that difficult the study. The barriers to psychological research are related to the following aspects: (1) psychological issues are subjective, variables or constructs are complex and difficult to operationalize, (2) psychological variables are difficult to measure, (3) the patients are fragile, their condition (both physical and psychological state) is mediated by the progress of the disease and the presence of impending death, (4) health professionals had limited time to conduct assessments or research, (5) and there was a lack of validated clinical tools.³⁻⁶

In psychological research, in many cases, the complexity of construct to study has been conceptualized in various ways, aspect that difficult research. It is particularly important to provide as clear a definition as possible for what is assessed. For example, the complexity of the meaning of life construct or the well-being construct reflects a lack of consensus among researchers as to what constitutes the essential dimensions of these constructs.⁷⁻⁹

One of the crucial aspects of psychological assessment is related to the instruments of assessment or screening used. In this sense, it is necessary to have adequate tools to assess emotional distress or suffering and the specific emotional reactions that occur in this difficult situation.¹⁰

These inherent aspects at the end of life situation difficult in many case the assessment of psychological aspects and the effectiveness of psychological intervention. The causes of emotional distress or suffering are multiple and changing in time and with the progress of disease, which implies the need to assess the patient's condition holistically and continuously.⁹ These difficulties are evident, therefore, in the development of assessment instruments or screening measure.

Bearing in mind the specific characteristic of patient at end of life, the ideal assessment tool should meet the following criteria: 1) simplicity and ease of implementation; 2) language of questions adapted to patients; 3) avoid the iatrogenic with a excessive number of items; 4) to assess relevant aspects for the patient in their situation; 5) short implementation time; 6) that allows

monitor the evolution of emotional patient's condition over time; and 7) to facilitate their derivation, if necessary, to a qualified professional for specific assessment and intervention.^{5,6,11}

In addition to these characteristics, to facilitate clinical implementation, the assessment tools should be easy to use, without requiring extensive training.⁴

Given the above comments, we find that there are few tools developed to analyze psychological reactions of dying patient and his family, i.e., specific instruments to assess psychological aspects in palliative care.⁶ However, this should not be an obstacle, but an opportunity to research and develop specific and validated clinical tools. For example, in the nineties we developed an easy screening tool to assess suffering in patients at the end of life based on the subjective patient perception of time. We asked the patients how long did yesterday (long, short or regular) and the reason of their answer. We obtained the subjective perception of time, as an indirect indicator of well-being or discomfort and the factors that positively or negatively may contribute to the same.^{12,13}

In this field, is very important to take in consideration a theoretical framework of reference to understand the emotional reactions of dying patients or their caregivers as well to develop a screening tool.⁶ For this, we have to take time to reflect, search psychological models to apply in this field or built a new model based in previous models or in research finding, as for example the Threat and Resources Model of Bayés et al¹⁴ or the Integrated View Model of Suffering.³ In this last model, for example, suffering is defined as a multi-dimensional and dynamic experience of severe stress that occurs when there's a significant threat to the person and coping efforts are insufficient, leading to perceived loss of control and loss of balance or homeostasis. In the case of end of life, threat occurs both at a mind and body level; therefore suffering entails cognitive, emotional, spiritual and physiological changes and responses oriented to recover homeostasis.

In this sense, at the beginning of palliative care, the focus on psychological aspects relied in the study of the phases of emotional reactions of dying patients, e.g. Kubler Ross,¹⁵ currently, the research are diverse and are related for example to the following topics: discrete or complex emotions, emotional distress and suffering, coping strategies, resilience, spirituality, dignity, psychological interventions..., both the patient and his family. In this sense, we want to emphasize Dignity Therapy intervention developed by Chochinov¹⁶ to enhance dignity and the sense of legacy in the terminally ill and the Meaning-Centered Psychotherapy developed by Breitbart¹⁷ to help to the patients with cancer to live with sense, of a full way, keeping and expanding the sense of his life, living in peace and with an aim in the life. These two models appointed the need to structure the intervention, giving the possibility to replicate the same models in different contexts, and with different therapists. Also, they guide us in the objectives, the process and therapeutic techn

iques and the future results expected with our intervention.¹⁸

Despite the achievements of the previous psychological interventions, a recent review of psychological intervention in cancer highlights the difficulty of comparing different psychological therapies, since the elements that compose or the mechanisms underlying them are not specified in many cases. This lack of clarity is a potential obstacle to the provision of a coherent evidence base if we compare with drug treatment that is more concrete.¹⁹

The legacy of psychological research is not very big, but is a great help to better understand the emotional reactions of dying people and help us to design the most effective psychological interventions. But isn't enough, the challenge of psychological research in palliative care is enormous,²⁰ further research is needed, despite the difficulties, since the psychological care is the cornerstone of palliative care.

REFERENCES

1. Krikorian A, Limonero JT, Mate J. Suffering and distress at the end-of-life. *Psychooncology*. 2012; 21(8): 799-808. doi: [10.1002/pon.2087](https://doi.org/10.1002/pon.2087)
2. World Health Organization. WHO Definition of Palliative Care. World Health Organization. 2014. Retrieved 04-02-2014 from <http://www.who.int/cancer/palliative/definition/en/>
3. Krikorian A, Limonero JT. An integrated view of suffering in palliative care. *J Palliat Care*. 2012; 28(1): 41-49.
4. Bruera E and Hui D. Palliative care research: lessons learned by our team over the last 25 years. *Palliat Med*. 2013; 27(10): 939-951. doi: [10.1177/0269216313477177](https://doi.org/10.1177/0269216313477177)
5. Bayés R, Limonero JT. Influencia de la proximidad de la muerte en los factores que pueden ayudar a morir en paz. [Influence of proximity to death on the factors that can help you die peacefully]. *Med Clin*. 2005; 124(14): 556. doi: [10.1157/13073946](https://doi.org/10.1157/13073946)
6. Limonero JT, Mateo D, Maté-Méndez J, et al. Evaluación de las propiedades psicométricas del cuestionario de Detección de Malestar Emocional (DME) en pacientes oncológicos. [Assessment of the psychometric properties of the Detection of Emotional Distress Scale in cancer patients]. *Gac Sanit*. 2012; 26(2): 145-152.
7. Brandstätter M, Baumann U, Borasio GD, Fegg MJ. Systematic review of meaning in life assessment instruments. *Psychooncology*. 2012; 21(10): 1034-1052. doi: [10.1002/pon.2113](https://doi.org/10.1002/pon.2113)
8. Bassett KA. Consensus Operational Definition of Palliative Care In Action. *Institute for Clinical Systems Improvement and the University of Minnesota*. 2012.
9. Limonero, JT, Bayes R. Bienestar en el ámbito de los enfermos en situación terminal.[Well-being in the terminally ill

situation]. *Med Paliat.* 1995; 2: 53-59.

10. Kelly B, McClement S, Chochinov HM. Measurement of psychological distress in palliative care. *Palliat Med.* 2006; 20: 779-789. doi: [10.1177/0269216306072347](https://doi.org/10.1177/0269216306072347)

11. Bayés R, Limonero JT. Prioridad en el tratamiento de los síntomas que padecen los enfermos oncológicos en situación terminal.[Priority for the treatment of symptoms suffered by terminally ill cancer patients]. *Med Paliat.* 1999; 6(1): 19-21.

12. Bayés R, Limonero JT, Barreto P, Comas M. Assessing suffering. *Lancet.* 1995; 346: 1492.

13. Bayés R, Limonero JT, Barreto P, Comas M. A way to screen for suffering in palliative care. *J Palliat Care.* 1997; 13(2): 22-26.

14. Bayés R, Arranz P, Barbero J, Barreto P. Propuesta de un modelo integral para una intervención terapéutica paliativa [Proposal of a comprehensive model for palliative therapeutic intervention]. *Med Paliat.* 1996; 3(3): 114-121.

15. Kübler-Ross E. On death and dying. New York, USA: *Macmillan*; 1969.

16. Chochinov HM. Dying, Dignity, and New Horizons in Palliative End-of-Life Care. *Cancer J Clin.* 2006; 56(2): 84-103.

17. Breitbart W, Gibson C, Poppito S, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry.* 2004; 49(6): 366-372.

18. Gil F, Breitbart W. Psicoterapia centrada en el sentido: "vivir con sentido". Estudio piloto. [Psychotherapy centered on the meaning, "living with purpose": Pilot study]. *Psicooncología.* 2013; 10(2-3): 233-245.

19. Hodges LJ, Walker J, Kleiboer AM, et al. What is a psychological intervention? A metareview and practical proposal. *Psychooncology.* 2011; 20(5): 470-478. doi: [10.1002/pon.1780](https://doi.org/10.1002/pon.1780)

20. Rodin G. Research on psychological and social factors in palliative care: An invited commentary. *Palliat Med.* 2013; 27(10): 925-931. doi: [10.1177/0269216313499961](https://doi.org/10.1177/0269216313499961)

Opinion

*Corresponding author

Michael Silbermann, PhD

Executive Director

The Middle East Cancer Consortium

P.O. Box 7495, Haifa 31074, Israel

E-mail: cancer@mecc-research.com

Volume 1 : Issue 1

Article Ref. #: 1000PMHCOJ1102

Article History

Received: April 24th, 2014

Accepted: May 15th, 2014

Published: May 17th, 2014

Citation

Al-Zadjali M, Silbermann M. The Fight against the "Human Disaster" of Cancer in the Middle Eastern Countries. *Palliat Med Hosp Care Open J*. 2014; 1(1): 4-7. doi: [10.17140/PMHCOJ-1-102](https://doi.org/10.17140/PMHCOJ-1-102)

The Fight against the "Human Disaster" of Cancer in the Middle Eastern Countries

Manal Al-Zadjali¹ and Michael Silbermann^{2*}

¹The Oman Specialized Nursing Institute, Sultanate of Oman

²The Middle East Cancer Consortium, P.O. Box 7495, Haifa 31074, Israel

Cancer is considered to be one of the leading causes of death globally. With the increasing prevalence of cancer, the World Health Organization (WHO) expects cancer cases to surge in the next two decades from 14 million in 2012 to 22 million in 2022.¹ Tremendous efforts are exerted world-wide to fight this "human disaster".

An important example of such efforts is the International Palliative Care Conference sponsored by Turkey's Health Ministry in Ankara during April 2-4, 2014, highlighting the Turkey's 13th National Cancer Awareness Week. Organizing bodies were the Middle East Cancer Consortium (MECC), in collaboration with the Oncology Nursing Society (ONS), the National Cancer Institute (NCI), and the American Society of Clinical Oncology (ASCO). More than 70 participants from the following countries attended the conference: United States of America, Egypt, Iran, Iraq, Israel, Jordan, Lebanon, Pakistan, Palestinian, Qatar, Kingdom of Saudi Arabia, Sudan, Sultanate of Oman, Turkey, United Arab Emirates and Yemen.

PALLIATIVE CARE IN MIDDLE EASTERN COUNTRIES

The population in the Middle Eastern countries, as in all other countries world-wide, is aging. Simultaneously, the risk of cancer and cancer prevalence is increasing, presenting a major challenge to the healthcare system.^{2,3,4} Meeting this challenge requires the availability of planned and organized palliative care. Palliative care is a medical service that is delivered to people with life-threatening disorders, aimed at improving quality of life for patients and their families. Palliative care services are provided by a multidisciplinary team to patients at any stage of life and illness.⁵ It is a relatively new field in the Middle Eastern countries; however, it is available in one form or another in almost all of these countries either as an individually established service unit or as an integrated service.⁶

MIDDLE EASTERN CULTURE AND THE CHALLENGES FACED IN TREATING CANCER PATIENTS

The conference started with a presentation discussing the diversity of the Middle Eastern culture that demands the provision of individualized, culturally relevant care to patients.² For example, in the Middle East, the code status is discussed at a terminal, end of life stage, and is usually decided by others, rather than by the patient, despite the patient's cognitive ability to make decisions.² Moreover, the identity of a person in this culture is determined by his/her affiliation to a group-usually a tribal group - on whom he/she depends when trying to cope with illness.² Patients seek treatment in the presence of their extended family, with the family viewing their presence in this situation as an obligation. Bad news is conveyed first to the family, especially to the oldest son to the son's spouse, who are often the family leaders. Females usually leave the decision-making to their husbands.² Bad news is often delivered in stages. Families prefer not to reveal bad news to elder patients, and the truth is often hidden, or a less serious diagnosis is given to the patient to protect him/her emotionally.² In order to accommodate these cultural norms when providing palliative care to Middle Eastern patients, healthcare institutions must surmount a series of barriers ranging from palliative care being focused at the tertiary care level, to the lack of trained personnel or resources; a lack of awareness of patients and professionals of geriatric specialty; and poor communication between professionals, patients and their families.²

Copyright

©2014 Silbermann M. This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

The issue of communication is a major one. It is a vital skill for healthcare professionals in caring for their patients. Since the Middle East is made up of multilingual and multi-ethnic groups, people in diverse regions use language in different ways, with the result that many patients view language as a barrier to seeking healthcare in the health system. Health literacy, and deeply rooted ideas about health and death, can be major barriers in communicating with patients who have cancer. For example, some people believe that illness is a test of their faith, or that it can reduce the burden of their sins.⁷ Such beliefs can hinder communication between the healthcare provider and the patient. This generates a deeper problem in the delivery of healthcare, namely the patients' mistrust of the healthcare system, leading them to seek help from traditional healers and the use of alternative medicine.^{6,8} Consequently, such patients delay seeking help from medical personnel, with the result that cancer is diagnosed only at a late stage⁶ when the prognosis is poor, thus worsening the relationship of the patient and his family with the healthcare provider due to lack of trust.

PALLIATIVE CARE NEEDS ASSESSMENT IN MIDDLE EASTERN COUNTRIES

This year's conference in Ankara was highlighted by the results of a survey of needs assessment carried out in Middle Eastern countries. The survey aimed to assess awareness, activity, and available resources related to palliative care in Middle Eastern health care settings; understand barriers, challenges, and satisfaction in organizing palliative care in the Middle East; and review topics of previous educational programs attended by respondents and their preferred learning methods. Some 16 Middle Eastern countries took part in this survey, constituting a response rate of 78%. The results of the survey further validated the points discussed during the conference. The most often available palliative care services in the healthcare institutions in which the respondents worked were in descending order: pain management consultative team or service; discharge planning for patients with chronic illness; palliative care team or consultative service; ethics committee; palliative care unit; interdisciplinary care program for dying patients; nurses certified in hospice and palliative nursing; professional education program in palliative care; contractual relationship with one or more hospice programs; program to promote advanced care planning; and program for staff support in caring for dying patients. The least available service was the bereavement program.⁹

Middle Eastern healthcare professionals are aware of the lack of time, resources, and educational opportunities available. They are eager to learn more about palliative care and communication, with special attention to specific population groups. They also recommend moving palliative care to home care.⁵ This motivation and readiness to provide improved services is welcomed by several organizations that are ready to strengthen their international collaboration with the aim of advancing palliative care services worldwide. An excellent example of such an organization is the American

Society of Clinical Oncology (ASCO), which works to improve quality of care delivered; enhanced research and innovation; and health care professionals' support and development. In doing so, ASCO provides an International Development and Education Award (IDEA) in palliative care, pairing the recipient of the award with a mentor in palliative care who, after training, will return to his/her home country to serve as an agent of change in integrating palliative care into local services. ASCO also runs international workshops in palliative care and oncology for non-oncologists consisting of short, 2-5 day courses in various aspects of palliative care and oncology. ASCO volunteers travel to different countries to deliver clinical instruction. These are just a few examples of the many services provided by ASCO to enhance global services provided to low-to-middle income countries that can be utilized in the fight against cancer.⁴

ASSESSING AGING CANCER PATIENTS

One of the main areas of focus for preparing professionals in caring for the aging population is training them in the skills necessary to assess this population. Several factors other than age can affect mortality and morbidity, namely functional status, comorbid medical conditions, cognition, nutritional status, psychological state, social support and medications (poly-pharmacy). Consequently, a comprehensive geriatric assessment can be highly productive in predicting mortality and morbidity as well as the toxicity of cancer patients. This can result in better drug toxicity and survival prediction. It can also detect any further undetected co-morbidities, leading to better and more comprehensive care provision for these older adults, and improved pain control and quality of life.¹⁰ For instance, starting a comprehensive geriatric assessment, or assessing the functional status of a patient, is considered a valuable starting point in drawing up a care plan for the geriatric patient. A comprehensive geriatric assessment, however, can predict a better match of treatment and fitness than clinical judgment alone.¹¹

One of the methods to assess the aging cancer patient is by using an exploratory model that assists in planning better care for these geriatric patients. The model should consider involving a geriatrician, and age bias, or ageism, should be considered. A functional assessment should be performed at the start of the provision of palliative services. Additionally, when treating a patient, his/her life expectancy should be considered. The decision-making norms in the patient's family and their preferred communication style should also be assessed. Local resources, community agencies and available support should be sought. Technology should be used wisely and creatively. An interdisciplinary team should be on hand, involving community workers as well. Data should be collected and lessons should be learned from mistakes. The pain threshold is high in the older adult and their symptoms are often underreported. Pain management can face several barriers, including medical co-morbidities, fear of causing delirium or presence of delirium, and age bias. In addition, culture can play a major role in pain expression, although this has not yet been studied systematically.³

CHALLENGES AND OPPORTUNITIES IN ESTABLISHING PALLIATIVE CARE SERVICES IN MIDDLE EASTERN COUNTRIES

Palliative care faces many access and utilization barriers in Middle Eastern countries, ranging from lack of time, lack of funding and resources, and lack of governmental support, to problems related to political instability in some of the countries. These challenges were also supported in a review earlier by Abu Zeinah, Al-Kindi and Hassan (2012).⁶ However, with these challenges come many available opportunities which can be utilized to address the challenges faced by the palliative care. The healthcare professionals in Middle Eastern countries are well aware of the obstacles encountered regarding palliative care. Persistence and advocacy are the key components in establishing palliative care services. Several Middle Eastern countries have established successful non-governmental agencies that provide palliative care. These efforts were exerted by individuals in these countries who were persistent in their demand for this service. An example of such an organization is AlSadeel, established in Palestine.¹²

Several cultural barriers, as well as a lack of awareness, regarding palliative care services persist among healthcare professionals, patients and their families. In order to advance palliative care in these communities, healthcare professionals need to be educated and their awareness of palliative care must be raised by offering them training programs that will enrich their knowledge and skills. This knowledge, in turn, can influence the public and heighten their awareness of the importance of quality of life in caring for terminally ill patients. It will encourage families to advocate and demand such services, rather than leaving the patient unaware of his/her diagnosis, or suffering pain due to a lack of availability of pain medication.

In order for palliative care to be widely accessible and acceptable, the approval of the healthcare organization, and support from larger organizations, is necessary.¹³ Many participants in the conference agreed that the support of organizations such as MECC, ASCO and WHO can be very useful in establishing and running successful palliative care programs. For example, support by the government of the State of Qatar¹⁴ and by the Republic of Yemen¹⁵ was clear, and, although at a tertiary care level, had nevertheless established large units for palliative care. In addition, the integration of palliative care in the health professionals' education curriculum, such as in Oman, is thought to play a vital role both in raising awareness and in heightening the understanding of palliative care among healthcare professionals and the organizations they serve.¹⁶ Consequently, these organizations can raise public awareness to promote the acceptance of palliative services. Participants at the conference suggested several methods of heightening public awareness relating to palliative care, including the use of media, information technology, celebrities, and interpersonal relationships with the larger community.

In discussions about the improvement of palliative care in the Middle Eastern countries, the conference participants suggested several plans that included raising the awareness of the public, the healthcare professionals and the health organizations. They called for the creation of multidisciplinary teams that can provide care based on the best available evidence. These plans, however, were thought to be non-functional without the availability of proper funding and human resources. Notably, human resources referred to health professionals as well as lay people in order to raise public awareness. One of the main suggestions that were discussed in this conference, as at several previous ones, was supporting the availability of treatment modalities-especially pain medication-in community settings, as well as moving palliative care from tertiary care settings to primary healthcare settings, namely, community and home care.

In conclusion, while Middle Eastern culture is diverse in its characteristics, including languages and religions, the aim of the healthcare professionals is one and the same: to improve the quality of life and the care delivered to all patients regardless of color, language, religion and origin. This can be accomplished if people, organizations and policies are put in place to strengthen the base of palliative care in Middle Eastern countries.

REFERENCES

1. World Health Organization (WHO). All cancers (excluding non-melanoma skin cancer); Estimated incidence, mortality and prevalence worldwide in 2012. Website: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx 2012; Accessed April 23rd, 2014.
2. Hajjar R. Cultural Perceptions of Being Old and Their Implications on Cancer Patients. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.
3. Schapira L. Construction of an Exploratory Model of Treating Older Cancer Patients. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.
4. Swain S. Building Regional and Global Bridges to Alleviate Cancer Fear and Suffering While Promoting Cancer Care. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.
5. Center to Advance Palliative Care. What Is Palliative Care? Website: <http://www.getpalliativecare.org/whatis/> 2012; Accessed April 23rd, 2014.
6. Abu Zeinah G, Al-Kindi S, Hassan A. Middle East Experience in Palliative Care. *American Journal of Hospice and Palliative Medicine*. 2012; 30(1): 94-99. doi: [10.1177/1049909112439619](https://doi.org/10.1177/1049909112439619)
7. Silbermann M, Hassan A. Cultural perspectives in cancer care: Impact of Islamic traditions and practices in Middle Eastern countries. *J Pediatr Hematol Oncol*. 2011; 33(Suppl 2):

S81-S86. doi: [10.1097/MPH.0b013e318230dab6](https://doi.org/10.1097/MPH.0b013e318230dab6)

8. Obeidat R. Psychological and Social Difficulties in Communicating Older Cancer Patients. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

9. Fink RA. Palliative Care Needs Assessment of Middle Eastern Countries. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

10. Tew W. Geriatric Assessment. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

11. Smith T. The Geriatric Patient Facing Cancer: Coming up With a Consensus of a Step-by-Step Model. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

12. Khelif M, Al Sadeel. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

13. Moore S, Pirrello R, Christianson S, Ferris F. Strategic planning by the palliative care steering committee of the Middle East Cancer Consortium. *J Pediatr Hematol Oncol.* 2011; 33(Suppl 1): S39-S46. doi: [10.1097/MPH.0b013e3182121d91](https://doi.org/10.1097/MPH.0b013e3182121d91)

14. Hassan A. Palliative Care in Qatar. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

15. Ahmed J. Palliative Care in Yemen. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

16. Al Jabri K. Palliative Care in Oman. Oral presentation, The International Palliative Care Conference, Ankara, Turkey, April 02-04, 2014.

Review

*Corresponding author

Joann B. Hunsberger, MD

Anesthesiology Fellow
Department of Anesthesiology and
Critical Care Medicine
The Johns Hopkins University
School of Medicine
1800 Orleans Street, Room 6349,
D1 Baltimore, Maryland 21287, USA
E-mail: jhunsbe1@jhmi.edu

Volume 1 : Issue 1

Article Ref. #: 1000PMHCOJ1103

Article History

Received: August 31st, 2014

Accepted: November 14th, 2014

Published: November 17th, 2014

Citation

Hunsberger JB, Cheng MJ, Aslakson RA. Spirituality and religiosity during the perioperative period for cancer patients and their family: An Integrative systematic review. *Palliat Med Hosp Care Open J*. 2014; 1(1): 8-15. doi: [10.17140/PMHCOJ-1-103](https://doi.org/10.17140/PMHCOJ-1-103)

Copyright

©2014 Hunsberger JB. This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Spirituality and Religiosity during the Perioperative Period for Cancer Patients and their Family: An Integrative Systematic Review

Joann B. Hunsberger^{1*}, M. Jennifer Cheng² and Rebecca A. Aslakson³

¹Department of Anesthesiology and Critical Care Medicine, The Johns Hopkins University School of Medicine, 1800 Orleans Street, Room 6349 D1 Baltimore, Maryland 21287, USA

²Staff Clinician, Pain and Palliative Care Service Clinical Center, National Institutes of Health, Bethesda, Maryland 20892, USA

³Department of Anaesthesiology and Critical Care Medicine, Palliative Care Program, the Kimmel Cancer Centre at Johns Hopkins, Core Faculty, The Armstrong Institute for Patient Safety and Quality, The Johns Hopkins School of Medicine, 1800 Orleans Street St. Meyer 297A Baltimore, MD 21287-7294, USA

ABSTRACT

Background: Religion and Spirituality (R/S) may influence cancer patient's emotional distress, mental health and healing throughout their diagnosis and treatment.

Objective: This systematic review examines studies exploring R/S of cancer patients and their family in the perioperative period.

Design: We completed a systematic review of the databases MEDLINE, EMBASE, CINAHL, SCOPUS, the Web of Science, and Cochrane library concerning the terms "religion and spirituality" and "cancer surgery". Inclusion criteria included qualitative or quantitative studies evaluating R/S of cancer patients or their family members within the perioperative period (one month pre- and post-surgery). Exclusion criteria included review articles, grey literature, editorials, case studies and studies evaluating R/S of healthcare providers.

Results: Seven publications met criteria for analysis. Five studies described cross-sectional surveys, one used a focus-group approach, and one utilized in-person interviews. Studied populations predominantly were female breast cancer patients. There were considerable heterogeneity in survey instruments, variables, and outcomes. Based on these studies:

- 1) Faith and religious beliefs were used as coping mechanisms during the perioperative period;
- 2) Evangelical Christians tended to differ in religious coping compared to Catholics;
- 3) R/S correlated with coping styles and distress;
- 4) There was increased religious coping and religious involvement during the perioperative period;

Conclusions: Studies evaluating R/S of cancer patients and their families in the perioperative period are few and heterogeneous in design. Direct comparison is difficult, but data suggests that R/S during the perioperative period may increase as compared to R/S during other stages of cancer diagnosis and treatment.

KEYWORDS: Religion; Spirituality; Religiosity; Cancer; Tumor; Surgery; Perioperative.

ABBREVIATIONS: R/S: Religion and Spirituality; HADS: Hospital Anxiety Depression Scale; NORA: Non-Organized Religious Activity; MOS-SSS: Medical Outcomes Study Social Support Survey; PSS: Perceived Stress Scale; IES: Impact of Event Scale; BSI-18: Brief Symptom Inventory-18; RCOPE: Religious COPE; FACT-B: Functional Assessment of Cancer Treatment-Breast; MADRS: Montgomery-Asberg Depression Rating Scale; DRI: Duke Religious.

Index; HADS: Hospital Anxiety Depression Scale.

INTRODUCTION

Many people use religion for comfort and support when faced with a life-threatening illness such as cancer.^{1,2} Patients who had previously disregarded religion and spirituality may search it out when faced with illness.^{1,3} Carver found that all forms of coping, including religious coping, peaked early around the time of surgery for breast cancer patients and then declined over time.⁴ Emerging literature also describes the positive benefits of Religion and Spirituality (R/S) in helping patients cope with distress, pain and anxiety.^{2,5} For cancer patients, R/S has been associated with positive attributes, specifically with enhanced well-being, decreased depression and anxiety, increased meaning and feelings of hope, increased optimism and inner peace and preventing end of life despair.² However, Cohen described a positive correlation between R/S coping and increased pain reporting and post-operative analgesic use amongst women undergoing major abdominal surgery. Though this study was not specific to oncologic patients, it does suggest that increased R/S may not necessarily relate to what medical providers consider “improved outcomes”.⁶

Religion and spirituality have traditionally been combined in the literature; however they are two separate concepts.⁷ Religion refers to an organized system of faith beliefs within the context of structured practices and ways of worship (e.g. Catholicism, Islam, Judaism) and codified beliefs.^{8,7} Religion is a social institution, often culturally based and a way to express spirituality.⁷ The concept of spirituality is broader than the concept of religion and refers to a personal connection with something that provides meaning to one’s life.^{8,9} Spirituality does not require specific rituals, practices or even a belief in God but encompasses the transcendent and non-worldly quality of relating to other persons, a God-being or material nature.⁸ Spirituality does not have the boundaries of the religious institution but instead is a dynamic concept that refers to the ongoing search to discover meaning.⁹ However, for this systematic review, religion and spirituality are combined as a single concept because this is how it is presented in the literature and we are unable to separate the two concepts from the available data.

Many studies examine R/S but only do so several months after initial diagnosis and/or after months of treatment, when coping and adjustment mechanism are already in place. Yet, for many cancers, a first and major treatment option is surgery and this may be a time when R/S needs are high. The perioperative physicians, including anesthesiologists, surgeons and hospitalists, care for patients during this stressful time period, yet have very little guidance on how to manage the patient’s heightened stress of the day of surgery and the time period immediately adjacent to it. As an example of a type of cancer surgery for which there is which there is a major perioperative adjustment for both the patient and family member, Grandstaff outlines four crucial periods of adjustment to mastectomy: 1) the days surrounding surgery as the patient has fear and apprehension about

the surgery, 2) immediately after the surgery when the patient realizes the post-operative physical changes, 3) 2-3 weeks after surgery when the patient’s partner responds to the surgical incision and 4) 4 weeks post operatively when the patient and partner resolve issues of intimacy and acceptance of physical changes from mastectomy.¹⁰

As Grandstaff notes, there is an exaggeration of stress immediately prior to surgery, due to apprehension about the surgery, and then for the next several weeks after surgery, but within one month of surgical treatment. This is the time period that the perioperative physician provides care. In order to summarize the studies exploring cancer patient’s perioperative R/S experience and needs, we completed this systematic review, with the intention of laying the ground work for future studies that will guide development of interventions for perioperative spiritual support.

MATERIALS AND METHODS

Data Sources and Searches

This systematic review includes published studies using interview, survey or questionnaire studies that examined the spiritual or religious experiences of patients during the perioperative period. We searched MEDLINE, EMBASE, CINAHL, SCOPUS, the Web of Science, and Cochrane library as of July 27, 2012. A Johns Hopkins Medical Institution Clinical Information’s assisted in defining the search terms and strategy. The terms used to define each concept included a combination of controlled vocabulary and key word terms and phrases such as “religion” or “religion and medicine” “spirituality” and “surgery” or “resection” or “carcinoma” or “tumor” or “cancer.”

Study Selection

Inclusion criteria included studies: exploring religious or spiritual experiences, in the English-language, and which involved adults (greater than 18 years of age) with cancer or a potential diagnosis of cancer and which were conducted during the perioperative period. The perioperative period was defined as one month prior to or after surgery. We excluded review articles, studies that did not have data reported and unpublished grey literature. Dual, independent investigators completed title/abstract and then full article screens. Disagreements about article inclusion and exclusion were resolved through discussion between the reviewers.

Data Extraction and Analysis

Formal abstraction sheets were used to extract information from included articles. Abstracted data included study population demographics, type of study, perioperative timing and outcome. For analysis, the data was divided between pre-surgery and post-surgery outcomes. We characterized outcomes

based on their relevance to religion or spirituality, including support from church or church groups, comparison between religious groups, religious coping and religious practices. Emotional coping and support was also abstracted and analyzed. If applicable, comparison between family member and patient coping was made. Data abstraction and analysis was completed concurrently by two independent reviewers and any discrepancy between reviewers was clarified through discussion.

RESULTS

The search strategy returned 1499 articles and de-duplication yielded 972 articles for title/abstract screen. Of this, 53 studies were included for full article review which yielded a final seven articles (see Figure 1).^{1-3,5,11-13}

Of the seven included studies, six enrolled women with breast cancer and one study enrolled men with urologic cancers, primarily prostate cancer. The study populations were ethnically and geographically diverse with one study conducted in Turkey, one in South Korea, one in Canada, one in the United Kingdom. Of the three studies conducted in the United States, one study specifically focused on Hispanic women while the other two studies did not have an ethnic focus. Sample sizes were small and ranged from 20 to 284. One study about breast cancer patients also included the patient’s spouses.

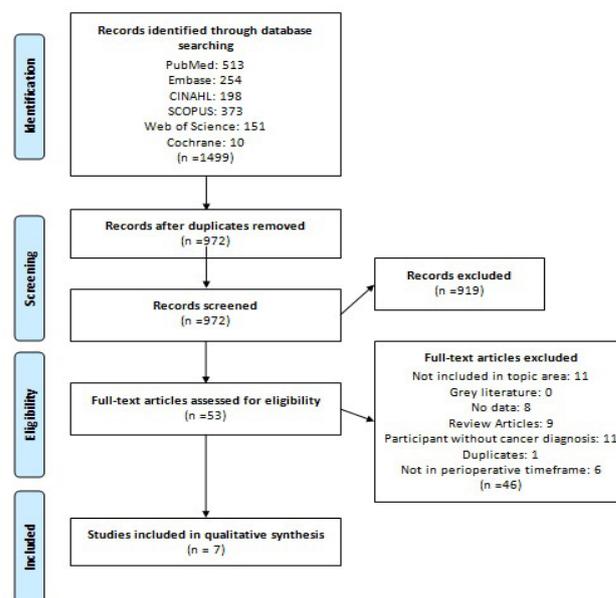


Figure 1: Flow diagram showing inclusion and exclusion of articles

Six of the studies were prospective while one included a retrospective section requiring patients to recall information about them one year prior to the study.¹¹ All studies except for two used a questionnaire or survey for assessing outcomes. Sixteen different outcome measures were used (see Table 1 and Table 2), such as: religiosity/spirituality, patient stress coping,

Publication	Study Population	Faith Tradition	Type of Study	Perioperative timing	Outcome measures
Alferi SM et al, J Health Psychol 1999 ¹	N=49 Hispanic women (FL) lower socio-economic status Average age= 56.37 yrs Early stage (stage 0/II) breast CA 47% married, 12% separated, 18% divorced, 16% widowed	72.5 % Catholic Evangelical group: Jehovah's Witness, Evangelist, Pentecostal, Baptist, non-denominational	Prospective study, single arm, single center	Initial interview, post-surgery interview 7-10 days after surgery, follow-up interview 3,6, and 12 months after surgery	<ul style="list-style-type: none"> Religious involvement COPE POMS
Biegler K et al, Integr Cancer Ther 2011 ²	N=115 men (TX); Average age= 58.3 yrs 89% prostate cancer, 10% renal cancer, 1% bladder cancer, 71% some college education, 75% Caucasian, 90% Married or living with partner	93% Christian (Catholic or Protestant)	One time, cross sectional survey	Pre-op visit, about 7 days prior (range 1-29 days)	<ul style="list-style-type: none"> Intrinsic religiosity ORA, NORA Brief COPE MOS-SSS Distress: PSS, IES, BSI-18, POMS
Demir F et al. J Clin Nurs 2006 ³	N=20, women (Turkey) with excisional breast biopsy, returned one week later for monitoring.	Not noted	Phenomenological approach	1 week post-op office follow-up visit. One hour interview.	Patients were invited to talk about their experiences. Allowing patients' own practical worlds and concerns to be revealed.
Gall TL et al, Psycho-Oncology 2009 ⁵	N=93 breast cancer N=160 benign diagnosis, women (Canada) Average Age=60.9/52.7 yrs, 96.8/93.8% Euro-Canadian 66.7/70.6% Married or Common law, 14/6.2% Single, divorced	44.1/42.7% Catholic 36.6/42.0% Protestant 11.8/11.5% No religion	Prospective study, single arm, single center	Pre-diagnosis, 1 week pre-surgery, and 1 month, 6 mo, 1 yr, and 2 yrs post-surgery	<ul style="list-style-type: none"> Religious involvement (pre-diagnosis) Modified RCOPE 10 subscales POMS FACT-B: only emotional well-being
Jang, Ji-Eun et al, Psycho-Oncology 2012 ⁵	N=284; women, breast cancer patients pre surgery (South Korea) Mean Age= 49.8 yrs, mean years education: 11.0	35.2% Protestant 26.4% No religion 22.2% Buddhists 16.2% Catholics	Prospective Study, questionnaire and interview	Baseline (within 5 days of surgery) and 1 year post-surgery	<ul style="list-style-type: none"> DRI MADRS HADS EORTC QLQ-C30
Northouse, L. L., Cancer Nurs 1989 ¹²	N= 50; Women, post mastectomy and husbands (Southwestern Michigan) Mean age: 50.4 yrs patients, 52.3 yrs husbands Ave yrs education= 13-14	None noted	Prospective, qualitative study, two phase, multiple centers.	Baseline (1 to 6 days post surgery) and 30 days post surgery. Interviews conducted separately with patient and husband	Structured interview developed by investigator. Patients described greatest concerns about illness and reaction to seeing the mastectomy site; identified most stressful phase of illness and factors that helped them to cope
Thune-Boyle, I.C.V. et al, J Relig Health 2011 ¹¹	N= 202 Newly diagnosed breast cancer, women (UK) N=110 healthy, matched, control subjects. 81/84% Caucasian, 44/49% Married, 15/16% Single, Mean yrs education: 14.4/14	42/44% Protestant 23/22% Catholic 18/27% No religion 8/1% Jewish	Retrospective, between-subject design and within subject design	Post surgery (average=3 days) Retrospectively compared newly diagnosed patient's current religious/spiritual beliefs with beliefs in year prior	<ul style="list-style-type: none"> Single item questions to evaluate R/S beliefs ORA and NORA

Coping Responses (COPE, Brief-COPE), Profile of Mood States (POMS), Organized religious activity (ORA); Nonorganized religious activity (NORA), Medical Outcomes Study Social Support Survey (MOS-SSS), Perceived Stress Scale (PSS), Impact of Event Scale (IES), Brief Symptom Inventory-18 (BSI-18), Religious COPE (RCOPE), Functional Assessment of Cancer Treatment-Breast (FACT-B), Montgomery-Asberg Depression Rating Scale (MADRS), Duke Religious Index (DRI), Hospital Anxiety Depression Scale (HADS), European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30)

Table 1: Summary of studies included in the review

Outcome instruments Studies	Description
Religious Involvement Alferi ⁷	<ul style="list-style-type: none"> • Items from General Social Survey • Importance of religion, frequency of church attendance, frequency of prayer, extent to which she turned to religion for comfort, extent to which she considers herself spiritual • Frequency of doubts about faith, and degree to which religious beliefs influenced treatment decisions
Coping Responses (COPE, Brief-COPE) Alferi, Biegler ^{1,2}	<ul style="list-style-type: none"> • <u>Alferi used religious coping portion of COPE</u>: Religious coping (Emotional support from the people in my church; going to church or prayer meetings; talking with my priest or minister; trying to find comfort in my religion or spiritual beliefs); Behavioral disengagement (I've been giving up trying to deal with it); Denial (I've been saying to myself 'this isn't real') • <u>Biegler separated coping responses into two categories</u>: Engagement coping: active coping, planning, acceptance, and positive reframing; Avoidant coping: denial and behavioral disengagement
Profile of Mood States (POMS, POMS-SF) Alferi, Biegler, Gall ^{1,2,3}	<ul style="list-style-type: none"> • Check list of mood-descriptive adjectives • Participants indicate the degree to which they have experienced the emotion in the past week • 6 subscales: tension-anxiety, depression-dejection, anger-hostility, vigor, fatigue, and confusion-bewilderment
Intrinsic religiosity (IR) Biegler ²	<ul style="list-style-type: none"> • Statements about religious beliefs or experience
Multidimensional measurement of religious/spirituality (ORA, NORA) Biegler, Thune-Boyle ^{2,11}	<ul style="list-style-type: none"> • Organized religious activity (ORA): 2 item subscale • Nonorganized religious activity (NORA): 3 item subscale
Perceived Stress Scale (PSS) Biegler ²	<ul style="list-style-type: none"> • 14 items measuring perceptions of ongoing stress
Impact of Event Scale (IES) Biegler ²	<ul style="list-style-type: none"> • Measures intrusive thoughts or the tendency to ruminate on or avoid thoughts about stressors
Brief Symptom Inventory-18 (BSI-18) Biegler ²	<ul style="list-style-type: none"> • Assess different aspects of psychological distress • Depression, anxiety, somatization
Religious involvement Gall ³	<ul style="list-style-type: none"> • Frequency of religious service attendance • Perceived importance of religion in one's life • Perceived importance of spirituality in one's life
Religious coping (modified RCOPE) Gall ³	<ul style="list-style-type: none"> • 10 Subscales of RCOPE: Benevolent Religious Reappraisal (redefining stressful event as part of God's plan); Collaborative Religious coping (working together with God); Active Surrender (willingly giving control of events to God); Passive Religious Deferral (passively relinquishing the event to God); Pleading for Direct Intercession (asking for a miracle); Seeking Spiritual Support; Religious Focus (using religious activities as a distraction) Spiritual discontent (disappointment with God); Religious Helping (providing spiritual support to others); Seeking Religious Direction (looking to religion for new meaning and purpose)
Functional Assessment of Cancer Treatment-Breast (FACT-B) Gall ³	<ul style="list-style-type: none"> • only emotional well-being dimension was assessed and addressed in Gall's study
Duke Religious Index (DRI) Jang ⁵	<ul style="list-style-type: none"> • Religious activity (RA): organized religious activity + private religious activity • Intrinsic religiosity (IR)
Montgomery-Asberg Depression Rating Scale (MADRS) Jang ⁵	<ul style="list-style-type: none"> • 10 item instrument measuring depression
Hospital Anxiety Depression Scale (HADS) Jang ⁵	<ul style="list-style-type: none"> • HADS-A: 7 item anxiety subscale • HADS-D: 7 item depression scale
European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) Jang ⁵	<ul style="list-style-type: none"> • Global QOL • Different dimensions of functioning • Symptom subscale
Single item questions Thune-Boyle ¹¹	<ul style="list-style-type: none"> • Current belief: "I feel certain that God in some form exists." • To what extent they considered themselves R/S • Strength of faith

Coping Responses (COPE, Brief-COPE), Profile of Mood States (POMS), Profile of Mood States-Short Form (POMS-SF), Intrinsic religiosity (IR), Organized religious activity (ORA): Nonorganized religious activity (NORA), Perceived Stress Scale (PSS), Impact of Event Scale (IES), Brief Symptom Inventory-18 (BSI-18), Functional Assessment of Cancer Treatment-Breast (FACT-B), Montgomery-Asberg Depression Rating Scale (MADRS), Duke Religious Index (DRI), Hospital Anxiety Depression Scale (HADS), European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30), Quality of Life (QOL)

Table 2: Descriptions of outcome measurement instruments used in studies included in review

depression, anxiety, Non Organized Religious Activity (NORA), Organized Religious Activity (ORA), POMS (Profile of Mood States) and the COPE Inventory.¹⁴ One study used a phenomenological approach to explore the patient's perioperative experience.¹³

All studies, including the study with the retrospective section, completed at least one interview or questionnaire in the month prior to or after surgery. None of the studies used the same timeframe for interview/survey completion. Three of the studies compared pre and post-surgery outcomes from one month prior to one month post-surgery.^{1,3,12} One study included only post-surgery outcomes and three measured only pre-surgery outcomes.^{13,2,5,11} If the studies included time point data outside of the timeline of our systematic review, that data was not included in our review. See table 3 for study conclusions pre- and post-surgery.

In the study of US Hispanic women with early stage breast cancer, Alferi examined differences between the effects of

religious involvement of Evangelical Christians versus Catholics, showing that religiosity and religious coping were higher for Evangelicals and that for Catholic women, getting support from Church members predicted higher levels of distress post-surgery. For both groups, distress decreased post-surgery.¹ The second study of US patients used structured interviews of patients and their husbands, and showed that survival was the greatest concern for both groups and that the uncertainty of the diagnostic phase before surgery was the most stressful for 80% of women and 53% of men. Patients also expressed stress during the time while they waited for the mastectomy, knowing that the cancer was still present in their bodies, and 44% of husbands reported the day of surgery as the most stressful point.¹⁵ The study of men with urologic cancers was completed at the preoperative visit and showed that men reporting low R/S and greater education had greater perceived stress while those with no college education engaged in more avoidant coping. Overall, Religion/Spirituality (R/S) positively correlated with engagement coping.²

Author	Study Conclusions	Key Summary
Alferi ¹	<ul style="list-style-type: none"> Compared to Catholics, Evangelical women: reported higher religiosity, levels of all types of religious coping and talking to a minister related inversely to distress Distress fell pre- to post-surgery (p=.01) Religiosity correlated with obtaining emotional support from church, attending church or prayer meetings, taking comfort in religion Compared to Catholics, Evangelical women: reported higher levels of talking to their ministers and less denial Higher religiosity correlated with emotional support from church member and attending church or prayer meetings Catholics: getting support from church members at pre-surgery predicted higher levels of distress post-surgery Evangelical: pre-surgical distress predicted lower attendance of church or prayer meeting post-surgery 	Increased religiosity had different effects depending on the religious denomination of the patients.
Biegler ⁴	<ul style="list-style-type: none"> Religion/Spirituality (R/S) positively correlated with engagement coping Social support inversely correlated with POMS/PSS, positively correlated with engagement coping Engagement coping positively correlated with IES, BSI, avoidant coping was positively associated with all measures of distress. Those with lower R/S scores, greater engagement coping associated with greater distress For men who scored high on R/S, there is inverse association between social support and PSS and POMS Non Caucasian, no college education engage in more avoidant coping Men reporting low R/S and greater education associated with greater perceived stress 	The relationship between R/S with coping mechanisms is complex and simplistic correlations may not be sufficient to describe these relationships.
Demir ¹³	<ul style="list-style-type: none"> Fear: that the lump was cancer; of surgery; their breast would be removed Spiritual needs: prayed that it would not be something bad; "I prayed even though I'm an unbeliever." 	Three major themes emerged from this study including patient's need for information, fear and spiritual needs.
Gall ³	<ul style="list-style-type: none"> Religious coping at pre-diagnosis to 1 wk pre-surgery: Increase in active surrender coping; religious helping; use of religious direction; use of religious focus. <u>Religious coping as a predictor of concurrent adjustment</u> Active surrender and collaborative coping predicted less distress Religious direction coping and pleading predicted greater distress Better well-being correlated with less pleading and spiritual discontent coping and greater use of religious helping <u>Concomitant change between religious coping and adjustment across time</u> From pre-diagnosis to 1 wk pre-surgery Increased spiritual discontent and pleading coping predicted increase in emotional distress decreased spiritual discontent and increased religious helping predicted increase in emotional well-being From 1 wk pre-surgery to 1 mo post-surgery, a decrease in pleading and increase in use of religious focus coping predicted an increase in well-being <u>Religious coping as a predictor of concurrent adjustment at 1 mo post-surgery</u> Greater use of spiritual discontent predicted greater distress (p=.0001) Greater use of collaborative and passive deferral coping and lesser use of spiritual discontent contributed to better well-being (p=.0001) <u>Concomitant change between religious coping and adjustment across time</u> From 1 wk pre-surgery to 1 mo post-surgery: increase in spiritual discontent and pleading coping predicted increased emotional distress From 1 wk pre-surgery to 1 mo post-surgery: decrease in pleading and increase in the use of religious focus coping predicted increase in well-being 	At the time of diagnosis with breast cancer, women used religious coping. At the time of surgery, use of support and comfort-related strategies peaked.
Jang ⁵	<ul style="list-style-type: none"> Scores on RA were significantly higher in Protestant than Catholic, Buddhist, and no-religious groups, in that order In all the groups with high intrinsic religiosity (IR), IR was negatively associated with depression Buddhist group: scores on the RA subscale negatively correlated with the HADS-D scores Catholic group: scores on the RA subscale were positively correlated with HADS-A scores Protestant group: scores on the RA subscale were positively correlated with the global subscale of the QLQ-C30 No religious preference: scores on the IR subscale were negatively correlated with HADS-D 	Intrinsic religiosity was higher among Protestant and Catholics than for Buddhists or those with no religious preference, and increased intrinsic religiosity correlated to decreased HADS scores implying that it is not the religion but the intensity of religion that corresponds to decreased depression.
Nort-house ¹²	<ul style="list-style-type: none"> 83% of women and 50% of husbands describe the diagnostic phase before surgery as the most stressful time: uncertainty about whether they had cancer; waiting for the mastectomy 44% of the husbands reported the day of surgery as the most stressful <u>Factors that helped patients and husbands cope</u> Religious belief identified more frequently during the hospital period than at home 1 month later for women, 21% during hospitalization, 9% at home; for husbands, 13% during hospitalization and 4% at home Emotional support for patients, 87% during hospitalization, 72% at home; for husbands, 64% during hospitalization, 49% at home 	Patients and their husbands had different concerns around the time of surgery, with patients being concerned about the extent of disease and recurrence, while husbands worried about the survival of their wives.
Thune-Boyle ¹¹	<p>Patients both increased and decreased their R/S beliefs and practices at the time of surgery compared to the year prior</p> <ul style="list-style-type: none"> 26% of patients have increased private R/S practices 21% perceived their strength of faith increased 5-12% reported decreases in beliefs Belief in God was significantly higher at surgery Strength of faith increased at surgery Perceived levels of R/S and public R/S practices remained stable. 	In UK study, the patients perceived that they had an increased belief in God and strength of faith at the time of surgery, but no change in belief or practices. For most patients, there was an increase in beliefs and religious practices at the time of surgery.

Profile of Mood States (POMS), Perceived Stress Scale (PSS), Impact of Event Scale (IES), Brief Symptom Inventory (BSI), Hospital Anxiety Depression Scale-Anxiety (HADS-A), Hospital Anxiety Depression Scale-Depression (HADS-D), Quality of Life Questionnaire Core 30 (QLQ-C30), Religious Activity (RA)
Abbreviations: Week (wk), month (mo)

Table 3: Major study conclusions and key study summary

The phenomenological study of Turkish women who had excisional breast biopsies established three main themes: fear (that the lump was cancer, fear of surgery, fear breast would be removed); the need for information (about surgery and illness); and spiritual needs (prayer that the lump was not something bad).¹³ Baseline results of Jang's study of South Korean breast cancer patients showed that Religious Activity (RA) was higher for Protestants than Catholics, Buddhists and those associated with no religion. In all groups with high Intrinsic Religiosity (IR), IR was negatively associated with depression.⁵ The study of Canadian breast cancer patients included several data points, but the data pertinent to this review showed that from one week before surgery to one month after surgery, a decrease in pleading and increase in use of religious focus coping predicted an increase in well-being. Improved well-being correlated with lesser use of pleading and spiritual discontent coping and a greater use of religious helping.³ The patient population of the breast cancer patients from the United Kingdom (Protestant, Catholic, Jewish, no religion) was religiously diverse similar to the patient population from the South Korean study (Protestant, Catholic, Buddhist, no religion). The UK patients answered R/S questions post-surgery and recalled their beliefs in the year prior. Results showed that R/S beliefs both increased and decreased from the year prior to surgery to the immediate post-operative period, but overall, it showed that belief in God was significantly higher at surgery and that patients' belief in God was significantly higher at surgery.¹¹

DISCUSSION

As identified in this systematic review, the current literature is limited in its evaluation of R/S of the cancer patient in the perioperative period. Existing studies are almost exclusively in women with stage I and II breast cancer. Even though the studies evaluate patients of different cultures, the studies do not expand on the effect of ethnicity and culture on religious and spiritual needs.

Studies examined the stress response and coping, and their interplay with religiosity and spirituality, including the type of religious coping employed by the patient. Based on these studies, patients with higher religiosity/spirituality have better engagement or active coping but that simplistic associations between R/S and coping are inadequate to explain R/S needs of patients for coping and responding to stress. The data stating that R/S have a positive effect on patient outlook, physical and mental well-being is variable and this is identified not only when comparing US to UK cancer patients, but also when comparing patients of different faiths and different denominations of the same faith. One consistent theme from several of the studies is that the perioperative period is a time of exaggerated stress for patients and their families but the reason for the stressful nature of the time period is different for patient as compared to family member. During the perioperative period, patients expressed fear of the cancer and fear of the surgery, while the spouse of

the breast cancer patient expressed increased stress during both the pre-surgery diagnostic phase and the post-surgical treatment period.¹²

Factors of ethnicity and culture, which intrinsically are linked to religion and religious practices, likely contribute to variability in how R/S affect patient coping. When comparing US populations with other populations, the Gallup Daily tracking survey from 2011 reports that the US population is predominantly a Christian nation with 78% adults identifying with Christianity, 82.5% have some form of religious identity and 92% of Americans say that they believe in God.¹⁶ In comparison, 12% of the UK population attends church regularly, 51% with some belief in God and 12% without doubt of God's existence.¹⁷ Thune-Boyle et al argue that since most studies on the topic of R/S and patient coping have been completed in the US, their conclusion about R/S are difficult to transfer outside of North America,¹¹ even to other English-speaking patient populations. Pertinent to the three studies examining North American populations, Koenig finds that African Americans are more likely than other ethnic groups to use religion for coping.¹⁸ Within the US Latino population, patients come from a geographic background as large as the US itself and the religious and cultural practices vary even within populations from similar geography with patients mostly associating with either a Christian evangelical denomination church or Catholicism.¹ Even if direct comparison of the studies completed in the US cannot be made with non-US studies, Demir's phenomenological study made a clear argument that the female patients studied in Turkey needing excisional biopsies have spiritual needs in the perioperative period.¹³ R/S needs may vary by culture, but across cultures patients have unique R/S needs in the perioperative period.

STUDY LIMITATIONS

One limitation of this review is that these studies focused on cancer patients with good prognosis: female breast cancer patients with early stage disease and men with prostate cancer. Early stage breast cancer (stages I and II) has a 5 year survival rate of 93%.¹⁹ Similarly, the 5 year survival rate is over 99% for all stages of prostate cancer.²⁰ Many patients turn to R/S when faced with a life-threatening illness such as cancer^{17,3} but the aggressive nature of the cancer may affect a patient's emotional, spiritual and religious needs. For patients with advanced or incurable cancer, R/S may take on a different meaning as they face the inevitability of death. This is in contrast to patients with cancers of generally good prognosis who face the uncertain future of cancer survival.³ Another potential limitation is that these studies were geographically diverse and thus, generalizability to specific populations is unclear. Also, we included only English language studies and thus, may have missed important non-English studies.

In addition, the Mesh search terms for religion and

spirituality are still immature and current literature could have been misclassified and not captured in this search. Other important key words related to religion and spirituality such as sense of peace, meaning and purpose of life were not used as part of the search strategy and thus articles relevant to religion and spirituality through connection with these terms may have been missed in the systematic review.

FURTHER RESEARCH

Though inferences can be made from other studies that are broader in their time frame, more studies are needed that explore the religious and spiritual needs of perioperative patients and clinicians. The effect of R/S for oncologic surgical patients can be variable, having either a beneficial or negative effect on their outlook and sense of well-being.¹¹ In Nelson's study on religion and spirituality in prostate cancer patients, patients were found to have less depression when they had a sense of meaning and peace but not necessarily more religious involvement.²¹ Given the variable effect of R/S, future studies could focus more on spirituality and explore what gives the perioperative patient a sense of meaning and peace. Further research is needed to identify factors that make the perioperative time period a uniquely stressful experience for patients and their families and how religion and spirituality may affect perioperative coping. Understanding more specifically what causes stress for patients during the perioperative time period may help perioperative providers better understand the R/S needs of their patients and give more complete care during the time before and after their oncologic surgeries.

CONCLUSION

In the past, spirituality had a recognized role in health care, but during the 20th century, spirituality and health care were separated as health care became more scientific and technological.²² Physicians and other health care providers have received limited education in their role in caring for the spiritual and religious needs of the oncologic surgical patient, even though there are currently efforts to bring spirituality back to medical school education.²² Hospital chaplains should be part of inter disciplinary teams caring for the oncologic patient and physicians and other care providers should understand the uniquely stressful time of the perioperative time frame so that the patients can receive treatment of their whole person, not just treatment of their cancer.²³ The perioperative time frame is a stressful period for cancer patients and their family members as they encounter a diagnosis of cancer, experience the loss of control during surgery, and face uncertain recovery. Understanding that unique religious and spiritual needs of the oncologic patient requires an understanding of the exaggerated stress of the perioperative period and further research is needed to better understand how better incorporation of religious and spirituality practices can

improve the perioperative experience for patients, their families, and their providers

ACKNOWLEDGMENTS

The authors would like to thank Blair Anton Associate Director, Clinical Information's Services William H. Welch Medical Library Johns Hopkins Medical Institutions, for her assistance with this systematic review.

CONFLICTS OF INTEREST

The authors have no potential conflicts of interest with respects to the research or authorship of this article.

AUTHOR DISCLOSURE STATEMENT

JH and JC received no financial support for this research, authorship and/or publication of this article. RAA was supported by a Foundation for Anaesthesia Education and Research grant and a Johns Hopkins School of Medicine Clinician Scientist Award. No competing financial interests exist.

REFERENCES

- Alferi SM, Culver JL, Carver CS, Arena PL, Antoni MH. Religiosity, religious coping, and distress: a prospective study of catholic and evangelical hispanic women in treatment for early-stage breast cancer. *J Health Psychol.* 1999; 4: 343-356. doi: [10.1177/135910539900400304](https://doi.org/10.1177/135910539900400304)
- Biegler K, Cohen L, Scott S, et al. The role of religion and spirituality in psychological distress prior to surgery for urologic cancer. *Integer Cancer Ther e-Pub.* 2011. doi: [10.1177/1534735411416456](https://doi.org/10.1177/1534735411416456)
- Gall TL, Guirguis-Younger M, Charbonneau C, Florack, P. The trajectory of religious coping across time in response to the diagnosis of breast cancer. *Psychooncology.* 2009; 18: 1165-1178. doi: [10.1002/pon.1495](https://doi.org/10.1002/pon.1495)
- Carver CS, Pozo C, Harris SD, et al. How coping mediates the effect of optimism on distress, a study of women with early stage breast cancer. *J Pers Soc Psychol.* 1993; 2: 375-390. doi: <http://dx.doi.org/10.1037/0022-3514.65.2.375>
- Jang JE, Kim SY, Kim JM, et al. Religiosity, depression, and quality of life in Korean patients with breast cancer; a 1 year prospective longitudinal study. *Psychooncology.* 2012. doi: [10.1002/pon.3083](https://doi.org/10.1002/pon.3083)
- Cohen L, Fouladi RT, Katz J. Preoperative coping strategies and distress predict postoperative pain and morphine consumption in women undergoing abdominal gynaecologic

- surgery. *J Psychosom Res.* 2005; 2: 201-209. doi: <http://dx.doi.org/10.1016/j.jpsychores.2004.07.007>
7. Clark J. Religion and spirituality: A discussion paper about negativity, reductionism and differentiation in nursing texts. *Int J Nurs Stud.* 2006; 43: 775-785. doi: <http://dx.doi.org/10.1016/j.ijnurstu.2005.10.006>
8. Emblen JD. Religion and spirituality defined according to current use in nursing literature. *J Prof Nurs.* 1992; 1: 41-47. doi: [http://dx.doi.org/10.1016/8755-7223\(92\)90116-G](http://dx.doi.org/10.1016/8755-7223(92)90116-G)
9. Robinson S, Kendrick K, Brown A. Spirituality and the practice of healthcare. Hampshire, England. *Palgrave MacMillan.* 2003.
10. Grandstaff NW. The impact of breast cancer on the family. *Front Radiat Ther Oncol.* 1976; 11: 146-156.
11. Thune-Boyle ICV, Stygall J, Keshtgar MRS, Davidson TI, Newman SP. The impact of a breast cancer diagnosis on religious/spiritual beliefs and practices in the UK. *J Relig Health.* 2011; 50: 203-218. doi: [10.1007/s10943-010-9322-2](http://dx.doi.org/10.1007/s10943-010-9322-2)
12. The American Cancer Society, Inc. Atlanta [updated 2013 Dec 31; cited 2013 Dec 31]. Available from: <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-survival-by-stage>
13. Demir F, Donmez YC, Ozsaker E, Diramali A. Patients' lived experiences of excisional breast biopsy: a phenomenological study. *J Clin Nurs.* 2008; 17: 744-751. doi: [10.1111/j.1365-2702.2007.02116.x](http://dx.doi.org/10.1111/j.1365-2702.2007.02116.x)
14. Carver C, Scheier M, Weintraub J. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol.* 1989; 56: 267-283.
15. Gallup Inc. Princeton. 2011 Dec 23; cited 2014 Jan 15. Available from: <http://www.gallup.com/poll/151760/Christianity-Remains-Dominant-Religion-United-States.aspx>
16. Hughes M, Church J. *Lifestyles and Social Participation.* Social Trends No. 40 2010 Hampshire, England. *Palgrave MacMillan.* 2010; 185-198.
17. Norum J, Risberg T, Solberg E. Faith among patients with advanced cancer. A pilot study on patients offered "no more than" palliation. *Support Care Cancer.* 2000; 2: 110-114. doi: [10.1007/s005209900098](http://dx.doi.org/10.1007/s005209900098)
18. Koenig HG, Cohen HJ, Blazer DG, et al. Religious coping and depression among elderly, hospitalized medically ill men. *Am J Psychiatry.* 1992; 12: 1693-1700.
19. Northouse LL. The impact of breast cancer on patients and husbands. *Cancer Nurs.* 1989; 12: 276-284.
20. The American Cancer Society, Inc. Atlanta [updated 2013 Dec 31; cited 2013 Dec 31]. Available from: <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-survival-by-stage>
21. Nelson C, Jacobson CM, Weinberger MI, et al. The role of spirituality in the relationship between religiosity and depression in prostate cancer patients. *Ann Behav Med.* 2009; 38(2): 105-144. doi: [10.1007/s12160-009-9139-y](http://dx.doi.org/10.1007/s12160-009-9139-y)
22. Puchalski CM, Blatt B, Kogan, M, Butler A. Spirituality and health: the development of a field. *Acad Med.* 2014; 89(1): 10-16. doi: [10.1097/ACM.0000000000000083](http://dx.doi.org/10.1097/ACM.0000000000000083)
23. Sinclair S, Chochinov HM. The role of chaplains within oncology interdisciplinary teams. *Curr Opin Support Palliat Care.* 2012; 6(2): 259-268. doi: [10.1097/SPC.0b013e3283521ec9](http://dx.doi.org/10.1097/SPC.0b013e3283521ec9)

Review

*Corresponding author

Gianluca Villa, MD

Staff

Department of Health Science
Section of Anaesthesiology and
Intensive Care
University of Florence
Florence, Italy

E-mail: gianlucavilla1@gmail.com

Volume 1 : Issue 1

Article Ref. #: 1000PMHCOJ1104

Article History

Received: December 23rd, 2014

Accepted: February 6th, 2015

Published: February 10th, 2015

Citation

Villa G, Samoni S, Maggio PD, et al. Palliative care for nephropathic patients. *Palliat Med Hosp Care Open J*. 2015; 1(1): 16-23. doi: [10.17140/PMHCOJ-1-104](https://doi.org/10.17140/PMHCOJ-1-104)

Copyright

©2015 Villa G. This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Palliative Care for Nephropathic Patients

Gianluca Villa^{1,2*}, Sara Samoni^{2,3}, Paola Di Maggio¹, Alessandra Spinelli^{2,4}, Silvia De Rosa^{2,5}, Fabio O. Tartaglia², Iacopo Lanini¹, Claudio Ronco² and A. Raffaele De Gaudio¹

¹Department of Health Science, Section of Anaesthesiology and Intensive Care, University of Florence, Florence, Italy

²Department of Nephrology, Dialysis and Transplantation, San Bortolo Hospital, International Renal Research Institute Vicenza (IRRV), Vicenza, Italy

³Institute of Life Sciences, S. Anna School of Advanced Studies, Pisa, Italy

⁴Department of Emergency and Organ Transplantation, Nephrology, Dialysis and Transplantation Unit, University of Bari, Italy

⁵Department of Intensive Care and Anaesthesiology, Catholic University of the Sacred Heart, Rome, Italy

ABSTRACT

A new light has recently been shed on palliative care, especially, on its multidisciplinary approach developed to improve the Quality of life of seriously ill patients and their families. However, palliative care is still often mistakenly referred to as an end-of-life care and wrongly interchanged with hospice care. Nephropathic patients usually present a decrease in expectancy and Quality of life and may benefit from palliative care as opposed to hospice care. Palliative care requires a tight collaboration among different health care professionals, patients and their families, to share diagnosis, prognosis, realistic goals of treatment and therapeutic decisions. Several approaches may be attempted to improve the Quality of life of chronic nephropathic patients, such as palliative dialysis, conservative management and peritoneal dialysis. For example, personalized goals and a wider concept of adequacy of extracorporeal treatment are the bases of palliative dialysis. In specific subgroups of frail patients, the pharmacological conservative management could be more appropriate than extracorporeal treatment, as the former reduces the burdens derived from invasive procedures. Finally, peritoneal dialysis could be an important option for frail patients to avoid an aggressive extracorporeal treatment while maintaining a gentle solute and fluid control. However, only limited evidences are available on palliative and hospice care performed on patients with Acute Kidney Injury (AKI). Herein, the main variables affecting the medical decision-making on palliative care in nephropathic patients are described, and the different approaches available to improve quality of palliative care during Chronic and Acute Kidney Injury are analyzed.

KEYWORDS: Palliative care; Hospice care; Chronic Kidney Disease; End-Stage Renal Disease; Acute Kidney Injury; Renal Replacement Therapy.

ABBREVIATIONS: AKI: Acute kidney Injury; CKD: Chronic Kidney Disease; ESRD: End-Stage Renal Disease; RRT: Renal Replacement Therapy; ERA-EDTA: European Renal Association-European Dialysis and Transplant Association; MCM: Maximum Conservative Management; PD: Peritoneal Dialysis; ICU: Intensive Care Unit.

INTRODUCTION

Palliative care has recently been reconsidered as a multidisciplinary approach to care which has been developed to support clinicians in the management of patients with serious

illness.¹ This innovative perspective is aimed to improve the Quality of life of patients and their families through a multidimensional analysis involving: 1) identification and management of patients' physical, psychological and spiritual symptoms; 2) evaluation of patients' clinical condition and prognosis to establish realistic and appropriate treatment goals; 3) arrangement of individualized therapeutic plans according to patients' wishes; 4) attention to families' needs and 5) support for health care providers.¹

Currently, the specialty palliative care is mainly offered in patients within hospices or hospitals only when life-prolonging treatment has failed;² as a consequence, most of health care professionals perceive palliative care as a synonymous of End-of-life care.² However, limiting palliative care only to these situations may exclude the majority of serious conditions, such as advanced cancer or end-stage organ dysfunction, which severely affect patients' physical and psychological symptoms.^{2,3} For these reasons, palliative care should be provided together with life-sustaining treatments and considered as an integral component of comprehensive therapy for critical and non-critical care patients. Therefore, palliative care is neither a mutually exclusive alternative to intensive care, nor a sequel to failed attempts with life-prolonging care,¹ in fact, according to the definition developed by the Center to Advance Palliative Care and the American Cancer Society, "Palliative care is appropriate at any age, at any stage in a serious illness, and can be provided together with curative treatment".² On the other hand, hospice care is strongly recommended for patients who have a physician-estimated life expectancy of 6 months or less and who are undergoing restorative treatments and foregoing curative therapy.²

Despite the improvements in therapeutic options, patients with AKI as well as those with Chronic Kidney Disease (CKD), especially those with End-Stage Renal Disease (ESRD), have a shorter life expectancy compared to patients without nephropathies. Extracorporeal replacement therapies may increase survival rates of these patients; however, for a specific subgroup of acute critically ill patients, these procedures are often unable to improve outcomes and prolong the physiological process of death, worsening the quality of the End-of-life stage of these patients.

Several clinical trials have shown the benefits derived from the early application of palliative care in subgroups of seriously ill patients, such as those with advanced cancer,⁴ multiple sclerosis⁵ or congestive heart failure.^{6,7} However, the provision of palliative care to nephropathic patients with CKD or AKI is heterogeneous across different countries and often mistakenly identified with hospice care. Currently, the use of palliative care in the nephropathic population is inadequate; it is recognized in the UK, USA, Italy and Canada mainly for ESRD patients⁸⁻¹² and is usually limited to the last phase of life. Finally, an adequate approach for palliative care is still largely lacking for patients with AKI.

The aim of this review is to describe the main variables affecting the medical decision-making on palliative care in nephropathic patients and to analyze the different approaches to improve quality of palliative care during Chronic and Acute Kidney Injury.

PALLIATIVE CARE FOR CKD PATIENTS

Demand for dialysis is constantly increasing all over the world, especially in the elderly population.^{13,14} As clearly demonstrated by the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA), the European incidence of ESRD requiring dialysis procedures among patients aged > 65 years increased from 22% in 1980 to 55% in 2005.¹⁵ The recent technological advancements observed with the Renal Replacement Therapy (RRT) have increased feasibility of these techniques and have improved survival for a large number of patients with ESRD.

Despite the increased survival, an annual mortality rate of about 23% has been reported for ESRD patients undergoing RRT¹⁶ which mainly depended on the high prevalence of other chronic comorbidities, such as diabetes, hypertension and cardiovascular diseases.¹⁷ A reduction in the overall functional status during the first 12 months after initiation of RRT has been reported for patients with CKD and, specifically, for a subgroup of nursing home residents.¹⁸ Finally, an increasing burden of somatic and psychological symptoms as well as a worsening of social conditions have been often observed among ESRD patients undergoing RRT.¹⁹ These symptoms, whose prevalence is comparable to those observed in cancer patients,²⁰ severely affect the patient's Quality of life.¹⁹ In these conditions, a high proportion of elderly patients regrets the decision to start dialysis and thus, after agreeing with caregivers, prefers a conservative management for ESRD.²¹

Training, information and support for patients, their family and caregivers are pivotal for planning the management of care of ESRD patients. In particular, other therapeutic options such as, extracorporeal treatment, Peritoneal Dialysis (PD) or Conservative therapy should be discussed and comprehensively shared among patients, family and health care providers. Both for patients undergoing RRT and for those managed with conservative therapy, palliative medicine should be taken into consideration in order to improve the Quality of life.

EXTRACORPOREAL RRT

Extracorporeal therapy is the most utilized treatment to replace renal function in ESRD patients.²² Adequacy of extracorporeal treatment is often identified with the concept of solute clearance, which is usually quantified through Kt/V measurement. However, the strong effort in treatment personalization has recently encouraged to carefully evaluating the specific target of therapy, which has to aim not only at the solute removal

but rather at the improvement of the whole patient’s clinical picture. Although reasonable and attractive, this concept is still far from being applied in most dialysis centers in the daily clinical practice.

Indeed, following analysis of data on treatment targets in CKD patients from 12 countries, the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed no difference in dialysis prescription across subgroups of patients with different clinical requirements. For instance, the same treatment time, normalized by body weight, was prescribed both for patients aged < 45 years and frail elderly patients.²³ Targeting the normalization of dry weight, Kt/V and serum phosphorus, may not be the primary treatment objective for all patients.¹⁵ Apart from these specific clinical issues, the concept of adequacy of RRT should also take into account the ability to achieve other treatment goals, such as the improvement of the Quality of life of patients and their families, the prevention and relief from suffering, the identification and treatment of pain and other physical and psychosocial conditions.

In a recent paper, Romano and Palomba proposed the concept of palliative dialysis as a change in perspective for the treatment goals achievable by using either ultrafiltration or dialysis alone, depending on the clinical objectives.¹⁵ In this scenario, an individualized RRT prescription overlaps with the requirement of palliative care and it may improve the physical, emotive and autonomy-related issues (Figure 1).

As such, the delivery of palliative care should be started not during the last moments of patients’ lives but, concomitantly with RRT.¹⁵

The quality of care given to the patients may be eval-

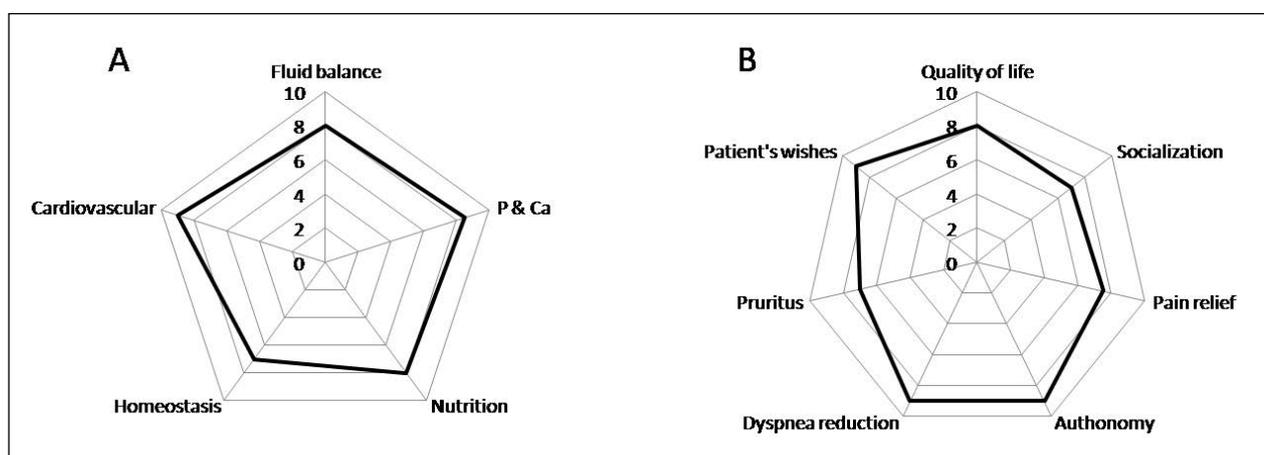
uated through the PEACE score: a simple tool addressing six domains on physical, emotive, autonomy-related symptoms; communication and completion of life issues; economic burden and religious beliefs.²⁴ However, although this tool may be of help for clinicians, the most important factor to consider when making a clinical decision is the autonomy of the patient who faces ESRD and of the relatives who provide support.¹⁵ In particular, Parlevliet et al. showed that caregivers are often forced to change their routine and professional schedules, and 84% of them feel overburdened by the situation.²⁰

Among the most frequent symptoms observed in ESRD patients, such as lack of energy, drowsiness, dry mouth, pain, sleep disturbance, restless legs, pruritus, dry skin and constipation,²⁵ dyspnea may be the most manageable with palliative dialysis.¹⁵ Indeed, although other symptoms can be treated with medications, fluid overload and acidosis are rarely controlled in ESRD patients conservatively managed.¹⁵

CONSERVATIVE MANAGEMENT

Conservative management should be taken into account for patients who are not eligible for extracorporeal treatment or who refuse it. It is based on a pharmacological and behavioral approach used to prevent the major complications of ESRD, such as hydro-electrolytic unbalance, acid-base disorders, hyperazotemia and anemia. This option is usually limited to patients with severe comorbidities and geriatric conditions, such as dementia and frailty.¹⁵

Frailty, in particular, is a multidimensional construct reflecting the decline in health and organ function observed in elderly; it occurs in approximately 67% of dialysis patients.²⁶ Frailty is correlated with an increased risk for disability, hospi-



Graph of a chronic extracorporeal renal substitution for CKD patient (panel A) and graph of palliative dialysis for “CKD end-of-life” patient (panel B). Each graph takes into consideration several variables differently affected by the treatments (0: the variable is minimally influenced; 10: the variable is strongly improved).

The adequacy of the treatment may be identified by the area within the graph: during an ideal therapy, the inner area covers 100% of the graph. For a treatment to be “adequate”, other parameters than solute clearance or fluid balances should be considered for end of life patients; in this scenario, an individualized RRT prescription should improve the physical, emotive and autonomy-related issues.

Figure 1: “Adequacy” of Extracorporeal treatment and the role of Palliative dialysis.

tialization, institutionalization and death²⁷ and it is clinically diagnosable through recognition of unintentional weight loss, slow walking speed, weakness, exhaustion and low level of physical activity.²⁸ The use of conservative management is recommended in patients with this clinical picture.

In line with this view, Maximum Conservative Management (MCM) is a European proposal based on a multidisciplinary approach with nutritionists, social workers, psychologists and other health professionals aimed at improving the Quality of life of frailty patients with ESRD.²⁹ Despite patients who received RRT showed a higher survival rate than those who received MCM, they had higher rates of hospitalization and in-hospital death.³⁰

Although necessitating the lowest institutionalization requirement, the conservative management requires close monitoring and treatment adjustment by several professional figures in order to avoid treatment failure. In particular, a constant sharing of achievable therapeutic goals should be encouraged between general practitioners or specialists on one side and patients and their families on the other. This procedure aims to reduce accesses in emergency department and thus invasive procedures and hospitalizations. Nevertheless, a multidisciplinary approach is required to limit patient's symptoms and suffering from a home delivery palliative care system.

PERITONEAL DIALYSIS

Another type of management available is Peritoneal Dialysis (PD); its use is suggested in frail patients as, in this specific subgroup of nephropathic patients, PD may offer advantages with respect to both extracorporeal RRT and conservative management. Indeed, hemodynamic instability and severe hypotension may affect extracorporeal RRT, further worsening frail patients' clinical conditions. PD is considered a less invasive treatment, which guarantees a slow, continuous dialysis and ultra filtration; it is usually more tolerated by patients and it may preserve better renal function, hence allowing a less restricted and more patient-friendly diet. As well as extracorporeal RRT, PD is able to compensate metabolic acidosis and fluid overload that may cause exacerbation of patients' condition in conservative management. However, similarly to conservative therapy, PD may be managed through home care and occasionally scheduled ambulatory visits, making it an effective choice for patients requiring palliative or hospice care.³¹

In 2008 ERA-EDTA pointed out some criteria that may be used to recommend PD.³² In particular, clinical conditions that may be usually identified in frail patients, such as aging complications, severe Cardiac Disease or Peripheral Vascular Disease, have been recognized as potential indicators for PD prescription. However, ERA-EDTA also identified factors with which use of PD may be contraindicated; these factors include inadequate patient's physical ability and lack of familiar or social support. In fact, the family involvement in the patient's disease is more

demanding in PD than in extracorporeal RRT and conservative management, considering that a technical training of the patient and/or caregiver to the peritoneal dialytic procedure is mandatory.

Despite a close cooperation between patients, their families, general practitioner, nurses and nephrologists is required, PD may guarantee a better quality of life, becoming thus the therapy of choice in a selected population requiring palliative or hospice care.

PALLIATIVE CARE FOR AKI PATIENTS

AKI frequently occurs in critically ill patients in the Intensive Care Unit (ICU), with an estimated global prevalence of 36%-67%;³³ it exhibits different etiologies and several pathophysiological mechanisms, and is correlated with a high mortality rate.³⁴⁻³⁸

Despite the poor prognosis associated with AKI, the concepts of palliative and hospice care are still underdeveloped for this specific subgroup of patients. Indeed, despite a growing interest in the literature on palliative care for critically ill patients in the ICU, only few papers have been focused on the withdrawal or withholding of invasive treatments in acute nephropathic patients. In particular, a systematic search of the published literature, performed on Pub Med using the following key words "Acute Kidney Injury" AND ("Palliative care" OR "Palliative medicine") and related MeSH terms, revealed 87 citations. Among them, 10 are specifically focused on "acute-on-chronic" conditions and advanced planning for ESRD patients; 32 couple AKI with other life-threatening conditions (e.g. heart failure or cancer) and underline the importance of palliative care medicine in these diseases; 39 are not relevant for this particular topic. Only 11 papers are specifically focused on palliative care for nephropathic patients with AKI. Among these, 5 reviews the ethical issues.³⁹⁻⁴³ and 3 specifically describe the epidemiology and clinical factors associated with End-of-life in AKI patients.⁴⁴⁻⁴⁶

For these reasons, while palliative and hospice care management is globally applied in CKD patients, even general indications are still lacking in AKI patients. Nowadays, clinicians are often faced with critically ill patients who meet the criteria for initiating RRT, however, there are uncertainties on whether the patient would likely benefit from these procedures.⁴⁷ In fact, although critically ill patients are often subjected to advanced and invasive diagnostic and therapeutic interventions, mortality in the ICU remains very high.⁴⁸ Therefore, in these settings, advanced life support procedures and systems, such as RRT, may only unreasonably postpone the time of death.⁴⁹

Scarce literature is available to guide clinicians in the decision to discontinue RRT in patients who will no longer benefit.⁴⁷ Although an evidence-based guideline on this use has been already produced by the Renal Physicians Association and the American Society of Nephrology,⁴² only a small number

of nephrologists and intensivists are aware of it.¹¹ As a consequence, clinical practice on withholding or withdrawal of RRT is variable and based primarily on the local institutional practice, physicians' clinical judgment, available resources and local management.^{36,38,50-52}

Several factors should be taken into consideration during the decision-making process regarding the withholding or withdrawal of RRT in patients with AKI, including feasibility, survival prediction, renal functional recovery prediction and quality of life.

Clinical *feasibility* is certainly an important limiting factor. Although several patients' clinical conditions (e.g., severe hypotension) might negatively affect the technical feasibility, new techniques such as continuous Renal Replacement Therapies have allowed performing RRT in the vast majority of patients.⁴⁷

An adequate medical judgment and an informed patient and family consent cannot ignore *survival prediction* as an important factor to be considered when deciding to continue, withhold or withdraw RRT. Despite several organ dysfunction scoring systems⁵³ and outcome prediction models available to help clinicians identify severely ill patients, none of them actually provide physicians with enough information on the suitability of intensive care treatments for the individual patient.⁴⁹ Short and long term mortality of critically ill patients who developed AKI and required RRT is globally high (46-75%).⁵⁴ The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), the largest prospective study investigating survival in critically ill patients, has shown that the mean survival time in patients who required dialysis was of approximately 30 days and that only 27% of patients were alive after 5 months.⁵⁵

Prediction of renal functional recovery after AKI should be considered as another important factor in determining long-term renal and non-renal outcomes⁵⁶⁻⁵⁹ in the decision-making process.⁴⁷

The *Quality of life* of patients and their families may be severely affected if ESRD occurs and chronic extracorporeal RRT is required after an episode of AKI. However, long-term outcomes and Quality of Life of critically ill patients requiring RRT have been examined only in few studies.⁴⁷ For instance, in the SUPPORT study, AKI patients who survived to the critically ill stage showed a median of one dependence in activities of daily living;⁵⁵ however, different results are shown in the published literature.^{43,60,61}

Unlike in CKD patients, in critically ill AKI patients the time frame window to discuss the decision to initiate or stop RRT is often unavailable. Therefore, not knowing the *patient's own wishes* make the clinical judgment even harder,⁶² and hence

pressure to make a decision builds up among family and the health care team.⁴⁷

According to the Renal Physicians Association/American Society of Nephrology guidelines of shared decision making in dialysis, a time-limited trial of RRT could be considered for patients with uncertain prognosis.⁶³ In particular, it may result useful when a disagreement in management occurs between physicians and nurses or patients' families.⁴⁷ End-points, goals and duration of this time-limited trial should be exactly defined in advance. In particular, specific criteria, their magnitude of change accepted as evidence for improvement and the time point of their evaluation should be established and agreed between physicians, nurses, patients and their families.⁴⁷ Notably, the decision making regarding the withholding or withdrawal of RRT in patients with AKI during a time-limited trial is an ongoing process: clinical outcomes as well as patients' prognoses should be reevaluated as needed.⁴⁷

In all cases in which RRT is withheld or withdrawn, physician should provide adequate End-of-life comfort care through non-dialytic therapy even for critically ill patients in the ICU.⁶⁴ For patients with a death prognosis, different approaches other than integrating palliative care with intensive care treatment should be adopted. Indeed, in these conditions, palliative care may be replaced by hospice care.¹ In patients with terminal prognosis, the strategies to ensure a good death often involve more than effective analgesia and, ideally, should aim at optimizing comfort and dignity for the patient and at offering the opportunity of a close support from the family. Allowing patients to die in their own homes is a way of providing this.⁶⁵ Unfortunately, many patients suffer prolonged dying in hospitals, receiving unwanted, expensive and invasive treatments which may cause additional discomforts, such as pain, dyspnea, thirst and anxiety.⁶⁶

New developed technologies, such as wearable artificial kidney, should be taken into consideration for hospice care in nephropathic patients. Although this concept may be hardly applied in daily clinical practice, it may be potentially useful in home care management even for patients with AKI. This miniaturized, wearable technology may allow the maintenance of mechanical support, mainly through continuous ultra filtration. By improving fluid overload and reducing dyspnea, the wearable artificial kidney may provide human basic needs in end-of-life care⁶⁰ even, with adequate support, at patient home.

CONCLUSIONS

Palliative care is usually limited to seriously ill patients at the end-of-life phase and is often wrongly interchanged with hospice care. An earlier utilization of palliative care for all seriously ill patients may improve the quality of life of the patients and their families. Nephropathic patients usually present a decrease in life expectancy and may benefit from palliative care.

Although limited to end stages of the renal disease, the concept of palliative care is still better defined for CKD than AKI patients. Indeed, several therapeutic strategies may be attempted to improve Quality of life of chronic nephropathic patients, such as palliative dialysis, conservative management and PD. All these approaches require a tight collaboration between different healthcare professional figures, patients and their families. Prognosis, realistic treatment goals and therapeutic decisions should be shared among all subjects involved in the management of CKD. On the other hand, poor literature data are available on the effects of palliative and hospice care in patients with AKI. A methodological, ethical and clinical effort needs to be made to improve knowledge and awareness on palliative care in acute nephropathic patients.

REFERENCES

- Aslakson RA, Curtis JR, Nelson JE. The changing role of palliative care in the ICU. *Crit Care Med*. 2014; 42: 2418-2428. doi: [10.1097/CCM.0000000000000573](https://doi.org/10.1097/CCM.0000000000000573)
- Parikh R, Kirch R, Smith T, Temel J. Early specialty palliative care-translating data in oncology into practice. *N Eng J Med*. 2013; 369: 2347-2351. doi: [10.1056/NEJMsb1305469](https://doi.org/10.1056/NEJMsb1305469)
- Zamperetti N, Bellomo R, Ronco C. Bioethical aspects of end-of-life care. *Eur J Anaesthesiol*. 2008; 42: 51-57.
- Greer J, Jackson V, Meier D, Temel J. Early integration of palliative care services with standard oncology care for patients with advanced cancer. *CA Cancer J Clin*. 2013; 63: 349-363. doi: [10.3322/caac.21192](https://doi.org/10.3322/caac.21192)
- Higginson I, Costantini M, Silber E, Burman R, Edmonds P. Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained. *Postgrad Med J*. 2011; 87: 769-775.
- Hauptman P, Havranek E. Integrating palliative care into heart failure care. *Arch Intern Med*. 2005; 165: 374-378. doi: [10.1001/archinte.165.4.374](https://doi.org/10.1001/archinte.165.4.374)
- Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007; 55: 993-1000. doi: [10.1111/j.1532-5415.2007.01234.x](https://doi.org/10.1111/j.1532-5415.2007.01234.x)
- Moss A, Holley J, Davison S, et al. Palliative care. *Am J Kidney Dis*. 2004; 43: 172-173.
- Douglas C, Murtagh F, Chambers E, Howse M, Ellershaw J. Symptom management for the adult patient dying with advanced chronic kidney disease: a review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus. *Palliat Med*. 2009; 23: 103-110. doi: [10.1177/0269216308100247](https://doi.org/10.1177/0269216308100247)
- Greaves C, Bailey E, Storey L, Nicholson A. Implementing end of life care for patients with renal failure. *Nurs Stand*. 2009; 23: 35-41.
- Davison SN, Jhangri GS, Holley JL, Moss AH. Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol*. 2006; 1: 1256-1262. doi: [10.2215/CJN.02040606](https://doi.org/10.2215/CJN.02040606)
- Holley JL, Davison SN, Moss AH. Nephrologists' changing practices in reported end-of-life decision-making. *Clin J Am Soc Nephrol*. 2007; 2: 107-111. doi: [10.2215/CJN.03080906](https://doi.org/10.2215/CJN.03080906)
- Collins AJ, Kasiske B, Herzog C, et al. Excerpts from the United States Renal Data System 2006 Annual Data Report. *Am J Kidney Dis*. 2007; 49(1 Suppl 1): A6-A7: S1-S296. doi: [http://dx.doi.org/10.1053/j.ajkd.2006.11.019](https://doi.org/http://dx.doi.org/10.1053/j.ajkd.2006.11.019)
- Jager K, van Dijk P, Dekker F, et al. The epidemic of aging in renal replacement therapy: an update on elderly patients and their outcomes. *Clin Nephrol*. 2003; 60: 352-360.
- Romano T, Palomba H. Palliative Dialysis: A Change of Perspective. *J Clin Med Res*. 2014; 6: 234-238.
- Cohen L, Germain M, Poppel D. Practical considerations in dialysis withdrawal: "to have that option is a blessing". *JAMA*. 2003; 289: 2113-2120. doi: [10.1001/jama.289.16.2113](https://doi.org/10.1001/jama.289.16.2113)
- Hamer R, El Nahas A. The burden of chronic kidney disease. *BMJ*. 2006; 332: 563-564.
- Kurella Tamura M, Covinsky K, et al. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med*. 2009; 361: 1539-1547. doi: [10.1056/NEJMoa0904655](https://doi.org/10.1056/NEJMoa0904655)
- Weisbord SD, Carmody SS, Bruns FJ, et al. Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients. *Nephrol Dial Transplant*. 2003; 18: 1345-1352. doi: [10.1093/ndt/gfg105](https://doi.org/10.1093/ndt/gfg105)
- Parlevliet JL, Buurman BM, Pannekeet MMH, et al. Systematic comprehensive geriatric assessment in elderly patients on chronic dialysis: a cross-sectional comparative and feasibility study. *BMC Nephrol*. 2012; 13: 30. doi: [10.1186/1471-2369-13-30](https://doi.org/10.1186/1471-2369-13-30)
- Davison S. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010; 5: 195-204. doi: [10.2215/CJN.05960809](https://doi.org/10.2215/CJN.05960809)
- ERA-EDTA Registry. ERA-EDTA Registry Annual Report 2012. Academic Medical Center, Department of Medical Informatics, Amsterdam, The Netherlands. 2014.

23. Canaud B, Tong L, Tentori F, et al. Clinical practices and outcomes in elderly hemodialysis patients: results from the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Clin J Am Soc Nephrol*. 2011; 6: 1651-1662. doi: [10.2215/CJN.03530410](https://doi.org/10.2215/CJN.03530410)
24. Okon T, Evans J, Gomez C, Blackhall L. Palliative educational outcome with implementation of PEACE tool integrated clinical pathway. *J Palliat Med*. 2004; 7: 279-295. doi: [10.1089/109662104773709404](https://doi.org/10.1089/109662104773709404)
25. Murtagh F, Addington-Hall J, Edmonds P, et al. Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *J Palliat Med*. 2007; 10: 1266-1276. doi: [10.1089/jpm.2007.0017](https://doi.org/10.1089/jpm.2007.0017)
26. Johansen KL, Chertow GM, Jin C, Kutner NG. Significance of frailty among dialysis patients. *J Am Soc Nephrol*. 2007; 18: 2960-2967. doi: [10.1681/ASN.2007020221](https://doi.org/10.1681/ASN.2007020221)
27. Bortz W. A Conceptual Framework of Frailty: A Review. *J Gerontol A Biol Sci Med Sci*. 2002; 57: 283-288. doi: [10.1093/gerona/57.5.M283](https://doi.org/10.1093/gerona/57.5.M283)
28. Fried L, Tangen C, Walston J, et al. Frailty in older adults evidence for a phenotype. *J Gerontol A Biol Sci Med Sci*. 2001; 56: M146-M157. doi: [10.1093/gerona/56.3.M146](https://doi.org/10.1093/gerona/56.3.M146)
29. Burns A, Davenport A. Maximum conservative management for patients with chronic kidney disease stage 5. *Hemodial Int*. 2010; 14: 32-37. doi: [10.1111/j.1542-4758.2010.00488.x](https://doi.org/10.1111/j.1542-4758.2010.00488.x)
30. Smith C, Da Silva-Gane M, Chandna S, et al. evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pr*. 2003; 95: 40-46. doi: [10.1159/000073708](https://doi.org/10.1159/000073708)
31. François K, Bargman J. Evaluating the benefits of home-based peritoneal dialysis. *Int J Nephrol Renov Dis*. 2014; 7: 447-455. doi: [10.2147/IJNRD.S50527](https://doi.org/10.2147/IJNRD.S50527)
32. Covic A, Bammens B, Lobbedez T, et al. Educating end-stage renal disease patients on dialysis modality selection. *Clin Kidney J*. 2010; 3: 225-233. doi: [10.1093/ndt/gfq206](https://doi.org/10.1093/ndt/gfq206)
33. Moss AH. To dialyze or not: the patient with metastatic cancer and AKI in the intensive care unit. *Clin J Am Soc Nephrol*. 2012; 7: 1507-1512. doi: [10.2215/CJN.02030212](https://doi.org/10.2215/CJN.02030212)
34. Ostermann M, Chang RWS. Acute kidney injury in the intensive care unit according to RIFLE. *Crit Care Med*. 2007; 35: 1837-1843; quiz 1852.
35. Dennen P, Douglas IS, Anderson R. Acute kidney injury in the intensive care unit: an update and primer for the intensivist. *Crit Care Med*. 2010; 38: 261-275. doi: [10.1097/CCM.0b013e3181bfb0b5](https://doi.org/10.1097/CCM.0b013e3181bfb0b5)
36. Mehta R, PASCUAL M, Soroko S, et al. Spectrum of acute renal failure in the intensive care unit: the PICARD experience. *Kidney Int*. 2004; 66: 1613-1621. doi: [10.1111/j.1523-1755-2004.00927.x](https://doi.org/10.1111/j.1523-1755-2004.00927.x)
37. Liaño F, Felipe C, Tenorio MT, et al. Long-term outcome of acute tubular necrosis: a contribution to its natural history. *Kidney Int*. 2007; 71: 679-686. doi: [10.1038/sj.ki.5002086](https://doi.org/10.1038/sj.ki.5002086)
38. Uchino S, Kellum J, Bellomo R, et al. Acute renal failure in critically ill patients: a multinational, multicenter study. *JAMA*. 2005; 294: 813-818. doi: [10.1001/jama.294.7.813](https://doi.org/10.1001/jama.294.7.813)
39. Okon TR, Vats HS, Dart RA. Palliative medicine referral in patients undergoing continuous renal replacement therapy for acute kidney injury. *Ren Fail*. 2011; 33: 707-717. doi: [10.3109/0886022X.2011.589946](https://doi.org/10.3109/0886022X.2011.589946)
40. Johnson RF, Gustin J. Acute renal failure requiring renal replacement therapy in the intensive care unit: impact on prognostic assessment for shared decision making. *J Palliat Med*. 2011; 14: 883-889. doi: [10.1089/jpm.2010.0452](https://doi.org/10.1089/jpm.2010.0452)
41. Draper H. Ethical aspects of withdrawing/withholding renal replacement therapies on patients in acute renal failure in an intensive care unit. *EDTNA-ERCA J*. 2002; S2: 39-42.
42. Patel S, Holley J. Withholding and withdrawing dialysis in the intensive care unit: benefits derived from consulting the renal physicians association/american society of nephrology clinical practice guideline, shared decision-making in the appropriate initiation of and with. *Clin J Am Soc Nephrol*. 2008; 3: 587-593. doi: [10.2215/CJN.04040907](https://doi.org/10.2215/CJN.04040907)
43. Maynard S, Whittle J, Chelluri L, Arnold R. Quality of life and dialysis decisions in critically ill patients with acute renal failure. *Intensive Care Med*. 2003; 29: 1589-1593. doi: [10.1007/s00134-003-1837-5](https://doi.org/10.1007/s00134-003-1837-5)
44. Van Niekerk L, Raubenheimer P. A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town, South Africa. *S Afr Med J*. 2014; 103: 138-141.
45. Sykes E, Cosgrove J. Acute renal failure and the critically ill surgical patient. *Ann R Coll Surg Engl*. 2007; 89: 22-29.
46. Price C. Resources for planning palliative and end-of-life care for patients with kidney disease. *Nephrol Nurs J*. 2003; 30: 649-656.
47. Granado C, Mehta R. Withholding and withdrawing renal support in acute kidney injury. *Semin Dial*. 2011; 24: 208-214.
48. Hartog CS, Peschel I, Schwarzkopf D, et al. Are written ad-

- vance directives helpful to guide end-of-life therapy in the intensive care unit? A retrospective matched-cohort study. *J Crit Care*. 2014; 29: 128-133. doi: [10.1016/j.jcrc.2013.08.024](https://doi.org/10.1016/j.jcrc.2013.08.024)
49. Villa G, Di Maggio P, Baccelli M, Romagnoli S, De Gaudio AR. Outcome prediction models in end-of-life decision making. *Trends Anaesth Crit Care*. 2014; 4: 170-174.
50. Ricci Z, Ronco C, D'Amico G, et al. Practice patterns in the management of acute renal failure in the critically ill patient: an international survey. *Nephrol Dial Transplant*. 2006; 21: 690-696. doi: [10.1093/ndt/gfi296](https://doi.org/10.1093/ndt/gfi296)
51. Overberger P, Pesacreta M, Palevsky PM, VA/NIH Acute Renal Failure Trial Network. Management of renal replacement therapy in acute kidney injury: a survey of practitioner prescribing practices. *Clin J Am Soc Nephrol*. 2007; 2: 623-630.
52. Gatward JJ, Gibbon GJ, Wrathall G, Padkin A. Renal replacement therapy for acute renal failure: a survey of practice in adult intensive care units in the United Kingdom. *Anaesthesia*. 2008; 63: 959-966. doi: [10.1111/j.1365-2044.2008.05514.x](https://doi.org/10.1111/j.1365-2044.2008.05514.x)
53. Giannoni C, Chelazzi C, Villa G, De Gaudio AR. Organ dysfunction scores in ICU. *Trends Anaesth Crit Care*. 2013; 3: 89-96. doi: [10.1016/j.tacc.2013.01.008](https://doi.org/10.1016/j.tacc.2013.01.008)
54. Frost L, Pedersen R, Hansen H. Prognosis in septicemia complicated by acute renal failure requiring dialysis. *Scand J Urol Nephrol*. 1991; 25: 307-310.
55. Hamel M, Phillips R, Davis R, et al. Outcomes and cost-effectiveness of initiating dialysis and continuing aggressive care in seriously ill hospitalized adults. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med*. 1997; 127: 195-202. doi: [10.7326/0003-4819-127-3-199708010-00003](https://doi.org/10.7326/0003-4819-127-3-199708010-00003)
56. Abosaif NY, Tolba YA, Heap M, Russell J, El Nahas AM. The outcome of acute renal failure in the intensive care unit according to RIFLE: model application, sensitivity, and predictability. *Am J Kidney Dis*. 2005; 46: 1038-1048. doi: <http://dx.doi.org/10.1053/j.ajkd.2005.08.033>
57. Choi A, Li Y, Parikh C, Volberding P, Shlipak M. Long-term clinical consequences of acute kidney injury in the HIV-infected. *Kidney Int*. 2010; 78: 478-485. doi: [10.1038/ki.2010.171](https://doi.org/10.1038/ki.2010.171)
58. Swaminathan M, Hudson C, Phillips-Bute B, et al. Impact of early renal recovery on survival after cardiac surgery-associated acute kidney injury. *Ann Thorac Surg*. 2010; 89: 1098-1104. doi: [10.1016/j.athoracsur.2009.12.018](https://doi.org/10.1016/j.athoracsur.2009.12.018)
59. Thakar C V, Quate-Operacz M, Leonard AC, Eckman MH. Outcomes of hemodialysis patients in a long-term care hospital setting: a single-center study. *Am J Kidney Dis*. 2010; 55: 300-306. doi: [10.1053/j.ajkd.2009.08.021](https://doi.org/10.1053/j.ajkd.2009.08.021)
60. Ahlström A, Tallgren M, Peltonen S, Räsänen P, Pettilä V. Survival and quality of life of patients requiring acute renal replacement therapy. *Intensive Care Med*. 2005; 31: 1222-1228. doi: [10.1007/s00134-005-2681-6](https://doi.org/10.1007/s00134-005-2681-6)
61. Noble J, Simpson K, Allison M. Long-term quality of life and hospital mortality in patients treated with intermittent or continuous hemodialysis for acute renal and respiratory failure. *Ren Fail*. 2006; 28: 323-330.
62. Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc*. 1997; 45: 500-507.
63. Galla J. Clinical practice guideline on shared decision-making in the appropriate initiation of and withdrawal from dialysis. The Renal Physicians Association and the American Society of Nephrology. *J Am Soc Nephrol*. 2000; 11: 1340-1342.
64. Ishikawa H, Sakamoto J. Nondialytic Therapy for Elderly Patients in a Critical Care Setting. *Case Rep Nephrol Urol*. 2014; 4: 126-130.
65. Ryder-Lewis M. Going home from ICU to die: a celebration of life. *Nurs Crit Care*. 2005; 10: 116-121. doi: [10.1111/j.1362-1017.2005.00117.x](https://doi.org/10.1111/j.1362-1017.2005.00117.x)
66. The SUPPORT Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*. 1995; 274: 1591-1598. doi: [10.1001/jama.1995.03530200027032](https://doi.org/10.1001/jama.1995.03530200027032)

Case report

Corresponding author

Annekathryn Goodman, MD, MS

Associate Professor of Obstetrics
Department of Obstetrics and
Gynecology, Division of Gynecologic
Oncology, Reproductive Biology
Harvard, Medical School
Massachusetts General Hospital
Gillette Center for Women's Cancers
Yawkey 9E, 55 Fruit St.
Boston, MA 02114, USA

Tel. 1-617-724-5242

Fax: 1-617-724-6898

E-mail: agoodman@mgh.harvard.org

Volume 1 : Issue 1

Article Ref. #: 1000PMHCOJ1105

Article History

Received: January 19th, 2015

Accepted: February 16th, 2015

Published: February 19th, 2015

Citation

Goodman A, Black L. The Challenge of allocating scarce medical resources during a disaster in a low income country: a case study from the 2010 Haitian earthquake. *Palliat Med Hosp Care Open J*. 2015; 1(1): 24-29. doi: [10.17140/PMHCOJ-1-105](http://dx.doi.org/10.17140/PMHCOJ-1-105)

Copyright

©2015 Goodman A. This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

The Challenge of Allocating Scarce Medical Resources during a Disaster in a Low Income Country: A Case Study from the 2010 Haitian Earthquake

Annekathryn Goodman^{1*} and Lynn Black²

¹Associate Professor, Department of Obstetrics and Gynecology, Division of Gynecologic Oncology, Reproductive Biology Harvard Medical School, Massachusetts General Hospital, Boston, Massachusetts, USA

²Assistant Professor of Medicine, Harvard Medical School, Massachusetts General Hospital, Boston, Massachusetts, Chief Medical Officer, International Medical Surgical Response team, USA

ABSTRACT

Scarce medical resources during a natural disaster challenge the existing protocols for medical intervention. Triage decisions about which patient to care for can be extremely stressful for a medical team. This case analysis describes the experience of one mobile field hospital in Haiti in the aftermath of the January 12, 2010 earthquake. The medical team was confronted with the need to choose which of three critically ill patients should receive the remaining, dwindling oxygen supply. The ethical framework around these decisions is discussed. The development of an onsite ethics committee from team members is suggested to help lighten the burden of decision making off of the individual care provider.

KEYWORDS: Haiti earthquake; Disaster; Resources; Crisis; Palliative care.

ABBREVIATIONS: NDMS: National Disaster Management System; CIC: Commander-in-Chief; IOM: Institute of Medicine.

INTRODUCTION

Natural disasters in low income countries rapidly deplete available medical and social resources. Rescue teams are confronted with the challenge of medical triage of critically ill patients when there are not enough supplies to treat everyone. The complex and challenging decision to shift from active to palliative care in the disaster setting is rarely straight forward. The experience of one disaster team during their deployment after the 2010 Haiti earthquake is described and analyzed.

The National Disaster Management System (NDMS) of the United States recruits volunteer health professionals who train for disasters and are called up when the United States government declares a national or international disaster.¹ When on deployment, the disaster team members are federal employees. The command structure of NDMS follows the incident command system of the military. In Haiti, our team received our orders from our Commander-in-Chief (CIC) in Washington. On the ground, a direct commander in chief was selected. The organization structure of the team followed the incident command structure set by our CIC. Our CIC was an EMT fireman. He organized the 63 team members into modules based on our work assignments. Because we were working in an unsafe environment physically (there were

daily aftershocks and unstable buildings) and politically (there was no effective government in Haiti and there were riots, looting, and gang violence), safety and security was the first priority of the CIC. One of the modules in our group was logistics. They were involved in obtaining supplies to keep our hospital running. All supplies including medicines, medical equipment, food, and shelter were brought in from the United States. The team did not use any local resources so as to not deplete locally scarce supplies.

A chief medical officer was assigned to coordinate the medical efforts of the group. Daily briefings were held by the CIC about safety reports, supplies, team safety. The sign-out among the nurses and doctors occurred every 12 hours in their particular tent

This report describes three patients who required oxygen when oxygen supplies were running out. The dilemma of triage is discussed and ethical questions are raised. How does one decide whom to give a limited resource to? How is this decision made? Who is responsible for making this decision? What is the impact on the medical team of rationing or withdrawing resources? One solution, to develop an embedded ethics presence within the team to guide and validate these difficult decisions, is discussed.

CASE REPORT

United States Health and Human Services sent Medical Disaster Teams into Haiti after the January 12, 2010 earthquake. Our team of 63 people (including 11 physicians, 29 nurses, 3 pharmacists, 2 respiratory therapists, and 18 logistics and security people) arrived in Haiti forty-eight hours after the earthquake. A perimeter and a mobile hospital unit were set up in a devastated region of Port Au Prince on the grounds of a destroyed hospital called Gheskio. There were two general medicine tents, a minor procedures tent for dressings and debridements, an operating room, "ICU", and children's ward. We were able to shelter 35 souls at a time and tried to triage, treat, and discharge patients quickly. From the time the hospital was set up, we worked at full capacity and sheltered an additional twenty to thirty patients on army cots covered by mosquito netting on the grass perimeter.

We were surrounded by a tent city of survivors, rubble from buildings, and the constant shifting ground of aftershocks. Because the airport had been severely damaged and transport resources were devoted to a constant stream of people being airlifted out of Haiti, there was limited delivery of medicines, supplies, and food into Haiti during the first two weeks after the earthquake.

Supplies were initially insufficient. For instance, while the most common injury was compound fractures of the arms, legs, and hips, external fixators were not available until our second week. Creative solutions included tying pieces of stone from the rubble to ropes swung over the poles of the army cots to use

traction to realign the fractures.

One week after the earthquake, three critically ill patients arrived simultaneously to the Gheskio Field Hospital. N.S. was a 38-year-old woman who had decompensated congestive heart failure. She had been an inpatient at the University Hospital before the earthquake destroyed parts of the hospital. Her family had all died when their house crushed them. She was brought to us in severe respiratory distress. She received diuretics and oxygen.

J.P., the second patient, was a 25-year-old man who had survived under the rubble for three days until his family was able to dig him out. His severe crush injuries led to renal failure and then acute respiratory distress syndrome. He was emergently intubated and put on the respirator in the ICU tent.

The third patient was an infant with pneumonia who was intubated and ventilated manually as there was only one mechanical respirator at the field hospital.

On the morning that the three patients arrived, the chief logistics officer informed us that we were getting low on oxygen and gasoline. He was concerned that we would run out of gasoline used to run our generators. Requests for these supplies had been made but because of the precarious situation at the airport, it was uncertain when we would receive the needed supplies. Other medical supplies such as pain medication, antibiotics, and cardiac medications were adequate.

By that evening, it was clear that oxygen supplies were low; however there was no group meeting called to discuss how to manage the crisis. By midnight, oxygen supplies were running out. In the medical tent where N.S. was being treated, the medical officer made the decision to turn down the flow rate of her oxygen tank to try to ration it. She was treated with more diuretics and morphine to alleviate her panic from respiratory distress. The nurse taking care of N.S. spent the night trying to keep her comfortable. By morning, when the communications liaison identified another facility with resources, N.S. was transported without oxygen by a pickup truck to University Hospital in Port au Prince where oxygen was available. A doctor from our team transported her and tried to palliate her discomfort with inhalers. N.S. survived and was discharged after treatment.

J.P. and the infant were being managed in the ICU tent. The baby was hand ventilated using room air when her oxygen tank ran dry. The two respiratory therapists and the one pediatrician took turns squeezing the Ambu bag for 24 hours. The pediatrician who was ventilating the infant suggested that J.P. should not be intubated when he developed respiratory distress and be allowed to die. The other physician in the tent refused and intubated him. J.P. was given the last remaining tank of oxygen. The baby and J.P. were transported by helicopter to the USNS Comfort Hospital Ship that was docked in the harbor. J.P. died en route. The baby survived.

DISCUSSION

Triage in a Disaster Setting

Disaster triage includes assessing survivors for types of injuries and survivability from injuries. Triage categories are described based on the need for immediate versus delayed care, and scoring systems or universal color coding are used for quick communication of triage assessments.² For instance, an immediate triage category (color red) signals a group needing immediate attention to survive. The delayed category victim (color yellow) has wounds that can be treated after the red group. The minimal category victim (color green) does not have life-threatening injuries and can be managed at a later time. The expectant category (color black) will not survive and the focus should be on palliative care with a goal of alleviating suffering.

At the Gheskio Field Hospital, both the infant and J.P. had category red medical conditions. N.S, chronically ill for years was initially thought to be category yellow but actively decompensated when oxygen was withdrawn. All three patients were believed to have life-threatening conditions that could be reversed with the right therapeutic interventions.

Resource Availability

Resource availability is categorized as Normal, Good, Fair, and Poor.³ With normal resources (categorized as “conventional” by the Institute of Medicine (IOM)), normal care is provided. For good resource availability (categorized as “contingency” by IOM), the functional equivalent level of care can be maintained by substituting and conserving resources. Fair resources are considered in the “crisis” category by IOM and triage is needed to prioritize those with moderate life-threatening injuries. The rationale for this is that those with more severe life-threatening injuries will have higher resource requirements and worse prognosis even with treatment. For poor resource availability (also categorized as “crisis” by IOM), moderate life-threatening injuries are prioritized but resources can be inadequate to treat even this group. Severe casualties are triaged to the expectant category.

Resources at Gheskio Field Hospital were temporarily poor and in the “crisis” category for resource availability after a week of continuous disaster work in Haiti. The team hoped to keep the category red patients alive until more resources arrived. However, oxygen ran out before the camp could be resupplied. Using the IOM analysis, the survivability of these three patients should have been reconsidered. While J.P. was young and healthy, he had sustained a devastating injury and was developing multi-organ system failure. Realistically, the likelihood of his survival was low. However, it was emotionally impossible for the staff caring for him to disengage. This led to conflict among team members. A strong leadership presence with a “group huddle” to discuss events would have been helpful. In addition to these three patients, there were multiple other medi-

cal crises going on including a woman with a dysfunctional labor, five small children with amputations, and four people in the “expectant” category which included a woman dying of tuberculosis and AIDS, a woman with a severe crush injury, a pregnant woman with a broken neck, and a boy with tetanus. The CIC was chosen because of his strong logistics and security background, however because of his expertise in these areas, there was less leadership guidance on the challenges of medical management.

Using the same analysis, while in an environment with normal and “conventional” resources, N.S. would have been fitted with a home oxygen tank. She also might have been on a heart transplant list. In Haiti, a country without a single functioning hospital in Port Au Prince, it was only a matter of time before her chronic condition would deplete available resources. Given the huge need of other people who did not have chronic conditions and who could survive, one might argue that oxygen should be saved for them. The staff caring for N.S. could not make that decision and continued to give her the remaining oxygen.

Team Dynamics, Psychological & Behavioral Responses to Disaster Care

Our team and NDMS teams in general are required to participate in trainings through the year. Drills with volunteer victims to learn how to triage casualties and allocate scarce resources are routinely performed. Yet in the heat of real crisis, the primary role as patient advocates collided with the intellectual knowledge of triage developed from drills. Therefore, it is important that part of leadership in the disaster setting involves constant guidance and discussion when these distressing decisions arise about whom to treat and whom not to treat. Studies of emergency responders show that they have a powerful sense of duty and deep commitment to help.⁴ Despite adequate pre-disaster training, dysfunctional behavior can occur when responders are vastly overwhelmed and severely under-resourced. Additionally, dysfunction occurs when there are threats to personal safety and limited information about what is happening globally. In our team, we were physically uncomfortable due to the austere environment and heat. The air was filled with smoke from fires in buildings, from burning of bodies, and from burning of tires during riots. There was wide spread frustration at the lack of adequate supplies. There was limited communication with the outside world and with other rescue sites on the ground because of a lack of cell phone function and destruction of land line communications.

In the setting of severe stress, decision-making can be adversely affected. During Hurricane Katrina, thirty-four patients died at Memorial Medical Center. The staffs, who were not trained in disaster management, made decisions about patient care and triage that were later questioned. One editorial concluded that training and community discussions about what care should be provided when there are crisis category resources after a disaster.⁵ Our experience in Haiti suggests that training is not enough.

Ethical Resources for Disaster Work

Theoretical ethical analyses of disasters offer ethical frameworks to help professionals identify the obligation to preserve life, name crises in resources, and even to consider euthanasia in settings of irresolvable suffering.⁶ Pre-disaster training is important. Other tools include Edwards and Robey's "Virtual Mentor".⁷ They discuss three strategies for approaching ethical issues: 1 - anticipate and practice; 2 - use pre-existing ethical frameworks; 3 - build a scaffolding within which to place issues.

Hunt discusses the importance of establishing "moral bearings" in humanitarian work.⁸ He identifies specific challenges that impact the uncertainty of the ethical decision-making in acute emergencies that include 1- the level of achievable care is much lower than health care providers are used to; 2 - in contexts of resource scarcity, increased instability, and widespread health needs, population health concerns abound; 3 - in humanitarian settings the volume and urgency of needs of the local population are elevated and providers often work extremely long shifts causing exhaustion and have limited opportunity to debrief.; 4 - important differences exist between cultural frameworks in how health, wellness, disease and disability are understood and experienced; 5 - imbalances of power occur between providers and patients; and 6 - there is less regulatory oversight and professional accountability in the field than at home. Hunt suggests asking several focused questions to help understand the appropriate action.

These questions listed here in italics could have guided decision making during our dilemma of managing the three patients who required the diminishing supply of oxygen:

1. Identify/clarify the ethical issue

a) What is the issue that we are experiencing?

Who should receive the limited oxygen resource?

b) What is at stake and for whom?

All three patients are at risk of dying without the oxygen.

c) How is this issue experienced/understood from different perspectives?

All of the team is aware of the consequences of withdrawing oxygen from the three patients. There was disagreement about who should receive oxygen based on differing assessments of survivability.

2. Data gathering and attention to context

a) Who can contribute to helping us understand this issue better?

Information about when more supplies could be obtained would have been helpful. Understanding what resources other NGO tent hospitals in the area had available would have allowed earlier transfer of patients that we could not have taken care of.

b) How do organizational features influence the issue?

There was no embedded ethics committee within the organization of our team on the ground. It would have defused the tension to have an ethics subgroup of the team assigned to support team members about the dilemma of choice of who would receive oxygen. An ethics presence could have also weighed-in on who was the most appropriate recipient of our scarce resource.

c) What is the impact of the professional and social norms of our home countries on how we understand this issue?

The professional norms of the team heavily impacted the choices they made. The physician who decided to intubate J.P was an emergency room physician who could not watch the young man die when she knew she could prevent his death by intubation. The nurse, who worked in an intensive care unit in her home hospital, was traumatized by watching N.S. gasp for air all night long because of inadequate oxygen.

d) What is the impact of this issue on collaboration and trust among the team?

The team works because of collaboration and an acceptance of command decisions. When a situation such as running out of oxygen occurs, this stresses the trust relationship between team members. Trust between team members requires that there is open communication and collaborative problem solving.

e) How are imbalances of power relevant to the issue?

The command structure prevented a flexible problem-solving approach in this situation of crisis. The command focus was on the safety of the team members and did not allow problem solving about ethical issues. The choice of a logistics and security expert understandably occurred because of the unstable nature of the country. However, greater thought to structuring a medical leadership should have also occurred.

3. Exploration of ethics resources

a) What ethics resources and approaches can assist us in evaluating this issue?

The most important resource would have been an *a priori* establishment of an in-team ethics group. It would have been important to give the ethics group authority to weigh-in on contentious issues. The values and norms continue to be the observance of triage of victims by severity of injury plus an acknowledgement of the scarcity of resources. Group discussion of these limitations and emotional support to team members in distress is vital.

The Ethical Landscape of a Disaster

Disaster responders have a moral compulsion to help in a disaster. They come into the disaster environment with a developed sense of ethical justice. Justice in this setting includes a sense of obligation to the victims. In the field, the lack of resources and the overwhelming number of injuries and victims can lead to despair and post-traumatic stress on the part of the providers. Providing an ethical framework and a moral landscape can lighten the burden of these providers, reduce tension between colleagues, and help with difficult decisions. Edwards

and Robbey⁷ review the four ethical skills of:

1. *Recognition: What is the ethics issue in this case? Reasoning: What options are there, and what are the potential harms and benefits of each? What is at stake in this decision?*

2. *Responsibility: What are my professional obligations?*

3. *Respond: What will I do, and why?*

This simple articulation frames the most terrible of dilemmas. Additionally, the need for a disaster ethics committee takes the burden of these “Sophie’s Choices” off the individual providers. There is a need for training of selected individuals on the disaster team in ethics. The most workable model for an ethicist(s) on a disaster team is ethicist as a team member.⁹ The wisdom of who should decide life and death decisions in a non-disaster setting is useful to support a similar practice in the disaster setting. Decisions should reflect the various segments of the community and no decisions can be made in isolation of that community.¹⁰ Disaster medicine occurs within the fabric of a community that has been damaged or destroyed. One of the challenges of a disaster team is to identify local cultural leaders to help guide decisions. The ethics subgroup within the team should be tasked to explore community resources.

The United States National disaster team is, by its nature, a team that is trained to accept the authority of its commanders. The addition of an ethicist as an authority would be well received. The nature of authority *per se* and for an ethics consultant has been explored.¹¹ The two components to authority are epistemic and competence. Additionally, authority in action solidifies the status of the ethicist. This would definitely occur in the disaster field. Finally, the disaster team ethicist can help open up a moral space for discussion among team members. Having such a resource on the team emphasizes the importance of these issues in both decision-making and in the support of the team members. There is a need to find some existential meaning to the outcomes of disasters. Disaster responders feel that their participation in the alleviation of suffering gives meaning to the chaos and misery. The available ethical tools should be deployed to help bring clarity to impossible situations and prevent team members from feeling isolated when tough decisions need to be made.

Communication as Part of Ethics Work in Disasters

Decision making in disasters should use five domains to help guide responders: triage and allocation, ethical concerns of patients and families, ethical responsibilities to providers, conduct of research, and international concerns.¹² This report focuses on the dilemmas providers confront in the first domain: triage and allocation.

Disaster management communication is vitally important during disasters.¹³ Developing a language of quick sign-outs

to identify ethical issues will help teams work efficiently and reduce conflict. Research is needed into responders’ choices and how to best develop guidelines.¹⁴ Additional training with real life scenarios, development of triage plans, and the use of ethics consults can minimize the burden of emotional and cognitive dissonance on providers in the field.¹⁵

REFERENCES

1. Ebola Information for Healthcare Professionals and Health-care Settings, 2014. <http://www.phe.gov/preparedness/pages/default.aspx>. Accessed February 13, 2015.
2. Eastridge BJ, Butler F, Wade CE, et al. Field triage score (FTS) in battlefield casualties: validation of a novel triage technique in a combat environment. *J Surg*. 2010; 200(6): 724-727. doi: [10.1016/j.amjsurg.2010.08.006](https://doi.org/10.1016/j.amjsurg.2010.08.006)
3. Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations. <http://www.iom.edu/reports/2009/disaster-carestandards.aspx>. Accessed February 13, 2015.
4. Dodgen D, Norwood AE, Becker SM, Perez JT, Hansen CK. Social, psychological and behavioral responses to a nuclear detonation in a US city: implications for health care planning and delivery. *Disaster Med Public Health Preparedness*. 2011; 5: S54-S64. doi: [10.1001/dmp.2011.12](https://doi.org/10.1001/dmp.2011.12)
5. Okie S. Dr Pou and the Hurricane - Implications for patient care during disasters. *NEJM*. 2008; 358: 1-5. doi: [10.1056/NEJMp0707917](https://doi.org/10.1056/NEJMp0707917)
6. McCullough LB. Taking seriously the “what then?” question: an ethical framework for the responsible management of medical disasters. *J Clin Ethics*. 2010; 21: 321-327.
7. Edwards KA, Robey T. “Preparing for the Unexpected: Teaching ER Ethics”. *American Medical Association Journal of Ethics*. 2010; 12(6): 455-458. doi: [10.1001/virtualmentor.2010.12.6.medu1-1006](https://doi.org/10.1001/virtualmentor.2010.12.6.medu1-1006)
8. Hunt MR. Establishing moral bearings: ethics and expatriate health care professionals in Humanitarian work. *Disaster*. 2011; 35(3): 606-622. doi: [10.1111/j.1467-7717.2011.01232.x](https://doi.org/10.1111/j.1467-7717.2011.01232.x)
9. Fox MD, McGee G, Caplan A. Paradigm for clinical ethics consultation Practice. *Cambridge Quarterly Healthcare ethics*. 1998; 7: 308-314.
10. McGee DB. Issues of Life and Death. Understanding Christian Ethics an interpretive approach. In: Tillman W, ed. B&H Publishing Group. 1988; 11: 227-248.
11. Agich GJ. Why should anyone listen to Ethics consultants? The Philosophy of Medicine. In: Engelhardt HT Jr, ed. Copyright 2000, Kluwer Academic Publishers, Netherlands. 117-137.

doi: [10.1007/0-306-47475-1_6](https://doi.org/10.1007/0-306-47475-1_6)

12. Biddison LD, Berkowitz KA, Courtney B, et al. Ethical considerations: care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest*. 2014; 146(4 Suppl): e145S-e155S. doi: [10.1378/chest.14-0742](https://doi.org/10.1378/chest.14-0742)

13. Bradley DT, McFarland M, Clarke M. The effectiveness of disaster risk communication: a systematic review of intervention studies. *PLoS Curr*. 2014; 6.

14. Mathúna D. Research ethics in the context of humanitarian emergencies. *J Evid Based Med*. 2015; doi: [10.1111/jebm.12136](https://doi.org/10.1111/jebm.12136)

15. Ozge Karadag C, Kerim Hakan A. Ethical dilemmas in disaster medicine. *Iran Red Crescent Med J*. 2012; 14(10): 602-612.