


# Healing Beyond Cure

*A narrative medicine platform to facilitate conversations on palliative care*

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# Background

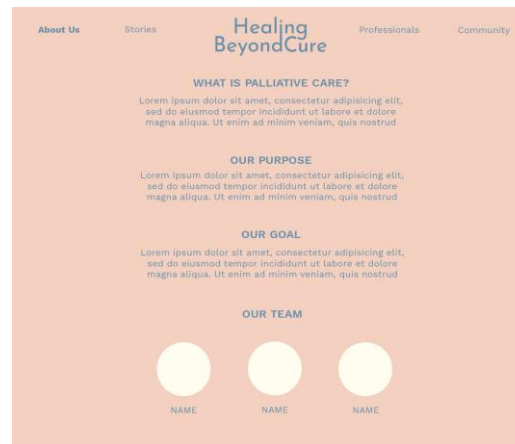
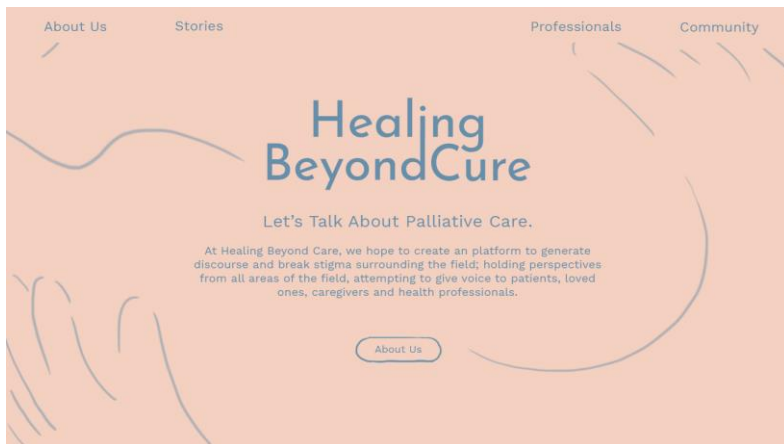
- In Hong Kong, there is a general **lack of understanding** of palliative care in patients and caregivers, the general public, and even in health professionals (1)
- Many junior doctors internationally **do not feel certain and confident in providing palliative care** to patients, owing to a lack of knowledge in this area (2,3)
- There is a need for research which aims to examine the **lived experiences of patients** receiving palliative care, which can further “generate evidence for identifying the optimal mix of providers, settings, and content of palliative care needed at different stages of an advanced illness, from diagnosis until death” (4)
- The element of **person-centred care** is especially important in palliative care, where patients’ experiences of illness and disease may be highly personal (5).
- Evidence has shown promising results for the use of telemedicine and **web-based patient-centred platforms** in initiating conversations on health-related issues between patients and healthcare professionals (6,7)



Source: [Care for Family 2021](#)

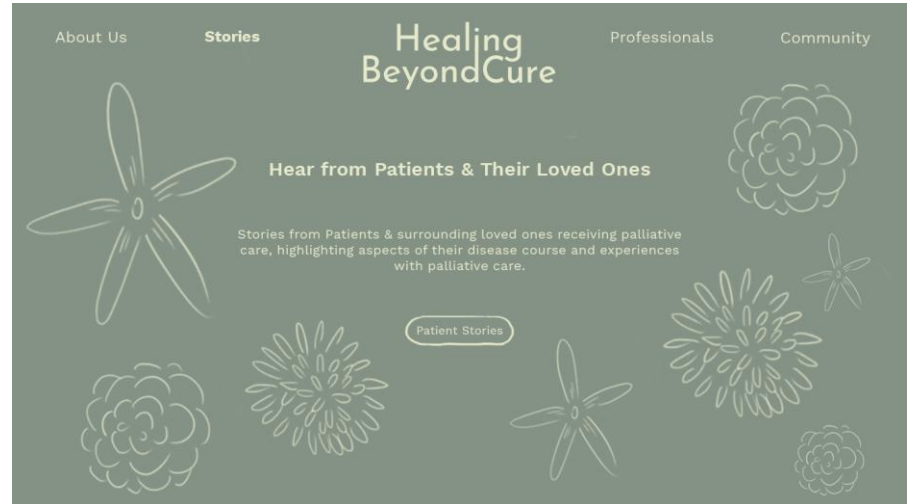
# Objectives

**Healing Beyond Cure**, as an online platform, aims to **generate discourse on palliative care** using a **narrative medicine** approach.



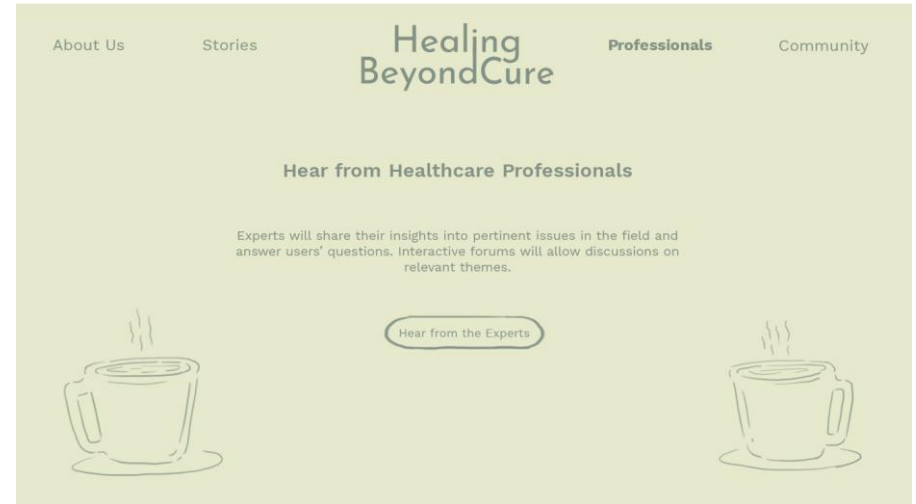
# Objectives

- **Public:**
  - To improve understanding of palliative care
  - To reduce stigma on topics such as chronic disease and death
- **Patients and caregivers:**
  - To provide a platform where patients can share their stories and experiences in palliative care with a greater community
  - To encourage engagement and dialogue between patients, caregivers, and healthcare professionals to improve their understanding of their health



# Objectives

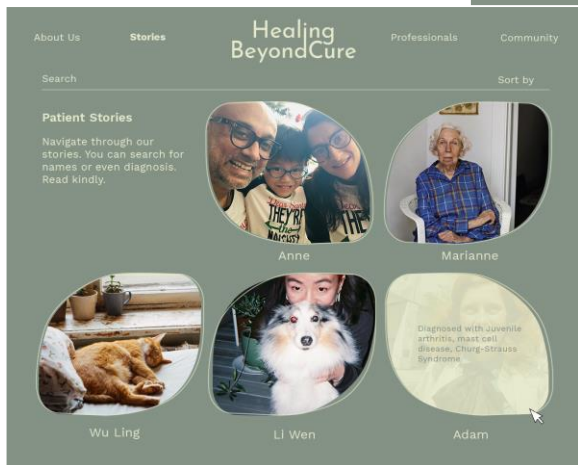
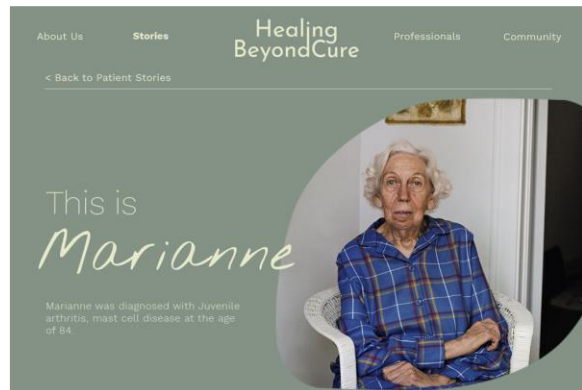
- **Healthcare professionals:**
  - To facilitate understanding of the patient perspective, to contribute knowledge and experiences
  - To engage with the public on misconceptions
- **Students:**
  - To strengthen knowledge and foster empathy
  - To better understand the patient narrative and the roles of healthcare beyond curing disease, by providing human voices in palliative care at an early stage of their training



# Practices

## Patient Narratives

- HBC feature narratives from interviews with patients, highlighting aspects of their disease course and experiences with palliative care, to emphasise the diverse forms of care that exist
- Various media types will be used to optimise accessibility



### Learning the diagnosis

My surgeries, treatments and a long list of medications kept me in bed most days feeling weak, growing thin and at rock bottom. I was spending every waking minute thinking about growth levels, medications and treatments, it didn't feel like me.

### What I did afterwards

Staying active. Traveling, gardening, feeling energetic and continually moving forward. I want to talk about having an active life, and not just about the cancer.

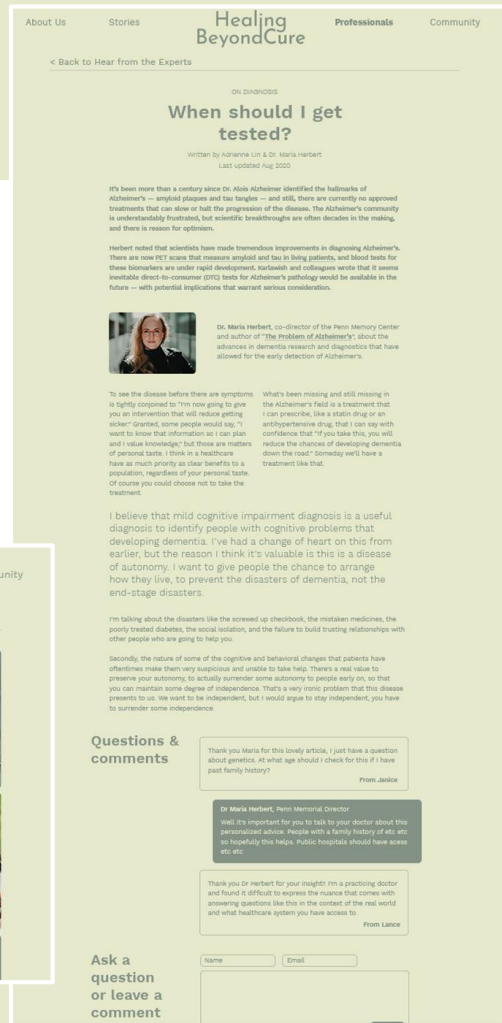
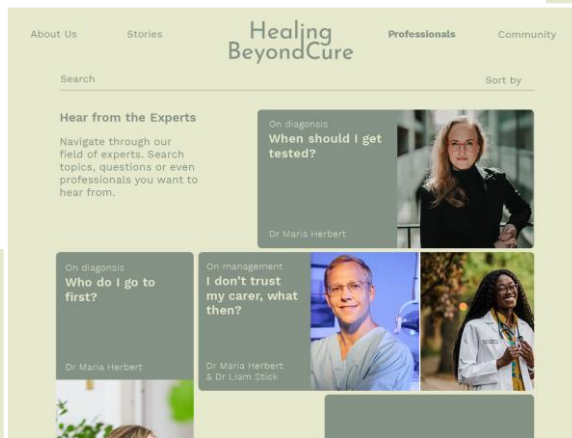
### My favourite memory

"Mom loved celebrations! Anniversaries, birthdays, any excuse for a get-together! She was a people person."  
- June, her daughter

# Practices

## Expert talks

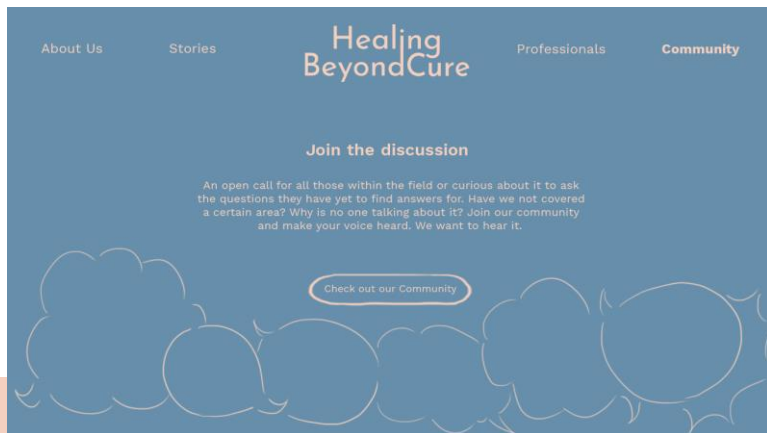
- Experts from different disciplines will share their insights and answer users' questions, further underscoring the interdisciplinary nature of palliative care
- Users will be able to submit questions for experts and suggest topics for expert talks



# Practices

## Community Engagement

- Interactive forums and the use of social media will allow for discussions on relevant themes
- Readers will be able to contribute to moderated pin boards based on prompts provided in narrative pieces or expert talks





# Implications

- **Patients, caregivers, and the general public:**
  - Encourages more dialogue on relevant topics that may be culturally taboo
  - Provides a channel for discourse between healthcare professionals and the public, in order to address misconceptions and knowledge gaps
  - Creates a sense of community for patients and caregivers
- **Healthcare professionals:**
  - Allows further learning so as to support decision-making processes in patient management
  - Provides an opportunity to engage with patients to understand their needs and concerns to support patient-centred care
  - Informs on potential new research questions



Source: [E-Care 2020](#)

# Implications

- **Students:**

- Encourages understanding of the role of palliative care, as part of their roles and responsibilities as future healthcare professionals beyond just curing disease
- Forms a deeper understanding of the patient experience, in order to develop empathy and communication skills
- Provides the opportunity to contribute to the platform through speaking with patients, interviewing professionals, and creating content
- Potential incorporation into medical education (e.g. HKU Medical Humanities curriculum)



Source: [Li Ka Shing Faculty of Medicine, University of Hong Kong 2021](#)

# Challenges & Progress



# References

1. Ho MK, Hsue CCY, Lai CHN, Chan KT, Cheng CN, Chow CF, et al. A cross-sectional study on the attitudes and perceptions of outpatients towards palliative care at the Hong Kong Queen Mary Hospital Hospice Centre. *Ann Palliat Med*. 2020;9(6):4522-33.1
2. Pieters J, Dolmans DHJM, Verstegen DML, Warmenhoven FC, Courtens AM, van den Beuken-van Everdingen MHJ. Palliative care education in the undergraduate medical curricula: students' views on the importance of, their confidence in, and knowledge of palliative care. *BMC Palliative Care*. 2019;18(1):72.
3. Hahne P, Lundström S, Leveälahti H, Winnhed J, Öhlén J. Changes in professionals' beliefs following a palliative care implementation programme at a surgical department: a qualitative evaluation. *BMC Palliative Care*. 2017;16(1):77.
4. Arora NK, Gayer C, DiGioia K, Mason N, Lawrence W, Clauser SB, et al. A patient-centered approach to research on palliative care for patients with advanced illnesses and their caregivers. *Journal of pain and symptom management*. 2017;54(4):e1-e9.
5. Lavoie M, Blondeau D, Martineau I. The integration of a person-centered approach in palliative care. *Palliative & supportive care*. 2013;11(6):453.
6. Frost J, Massagli M. Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *J Med Internet Res* 2008;10(3):e15. URL: <https://www.jmir.org/2008/3/e15>. DOI: 10.2196/jmir.1053
7. Paul Wicks, Dorothy L. Keininger, Michael P. Massagli, Christine de la Loge, Catherine Brownstein, Jouko Isojärvi, James Heywood. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy & Behavior*. Volume 23, Issue 1. 2012. Pages 16-23. ISSN 1525-5050. <https://doi.org/10.1016/j.yebeh.2011.09.026>.

# Thank you!

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