Online forums support palliative and bereavement care:
Machine learning and Natural Language Processing analysis of qualitative data from the internet

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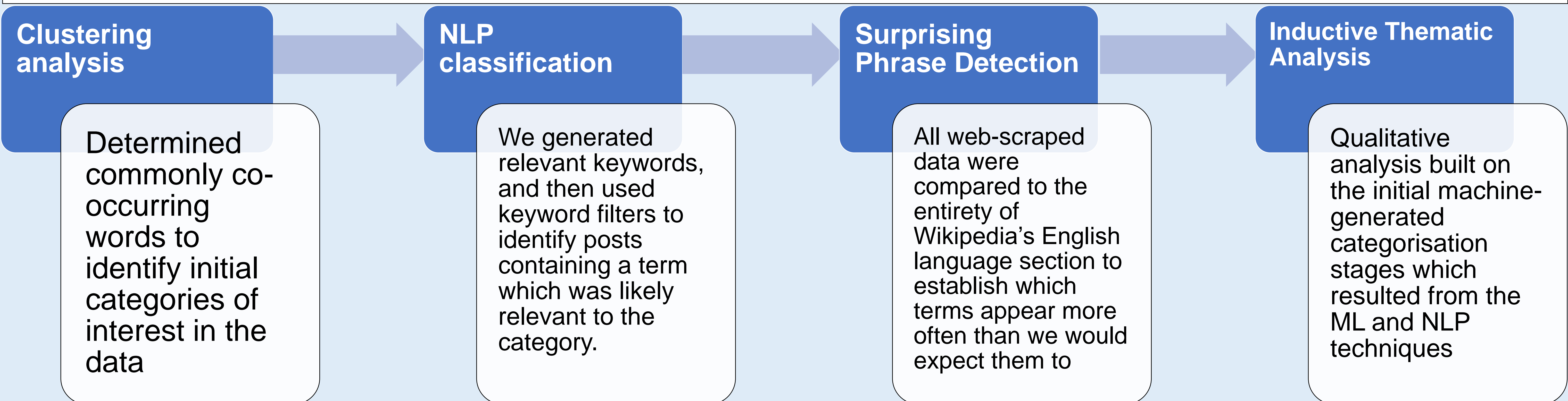
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The Art of Dying Well

Introduction

Palliative public health policy emphasises the value of sustainable community-led palliative care and psychosocial support.[e.g. 1] However, there are significant challenges to adequate palliative and bereavement care provision including precarious funding, inconsistent availability, and recent challenges presented by the COVID-19 pandemic.[2] Minority groups and those at the greatest socioeconomic disadvantage are among those least likely to receive the care they need.[3] Digital services may circumvent these challenges, allowing people to self-manage their needs.[4] This research aimed to investigate how community-led online forums are used to support people facing life-limiting illness, their caregivers, and bereaved people.

Methods

We identified seven online forums focusing on dying and grief, used by people with life-limiting illness, caregivers, and people experiencing bereavement. Data collection was conducted by web scraping using Method52[5] in September 2020 to obtain retrospective data. We obtained the contents of discussion threads, and then conducted Machine Learning (ML), Natural Language Processing (NLP), and human-led qualitative analysis of the anonymised data, in the following stages:

Clustering analysis → Determined commonly co-occurring words to identify initial categories of interest in the data

NLP classification → We generated relevant keywords, and then used keyword filters to identify posts containing a term which was likely relevant to the category.

Surprising Phrase Detection → All web-scraped data were compared to the entirety of Wikipedia's English language section to establish which terms appear more often than we would expect them to

Inductive Thematic Analysis → Qualitative analysis built on the initial machine-generated categorisation stages which resulted from the ML and NLP techniques

Results

We initially obtained 116,748 online posts from web scraping. After the application of ML and NLP techniques to identify posts relevant to our research aim, we included 7048 posts in final qualitative analysis. Analysis generated the following three major themes:

Comfort

Forum users seek support to ease psychological suffering. The need for this comfort may be exacerbated by experiencing uncertainty, pain, or fear. Forums may provide comfort of better quality and greater duration than what was available elsewhere (e.g. after time-limited bereavement care was no longer offered), and compensated for deficiencies in formal systems, especially during the COVID-19 pandemic

> "Our forum is like sitting down with a group of friends. We can gather and open up to each other about what is in our hearts. We can listen to each other in our grief... Our like button is a way to tell others they've been heard."

> "No one but the people here want to hear about it. I saw it in the face of the woman I had a [videoconferencing] visit with yesterday. I don't feel whiney here. It's safe and caring."

Community

Online forums provide community, where forum users build relationships based on mutual trust and shared experiences. Some users found it difficult to engage with in-person or specifically designated emotional support groups. In contrast, online forums provide an environment where people are free to share feelings on the issues they want to discuss and can engage as much or as little as they want, and enter and leave discussions freely, often distributed over long durations.

Capability

People use online forums to build their own capabilities and support others to do so. Such capability-building is done through information-seeking and giving, including information on managing technicalities (e.g., legal documents), self-managing symptoms, and information for carers on what to expect when someone is dying. Care systems were largely perceived as inadequate and disempowering by forum users, while online forums themselves acted as solutions, including increasing users' sense of empowerment, providing information on legal rights and benefits which may not be otherwise easily available, and facilitating collective advocacy.

> "They impose punishing austerity cuts with one hand and pat us on the back with the other. They'd prefer we're poor than to recognise that carers are being exploited".

Conclusions

Online forums developed and led by patients and carers can play an essential role in providing information and support, democratising care, and retaining agency when facing life-limiting illness and grief. Online support forums may therefore provide an effective and sustainable means to support people in meeting their needs, although they are not yet widely acknowledged as adjuncts to mainstream palliative and bereavement care. Future palliative and bereavement care research must focus on how online forums can be integrated into existing systems, made transparent and accessible to all who need them, be optimally funded and structured, and be used to provide consistent support, including compensating for service disruption encountered during future pandemics.

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