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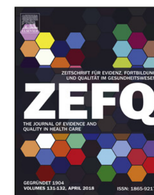

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Making Advance Care Planning a part of cancer patients' end-of-life care in Rwanda

Advance Care Planning als Bestandteil der Versorgung in der letzten Lebensphase von Krebspatientinnen und -patienten in Ruanda

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A B S T R A C T

After the devastating damage inflicted by the 1994 Genocide against the Tutsi, Rwanda made great strides in reconstructing its healthcare system from scratch. Although cancer mortality rates continue to rise, there is still a dearth of qualified healthcare workers for advance care planning (ACP) for terminally ill patients. I will draw on lessons learned through the literature search for the initiation of ACP and reflect on their adaptation to the existing policies, healthcare systems, and workforce in Rwanda. We hope to introduce advance care planning into the clinical package given to patients with cancers in terminal illness and their families in Rwanda.

The introduction of ACP by skilled, qualified, and specialized healthcare professionals in Rwanda will help establish a practical ACP strategy at the hospital and in the community to benefit patients and their loved ones for an enhanced quality of life in end-of-life care. There is a need for training, policy-making, and community mobilization for the awareness of ACP.

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Z U S A M M E N F A S S U N G

Nach den verheerenden Schäden, die 1994 durch den Völkermord an den Tutsi angerichtet worden sind, hat Ruanda beim Wiederaufbau seines Gesundheitssystems große Fortschritte erzielt. Ungeachtet des nach wie vor zu verzeichnenden Anstiegs der Krebsmortalitätsraten mangelt es noch immer an qualifizierten Gesundheitsfachkräften für eine ACP-Gesprächsbegleitung von unheilbar erkrankten Patientinnen und Patienten. Auf der Grundlage der durch die Sichtung der Literatur gesammelten Erfahrungen mit der Einführung von ACP wird sich der vorliegende Beitrag mit ihrer Adaptation an die bestehenden Richtlinien, das Gesundheitssystem und seine Beschäftigten in Ruanda befassen. Wir hoffen, Advance Care Planning in das Therapiepaket aufnehmen zu können, das unheilbar an Krebs erkrankten Menschen und ihren Angehörigen in Ruanda angeboten wird.

Die Einführung von ACP durch erfahrene, qualifizierte und spezialisierte Gesundheitsfachkräfte in Ruanda wird dazu beitragen, eine praktikable ACP-Strategie in Krankenhäusern und Kommunen zu etablieren, damit die Patientinnen und Patienten sowie ihre nächsten Angehörigen im Rahmen der Versorgung am Lebensende von einer verbesserten Lebensqualität profitieren können. Dazu sind Schulungen, politische Entscheidungen und eine Sensibilisierung für Advance Care Planning in den Kommunen vonnöten.

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Background of the health care system

Rwanda, the "Land of a Thousand Hills," continues to rebuild itself due to its resiliency and leadership following the Genocide against the Tutsi in 1994, in which one million people died in 100 days. Humanity itself seemed lost at that time. Though the healthcare system was destroyed quickly, the reconstruction took years with the tremendous efforts of the Government of Rwanda. Yet, a satisfactory level of equity and social justice for access to better healthcare is not achieved. The healthcare system is a pyramid whereby the community or villages are supported by community health workers, then health posts and health centres at the primary level; at the secondary level with district, provincial, and referral hospitals and then at the tertiary level with teaching hospitals and the regional hospital. Depending on the complexity of the ailments, the patient is referred from primary to tertiary level, while subsequent follow-up is from tertiary to primary level. Palliative care was considered among the Rwanda Ministry of Health's priorities during the HIV/AIDS pandemic. Rwanda became the first African country in 2011 to adopt a standalone policy in palliative care [1], including a strategic implementation plan for the next four years. The policy has been integrated into the national cancer control plan and the Non-Communicable Diseases strategic plan [2].

Regarding end-of-life care, Advance Care Planning (ACP) in Rwanda may help to unload the considerable bed occupancy rate at tertiary hospitals where patients with life-limiting illnesses prefer staying at the hospitals instead of returning home. Involving family members may facilitate the decision-making process, including the logistics, to allow for a smooth transition between the care expectations and the patient's quality of life. When talking about death and dying, the "Elephant in the Room," there is still a taboo culture in Rwanda [3]. Death and dying are apparent, but they cannot be discussed openly. The difficulty of healthcare personnel to understand palliative and end-of-life care hinders the adoption of ACP. ACP necessitates collaborative decision-making between the healthcare staff, the patient, and the patient's family.

Policy or legislative efforts/milestones to foster ACP implementation into the national health care system

The importance of developing palliative care to improve the quality of life of Rwandans with severe chronic illnesses is evident in the "National Palliative Care Policy" [1] and "Strategic Plan" [4]: "Even in the face of a chronic and incurable disease, steps can be taken to enhance the quality of life of patients. In the name of equal access to high-quality health care, the Ministry of Health is devoted to integrating palliative care into the Rwandan health system. All people, including children, living in Rwanda with a progressive life-limiting illness, their families, and caregivers will have access to a health system that provides high-quality palliative care services that are well coordinated, innovative, and responsive to their needs in an affordable and culturally appropriate manner by 2020." [1,5].

Although many efforts have been made to incorporate palliative care into the existing system through education and access to pain relief medications such as morphine, ACP has not been addressed in national policies or legislation designed to assist the patient, family, and healthcare team. The ACP process should not solely rely on the medical team's perspectives of treatment, the family's perception of care, or the patient's expectations to access better care, but instead on a clear policy or legislation integrated into the Rwandan healthcare system for the benefit of the medical team, the family, and the patient. This will prevent complications and unnecessary conflicts.

Definition(s) and Model(s) of ACP used

In general, ACP reflects a process by which decision-making is shared between a patient, their family, and their healthcare team. It involves having conversations about clear directives of care the patient wishes to have, reducing conflicts with families when wishes are not aligned with their perspectives. As ACP still needs to be developed in many health settings in most African countries where palliative care is not set, there is no consistent model of ACP implemented.

The model of ACP from Euro-American cultural experiences shouldn't be applied in Rwanda or in an African context where perspectives may be different [6]. For example, there is a saying that: "When you are well, you belong to yourself, but when you are sick, you belong to your family" [7], which emphasizes the transfer of decision-making from the patient to the family. The model of ACP, which will be used in Rwanda, must adopt the local perception of care and be adapted and validated by the local stakeholders.

Groups addressed

ACP addresses the social justice of vulnerable populations, particularly those with life-limiting conditions, such as chronically ill, seriously ill patients, children, people who cannot make decisions, and people with mental health conditions. Cancer diseases are among the leading causes of morbidity and mortality worldwide, with approximately 18.1 million new cases and 9.6 million cancer-related deaths estimates in 2018. In Rwanda, estimates of cancer burden are 10704 cancer cases and 6 044 deaths in 2020 [8]. In the developing world, including Rwanda, the survival rate for patients with cancer is appallingly low. In Rwanda, inadequate public understanding of cancer risk factors, early detection, preventive measures, diagnostic capacity, and treatment interventions are significant barriers to cancer control. Patients with cancer are at risk of deterioration, and ACP is relevant. Recognizing patients' preferences for the treatment they want and deserve requires opening a discussion with healthcare providers.

Education/Training of Health care professionals and non-healthcare professionals in ACP

There needs to be more education on ACP for healthcare and non-health professionals, which affects the decision-making process in end-of-life care. It's a win-win strategy to educate all parties involved in ACP: patients, families, and healthcare professionals. Without an appropriate comprehension of ACP, missed opportunities and frustration will ensue and continue to impact care outcomes. Education doesn't mean duplicating an ACP model from one health setting to another but rather; adopting and adapting knowledge and skills that can better apply to the local context.

Information Materials used, Documentation and Digitalization of ACP processes in the health care sector and beyond

The materials, documentation, and digitalization of ACP are inexistent in Rwanda's public health system, which needs to be developed at each level of care and adapted to rural and urban areas.

Examples of institutional and community implementation

ACP implementation has been shown to improve the quality of dying [9]. With ACP, there is respect for the autonomy of the individual patient, an improvement in the quality of care and relationships, a preparation for the end-of-life, and a reduction in overtreatment [10]. Organizational support is essential for sustainability through sufficient training, facilitation, collaboration, and consistent work routines across providers and other professionals [11] from various institutions. In Rwanda, the implementation will be from the Community level up to the Referral Hospitals and the Teaching hospitals, including the health professionals' training at different institutions [12]. Continuous education among professionals and the family's involvement is critical for collaboration in decision-making [13]. Apart from legislation, ACP can't be implemented without the participation of home-based care. This entails training community health workers [14–16] under the supervision of trained healthcare providers.

Research in ACP in Rwanda

In Rwanda, palliative care is starting to be integrated into the public health system to meet the needs of patients with life-limiting illnesses. Research is urgently needed to understand the gaps and opportunities during implementation. There currently needs to be a budget for research in ACP in Rwanda.

Patient and public involvement (patient movement) in the research and development of ACP

Having difficult conversations and making decisions seem tiresome for everyone without appropriate education. The community-centered approach in the research and development of ACP in Rwanda should focus on the following:

- Educating patients and the community about the benefits of having an ACP in the hospital and establishing patient and family advocacy groups who can continue to give feedback about their decisions and outcomes.
- Developing research questions during the design process should involve patients and families to evaluate how their needs and concerns impact their quality of life.
- Qualitative approach to understanding their experiences through different focus groups would help avoid mistakes and develop concrete guidelines for the benefit of all.
- Language is an important platform to disseminate critical information about ACP, which should be translated into the local language (Kinyarwanda) to ensure that all patients and families understand the meaning.

Addressing diversity and vulnerabilities (cultural social) regarding ACP access and use

The cultural and social vulnerability may result in difficulties for individuals and the community to access and use ACP. Training in cultural competency for the staff will be an excellent strategy to address this issue in Rwanda, especially regarding end-of-life care practices that focus on the disease instead of the person. Training in ACP conducted in the local language, including the broad spectrum of views and perspectives in Rwanda, can address myths and customs around death and dying that influence decision-making, potentially substantially affecting practice. In particular, the historical genocide against the Tutsi is a complex factor that may affect the course of ACP. This deserves investment in research to develop culturally sensitive approaches in ACP in Rwanda. The system needs to be community-centered because of the local practice of community-based approaches to vulnerability. Healthcare providers must work with other community organizations and stakeholders to promote ACP and educate people about the importance of this service. Regardless of the circumstances, social categorization, background, and catchment area, every individual should have access to and benefit from ACP services.

Main challenges and barriers

The implementation of ACP in Rwanda and Africa is still challenging due to many factors:

- Lack of awareness and education among healthcare professionals who need help communicating with the patients and families. Most patients and families need to be made aware of the benefits of ACP, and healthcare professionals are focused on cures rather than care beyond treatment.
- There are cultural and linguistic challenges to the implementation of ACP. Patients and families have different backgrounds and values, and beliefs regarding end-of-life care, which may affect the ACP discussions. Another critical point is the translation from English and French to Kinyarwanda which may impact the meaning of ACP.
- Ethical and legal considerations surrounding ACP may include capacity, consent, and the role of the proxy in decision-making. The main barriers are the limited resources to develop appropriate ACP, competing priorities in health facilities, and time constraints of healthcare providers.

Collaborations with other countries/programs regarding ACP

With the start of the ACP program in Rwanda, there is a potential for collaboration with other countries in East African Community (EAC) Region like Uganda [17], Kenya [18], and Tanzania [19], which have joined the ACP movement earlier. There is also potential for collaboration with other developed countries like Sweden [11], Germany [15], Japan [9,20], Singapore [21], USA [22], Australia, and New Zealand [23,24] among others which have proven the efficacy of ACP implementation and how applicable ACP can be in addressing the issues surrounding end of life care. Collaboration with other institutions can help the adaptation of ACP locally in Rwanda, especially by targeting underserved rural areas for community-based conversations [25].

Conflict of interest

The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors acknowledge that all the work was done by the authors.

CRediT author statement

CRN wrote the manuscript. TM proofread the manuscript. DAN contributed to the manuscript. LCS wrote the original draft, edited it and validated the final manuscript. AU contributed to the manuscript. FU contributed to writing the manuscript.

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