

Bridging gaps in palliative care using system's approach by empowering community, and people.

Dr Yakubu Salifu, SFHEA 23/09/24



# Research influencing 'local' practice Lancaster University

- A nurse (clinical skills)
- Academic (Teaching and research)
- Care delivery, what works what doesn't
- Lack of research that has explored the Ghanaian context







- 40 million people need of palliative
  - care; 14% receive it
- 78% of people needing palliative care live in lowand middle-income countries (WHO,2020)
- 86%: NO access to palliative and end-of-life care
- 63: Average age of death
- 5: Average number of days from a patient's referral to a palliative team to their death
- 48%: National Health Insurance Scheme (NHIS) or other medical health insurance.
- 30%: At least walk on foot to their local hospital







## Understanding what works, and for whom

Original Article



'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting 2021, Vol. 35(1) 97–108
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Yakubu Salifu<sup>1</sup>, Kathryn Almack<sup>2</sup> and Glenys Caswell<sup>3</sup>

#### Abstract

**Background:** Family caregiving is common globally, but when a family member needs palliative and end-of-life care, this requires knowledge and expertise in dealing with symptoms, medication, and treatment side effects. Caring for a family member with advanced prostate cancer in the home presents practical and emotional challenges, especially in resource-poor contexts, where there are increasing palliative cases without adequate palliative care institutions.

Aim: The study explored palliative and end-of-life care experiences of family caregivers and patients living at home in a resource-poor context in Ghana.

Design: This is a qualitative study using thematic analysis of face-to-face interviews at two-time points.

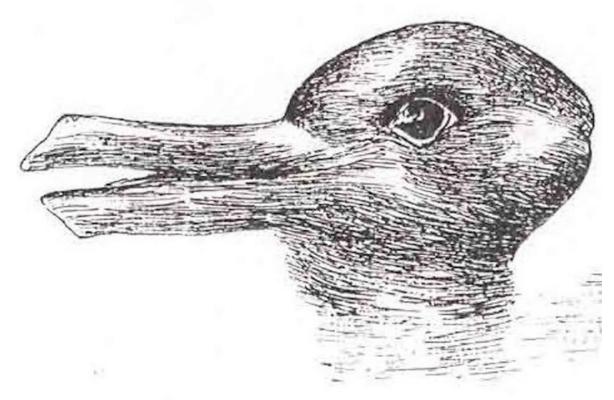
**Participants:** Men living with advanced prostate cancer (n = 23), family caregivers (n = 23), healthcare professionals (n = 12).

Findings: Men with advanced prostate cancer face complex issues, including lack of access to professional care and a lack of resources for homecare. Family caregivers do not have easy access to professional support; they often have limited knowledge of disease progression. Patients have inadequate access to medication and other practical resources for homecare. Caregivers may be overburdened and perform the role of the patient's 'doctor' at home-assessing patient's symptoms, administering drugs, and

providing hands-on care

Conclusion: Home-based care is promoted as an ideal and cost-effective model of care, particularly in Westernised palliative care models. However, in resource-poor contexts, there are significant challenges associated with the implementation of this model. This study revealed the scale of challenges family caregivers, who lack basic training on aspects of caring, face in providing home care unsupported by healthcare professionals.

Konwords



Is it a rabbit or a duck?

## What are the gaps?





- 1. Limited access to formal care-lack of hospices
- 2. Cultural barriers
- 3. Lack of trained professionals
- 4. Economic constraints- coverage of NHIS
- 5. Integration with mainstream healthcare (no national palliative care strategy)
- 6. Geographical challenge sweden is about 1.9 times bigger than Ghana

(Salifu et al, 2021, 2023).



## 'Best practice' is context specific



- Healthcare infrastructure,
- Access- culture, geography
- Capacity-skilled health personal
- Funding (GDP spent on health overall, and palliative care specifically)



No Longer a Luxury But a Necessity (Higginson & Foley, 2009)



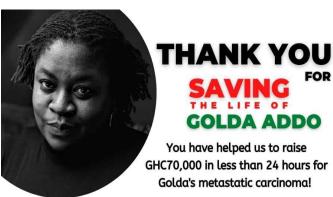
# How accessible is the care?





## Funding: Ad hoc support system





<u>PLEASE continue</u> to send in your donations, as we build a buffer fund for Golda to enable her have further treatment and rehabilitation after this round of surgeries and radio-/chemotherapy. We are hopeful that this first round of treatment will be all Golda needs, <u>but</u> if it isn't, your continuing donations will make all the difference.

MOMO NUMBERS: NETWORKS: MTN

0541817725 0244828322 054719999 NETWORKS: MTN
ACCOUNT NAME: SHE AID (Golda's NGO)
ACCOUNT NAME: GOLDA NAA ADAKU ADDO

**ACCOUNT NAME: EBO GYEBI** 



I AM A 13 YEARS OLD DIAGNOSED WITH A BRAIN TUMOR AND THE TOTAL COST OF TREATMENT IS \$30,000.

PLEASE HELP ME. PLEASE HELP SAVE MY LIFE.

#### BANK ACCOUNT NO:

MICHAEL KOFI ASIAMAH 9041300872 ZENITH BANK EAST LEGON

#### MOMO NUMBERS

0548727118 NANCY ADOBEA ANANE 0242273746 GEORGINA ASIAMAH 0202672025 CORDELIA AMA SELORMEY

Pls my brother needs your help. Pls donate any amount don't worry how small it is. Pls help save his life. God bless you for donating  $\bot$ 



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#### **NHIS**

- Subscription
- Extensive exemption
- Under funded
- No charitable organisations that fund care



# Western-centric vrs local perspectives Lancaster Western-centric vrs local perspectives University of palliative care.

- Home-based palliative care usually unsupported by health staff
- Cultural Responsemasculinity and Stigma
- Delivering palliative care in resource-poor settings



## COMPASS-Ghana



John Davies
Chief Operating Officer

E: john.davies@compass-gh.org

M: +44 (0) 7902 383 415

M: +233 (0) 50 818 0843



Dr Yakubu Salifu
Chief Executive Officer

E: Yakubu.salifu@compass-gh.org

M: +44 (0) 7835 340472

M: +233(0) 24 231 2074



Katie Eccles
Chief Clinical Officer

E: Katie.eccles@compass-gh.org

M: +233 (0) 20 684 6025

W: www.compass-gh.org | Linktree: www.linktr.ee/compassghana









## Heath staff Capacity



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#### Keywords

Family caregiver, Ghana, homecare, qualitative research, long-term care, palliative care, advanced prostate cancer







## Culture and Beliefs



Not man enough

'No balls'

'Erectile dysfunction'

'From head to tail'





Palliative Care & Social Practice

Original Research

### 'Out of the frying pan into the fire': a qualitative study of the impact on masculinity for men living with advanced prostate cancer

2023, Vol. 17: 1-14

Palliative Care & Social

DOI: 10.1177/ 26323524231176829

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Yakubu Salifu . Kathryn Almack and Glenys Caswell

#### Abstract

Background: Studies have highlighted how advanced prostate cancer causes biographical disruption and presents challenges to masculine identities for men. This article draws on a wider study that focused on the experiences of men living with advanced prostate cancer and their caregivers. Although men's experience of advanced illness is not overlooked in the literature, only a small body of work has taken an in-depth look at men's experiences with advanced prostate cancer and their caregivers in a non-Westernised cultural and social

Objective: To explore how advanced prostate cancer impacts on men's masculine identity from the perspective of patients and their caregivers.

**Methods:** A qualitative study of men living with advanced prostate cancer (n=23) and family caregivers (n = 23) in Ghana. We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) as the reporting guideline.

Results: The findings from this study highlight profound challenges for most men to their masculine identities, from both the treatment and the symptoms of advanced prostate cancer within a non-Westernised, patriarchal society. Four main themes were developed. These were the impact on masculinity in terms of: (1) physical changes, (2) sexual ability, (3) socio-economic roles and (4) expressing emotions. Changes in physical appearance, feeling belittled, having no active sexual life and the inability to continue acting as provider and protector of the family made some men describe their situation as one of moving out of the 'frying pan into the fire'.

Conclusion: This study revealed the impact of advanced prostate cancer on masculine identity. These narratives add a new dimension to what is already known about the impacts on men's masculine identities when dealing with advanced prostate cancer. This knowledge can help improve the care provided to men with advanced prostate cancer with emphasis on the cultures, beliefs and aspirations of these men and their caregivers.

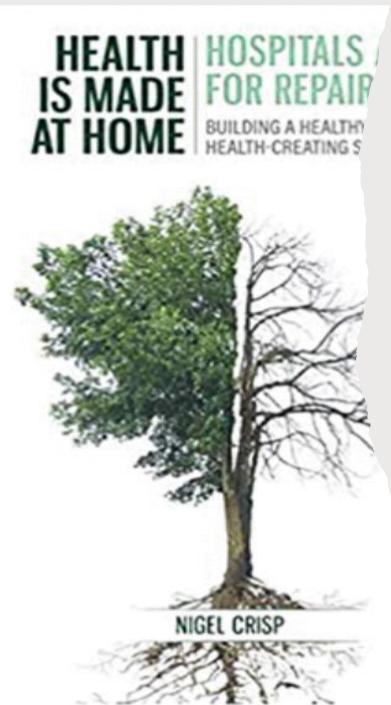
Keywords: advanced prostate cancer, African/Black men, culture, intersectionality, masculinity, men's health, physical appearance, sexual life, social construction

#### Correspondence to: Yakubu Salifu

Lecturer in Palliative Care, International Life Care, Division of Health Research, Faculty of Health and Medicine, University of Lancaster, Lancaster, LA1 4AT, UK. y.salifu@lancaster.ac.uk

#### Kathryn Almack Professor of Family

Lives and Care, Centre for Future Societies Research Communities



## Compass-Ghana's Approach

- The development of a whole system approach.
- Live to life as well as possible and to die with dignity, compassion and comfort.
- Ghana has some high expectations universal health care by 2030, 80% signed up to the NHIA (Health Insurance) programme by 2030.



## COMPASS-Ghana, a new da











































### Successful Ghana trip to promote palliative care

3 May 2023 12:34



Midwives' Association (GRNMA) National Secretariat in Accra

A team of researchers from Lancaster University have visited Ghana as part of ambitious plans to develop palliative

The trip by experts from the International Observatory on End of Life Care, the Division of Health Research, and Health Research and the Chief Executive of the charity COMPASS-Ghana

Their primary objective was to engage with various stakeholders involved in delivering palliative care services in Ghana, with the help of COMPASS Ghana. Additionally, the visit explored the potential for new research projects and

Among the team was the Associate Dean for Research and Co-Director of the International Observatory on End of Life Care (IOELC), Professor Nancy Preston, who said:



We witnessed the immense dedication of healthcare professionals in Ghana, who are working tirelessly to provide compassionate palliative care despite resource limitations

Dr Yakubu Salifu

Share this story





## Palliative Care Initiators course 2024

### By Katie Eccles, Clinical Nurse

Katie (Chief Nursing Officer) shares her views on the importance of her doing the course.

Hospice Africa Uganda is a not-for-profit NGO. Their vision is 'Palliative Care for all in need in Africa.' It was founded in 1993, over 30 years ago.



## Impact and Success Stories: Hubs







COMPASS-GHANA (COMPASSIONATE PALLIATIVE SERVICES)

Bringing Compassionate Palliative Care to Ashanti: Our £50,000 Mission

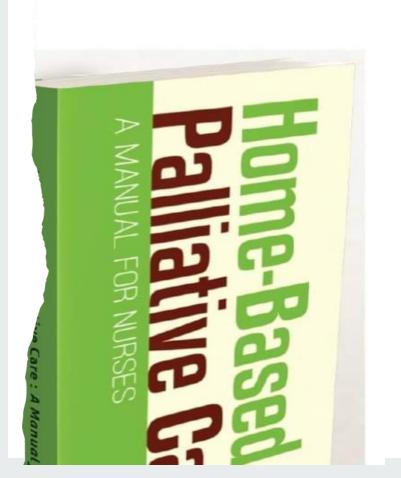
Join us in raising £50,000 for palliative care in Ghana. Every contribution matters. Support our mission today.

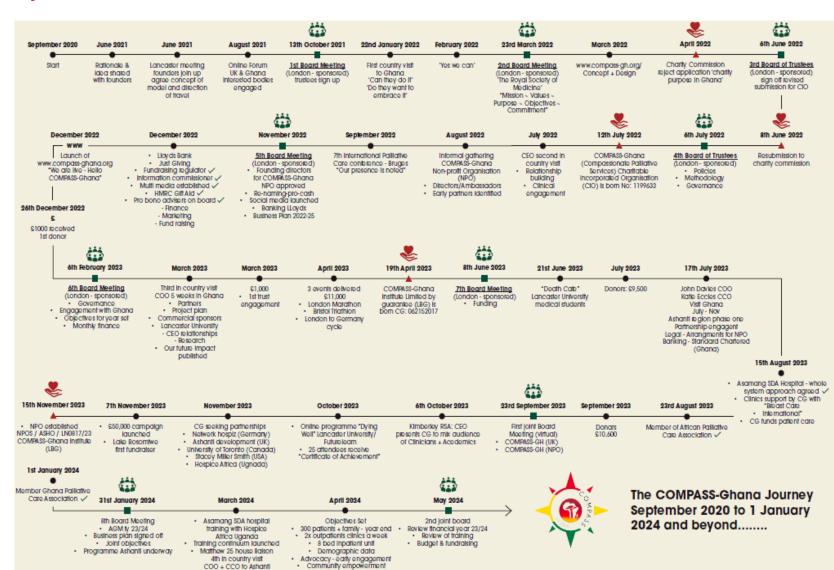




## Our journey so as



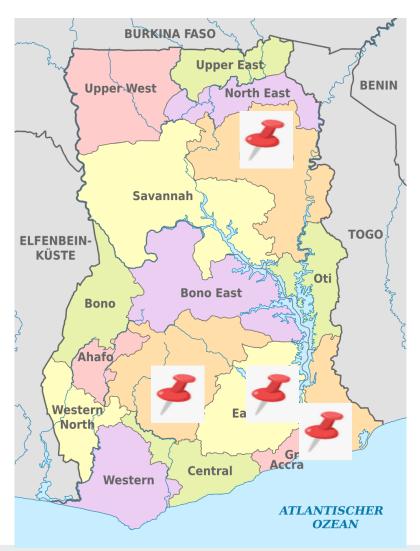




Training of clinical staff Ghana
 Hospice Africa Uganda
 Programme audit
 Impact + value Nov 2024

# Plan: Replicate The palliative care Hubs







# Things that must be there for change



key partners

Implementation and review

Influencers

Strategy/policies

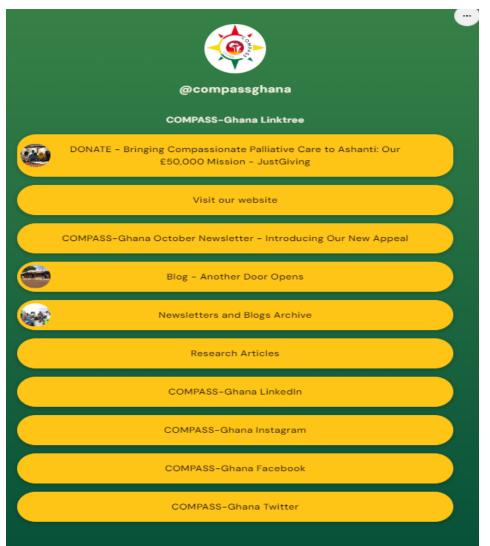
Aim

 FGD and deliberative discussion

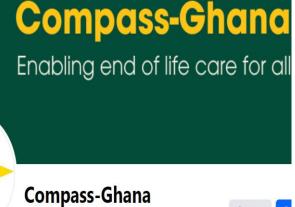




## Using social media to inform and create awareness











# Partnerships-In country



























# Partnership- Africa











## Partnership-International



















## Opportunities

- Willingness of the country, at least o paper
- 2. Established key partners
- 3. Good informal support system, perfectly aligns with concept of home, community and primary care
- 4. Training of nurses as palliative care specialist
- 5. Presence of association









## National palliative care strategy





1. There is a consultation for national palliative care strategy – one of the 6 pillars

2. Award £5,000 to develop guideline



## Challenges

- 1. Trained staff and inadequate charitable organisations
- 2. Donations/Funding
- 3. No dedicated policy and also budget
- 4. Capacity-but improving









## Research Interest

Patients and family caregiver experience of cancer (and non-cancer) care

### Minoritised population

Experience of people from minoristised population in the UK (bme, Muslims etc.) on cancer and non-naccer care.

Enhanced quality of life for patients and families with cancer and non-cancer.

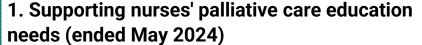
Palliative care in primary and community care settings

Interventions and policy to ensure community care.

**Masculinity and Stigma in Cancer care** 

**Decolonising Palliative Care** 

## **Grants/Awards**



This projects funded by Worldwide Universities Network Is looking at how nurses could be supported and equpped to provide palliative care for all (including cancer patients).

2. Black and minority ethnic men and their partners surviving prostate cancer: their perceptions, sexuality, and sexual intimacy

Awaiting decision from funder, The Dowager Countess Eleanor Peel Trust.

3. Decolonising palliative care: exploring British Muslims perspectives on End-of-Life Care in the UK, a qualitative study 2024-2027.

FHM Studentship staring in October 2024.

4. Advancing Palliative Care in Ghana: Development of a National Policy through Collaborative Partnerships.

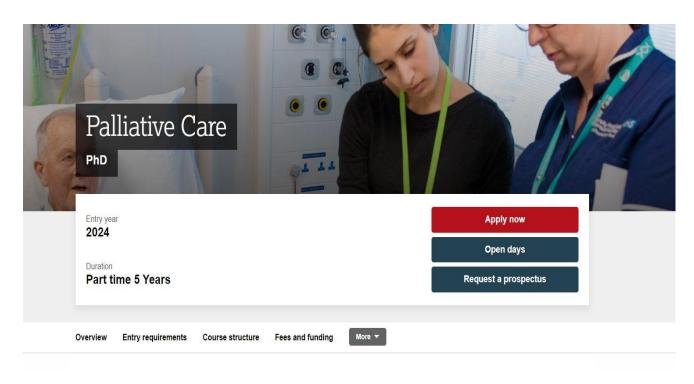
Awarded by Global Impact Small Grant, starting later this year



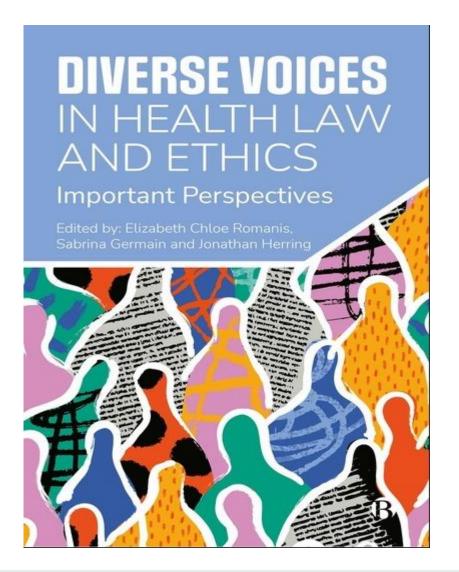
- 1. NHIR
- 2. Marie Curie
- 3. Medical Research Council (MRC)
- 4. North-West Cancer Research
- 5. Wellcome Trust
- 5. The North West
  Social Science
  Doctoral Training
  Partnership
  (NWSSDTP)
- 7. European Union

## Come study with us at Lancaster University





Part-time, international, distance learning programme.











**The Palliative Care Team** S.D.A Hospital, Asamang

Suretes you to

- ▶ Holistic Patient Assessment and History Taking
- ▶ Pain and Symptom Control
- ▶Breaking Bad News
- ▶ Advanced Care Planning
- ▶ Morphine production and how feasible it can be

done

Date: 2nd & 3rd September, 2024 Venue: Conference Room, S.D.A Hospital Asamang

Time: 8:00am - 2:00pm

### FACILITATORS:

Dr. Kumah Sampson (Palliative Care Trained M.O.) Debra Yaa Piesie (Palliative Care Trained Nurse) Frederick Frimpong Yaw



Target audience: Palliative Awareness Team

# In our learning, unlearning and relearning, we need each other





# Special thank you

Dr Yakubu Salifu

• Email: <u>y.salifu@lancaster.ac.uk</u>

• Twitter (X): @Salid32Salifu

LinkedIn: <u>here</u>

Lancaster University webpage

• COMPASS-Ghana webpage



