Title

Resisting the (re-)medicalisation of dying and grief in the post-digital age: natural language processing and qualitative analysis of data from internet support forums

Abstract

In the mid-twentieth century, the social movement of death revivalism sought to resist the medicalisation of dying and grief through promotion of the dying person retaining autonomy, and societal openness toward death and bereavement. Despite this advocacy, present-day dying in high income countries is largely institutionalised, with value placed on control over the body and emotions. These phenomena are at odds with the ambitions of death revivalism, and demonstrate the re-medicalisation of dying and grief. Furthermore, contemporary society is continually advancing into the post-digital age, reflected in digital technologies being a tacit part of human existence. Within this framework, this study aims to investigate how people living with life-limiting illness and their loved ones experience, negotiate, and resist medicalisation of dying and grief through online internet forums. We collected posts through web-scraping and utilised Natural Language Processing techniques to select 7048 forum posts from 2003-2020, and initially categorise data, before utilising Inductive Thematic Analysis, which generated two major themes. The theme of 'Comfort' describes online forums facilitating psychosocial support which was often used to compensate for systemic deficiencies, especially during the Covid-19 pandemic. Common sources of comfort included animal companions and spirituality, in stark contrast with the medicalised model. The theme of 'Capability' describes online forums acting as solutions for people facing disempowering care systems, including providing information on legal rights and benefits which may not be otherwise easily available, and facilitating collective advocacy. Our findings indicate that

community-led online forums can play an effective and sustainable role in democratising care and retaining agency when facing life-limiting illness and grief. Future palliative and bereavement care research must focus on how online forums can be integrated into existing systems, made transparent and accessible, be adequately funded and structured, and be optimised, including compensating for service disruption encountered during future pandemics.

Background

<u>Introduction</u>

In this article we present the novel application of machine learning analysis of big datasets to the exploration of how dying people and bereaved people negotiate issues of medicalisation through digital spaces in contemporary society. Taking a multidisciplinary approach, we analysed data from between 2003 and 2020, spanning a period of increasing digitalisation, now described as entering the post-digital age. The post-digital represents a time when digital technology has become inseparable from the physical, is a tacit component of everyday life, and where we must consider holistically the impacts of technology on society (Jandrić et al., 2023; Markauskaite et al., 2023). Within this framework, we present a study investigating how people living with life-limiting illness, caregivers, and bereaved people experience, negotiate, and resist medicalisation or re-medicalisation of dying and grief through online internet forums.

This article presents collaborative work between XXX, a cross-party independent think tank, and the XXX University. Data collection and analysis were carried out and published by XXX, in partnership with XXX (Anonymous, 2021a), and subsequently further analysis of the findings has been conducted by XXX. This article represents the synthesis of the two, presenting a novel theoretical perspective and analysis.

<u>Medicalisation, revival, and re-medicalisation of dying and grief</u>

Medicalisation is a term describing the pervasive social consequences of medicine on social life, including death, dying and grief, which has taken place through the expansion of healthcare systems from the 19th century (Illich, 1975; van Brussel and Carpentier, 2014).

Scholars have described death in pre-modern times as 'tamed': death which could be predicted, and was expected to occur in the company of family, with a sense of peace with God. The tame death was perceived as frightening but was accepted (Ariès, 1981). The tame pre-modern death contrasts with the modern view of death as, according to Ariès (1981), even less wild: medicalisation led to the rationalisation of death, where death came to be viewed as a failure to defeat illness. The dying person was no longer cared for in the community, but in the domain of the hospital, under the control of the doctor, creating a taboo around dying for everyday life (Lupton, 2012). Illich (1975) described 'structural iatrogenesis', where ageing and dying are seen as illnesses, leaving individuals and societies less able to deal with these natural processes. Furthermore, death became hidden and secret, with the doctor often withholding the prognosis from the patient (Illich, 1975), and death was no longer tame but dirty, polluting, and scandalous (Bauman, 1992). Individuals were expected to control their emotions and bodily processes. Dying was not an individualised process, but one where many external professional voices were amplified while the dying person was excluded from decisions affecting them and was expected to suppress expressions or signs of dying (van Brussel and Carpentier, 2014).

The death revivalist movement was born from discontent with this medicalisation of death and dying and inspired work to change death discourse from the second half of the 20th century (Seale, 1998; Walter 1994). Death revivalists sought for the dying person in late modernity to participate in the organisation of their dying process, to be told the truth about their condition, and be given agency to make their own end-of-life decisions, reducing the power imbalance with the physician (Cottrell and Duggleby, 2016). Subsequently, there have been attempts to removed social taboos and increase discussions around dying (Hospice UK, 2023; Institute for Healthcare Improvement, 2023). Contemporary ideas of the "good" and "bad death" were constructed: the "good death" where the dying person accepts that they are dying, has their identity preserved, their wishes met, and has family present during dying and at the time of

death; in opposition, the "bad death" is one which is invasive, over-medicalised, disempowering for the dying person, and there is no acceptance of death before it occurs (Lang et al., 2022). The modern hospice movement and palliative care emerged from the death revival movement and the ideal of the "good death" (Lang, 2020). In the 20th century, hospices developed ostensibly to provide a place where the needs of any dying patients were met in a different context from other available healthcare: open communication and unconditional care (St Christopher's, 2023). This represented an attitudinal shift, contrary to mainstream biomedical care for the dying person (Lang et al., 2022). The often-stated aim of palliative care, which emerged from the hospice movement, is to prevent and relieve the health-related suffering of adults and children facing problems associated with life-threatening illness. This encompasses physical, psychological, social, and spiritual suffering, and includes improving quality of life for caregivers of dying people (World Health Organization [WHO], 2020a).

However, critics have argued that the death revival movement, including palliative care, has floundered over time by becoming institutionalised and failing to match its stated premise (Floriani and Schramm, 2012). In high-income countries, death still mainly occurs in institutions, hidden in hospitals, hospices, or care homes (Adair, 2021). Medical decision-making is still central in the dying process, and even dying at home is professionally organised (van Brussel and Carpentier, 2014). Moreover, people with certain demographic characteristics, including minority groups and those at the greatest socioeconomic disadvantage, are least likely to receive high quality end-of-life care (Calazani et al., 2013; Marie Curie, 2014). The most disadvantaged people have the lowest levels of health literacy, challenging their ability to partake in decision-making about their care (Kennedy et al., 2020). Furthermore, the hospice movement has sought legitimacy by becoming increasingly aligned with the mainstream healthcare systems it originally sought to break away from (Wright and Katz, 2007). These developments may represent the hospice movement becoming influenced

by the medicalised model, losing its original charismatic character and values, and becoming increasingly restricted and inflexible due to bureaucratisation and regulation (Floriani and Schramm, 2012).

Van Brussel and Carpentier (2014) argue that the idea of the "good death" is constructed around two groups of nodal points: control and autonomy, and awareness and heroism. The medical revivalist view ostensibly puts the control with the dying person, but the emphasis on autonomy and self-mastery continues the medicalised ideas of the dying body being a polluting one that should be tightly contained and sanitised (Lupton, 2012). Likewise, discourses of awareness and heroism assert that it is necessary to have knowledge about one's condition, but they perpetuate the medicalised idea that the dying person must be virtuous, and exert emotional labour to face their situation as an uncomplaining "hero" (van Brussel and Carpentier, 2014). The contemporary model of death and dying, therefore, seems to be one of re-medicalisation where the dying body experiences surveillance and control.

The Covid-19 pandemic has caused additional challenges for dying people, those caring for them, and those who are grieving in contemporary society. Approximately seven million people have died worldwide from Covid-19 (WHO, 2023), and the risks of death posed by the pandemic have brought death and dying into consciousness, affecting how the public (Myers and Donley, 2022) and healthcare professionals consider death and dying (Qureshi et al., 2022). Public health rules preventing visiting others' homes, social distancing, and restrictions on visiting patients in hospitals and care homes have resulted in many people dying alone in institutionalised settings, often without the opportunity for preferences regarding the end-of-life being met (Strang et al., 2020). Restrictions have also affected people's ability to attend funerals, grieve publicly, and opportunities for in-person support (Smithers, 2020). Moreover, the pandemic has widened social inequalities (Marie Curie, 2021; Silva et al., 2023). Such evidence runs contrary to the revivalist view of the "good death", and instead suggests that the

medicalised approach to death, dying, and grief has been accentuated during the pandemic. We are therefore at an important juncture, where we must consider how issues of re-medicalisation and autonomy may be negotiated or counterbalanced in the face of these challenges.

Digital and Post-Digital for the end-of-life

The present study analyses data from 2003 to 2020, encompassing a period of major advancements in availability and acceptability of digital technology. Although the Digital Revolution (or Third Industrial Revolution) began in the 20th century with the advent of the internet, widespread accessibility of computers, and replacement of analogue technologies with digital ones, there has been further significant digital proliferation in the 21st century. Scholars of industry discuss the world having entered a new paradigm: the Fourth Industrial Revolution, represented, e.g., by the trend towards automation and data exchange in manufacturing, cloud technology, and artificial intelligence (Bai et al., 2020; Gazzaneo et al., 2020). From a sociological perspective, we are advancing into the post-digital age, now that technology informs every aspect of human life, not just as an adjunct to the physical, but incorporated and entangled into human existence (Cascone, 2000; Markauskaite et al., 2023; Negroponte, 1998). For example, the idea of "going online" has become irrelevant due to constantly connected smartphones and wireless networks (Berry, 2014).

Continuing digitalisation has great potential for impacting all aspects of society, including healthcare (Topol, 2019; WHO, 2020b). Health services are under pressure to innovate to meet the needs of increasingly frail populations with limited resources, and digital technology may help people manage their own health (Nwosu et al., 2022), improve access to and quality of care, and lower costs (Finucane et al., 2021). Technology may also have a role in empowerment to patients by helping people gain or maintain autonomy especially under-served

communities (Ostherr et al., 2016). The Covid-19 pandemic has led to the rapid advancement of digital health across the world, including swift increases in uptake of telehealth appointments and remote collections of biological samples for analysis (Getachew et al., 2023).

The use of technology in palliative and end-of-life care has been an area of research interest in digital health (Ostherr et al., 2016). Important research areas identified include investigating what digital data can tell us about the experiences of dying people (Taylor and Pagliari, 2018), how internet-based material can provide self-help and education (Brodbeck et al., 2017), use of technology to support patients and caregivers (Nwosu et al., 2022), and how digital palliative care interventions can align with patient and caregiver values and goals (Finucane et al., 2021).

We must consider how the needs of dying people and their caregivers can be met in the context of the post-digital age. It is vital to understand how the use of technology relates to people negotiating autonomy and medicalisation when facing dying and grief. In this article, we explore this through analysis of data obtained from online social media forums. Social media has an important role in communicating messages, but also shapes the way in which people communicate their experiences and even in how something is experienced (Groenevelt and de Boer, 2023). Online forums can provide valuable data relating to experience of illness, dying, and grief because users are free to express their experiences away from the constraints of the medical establishment. Conversely, social media platforms may be unjust, exploitative, or commit epistemic injustices by predetermining types of knowledge that users encounter (Scotto, 2020). We therefore identified online forums as a valuable area to study, providing rich data conveying complex experiences and capturing multiple voices, as we investigate the positive and negative roles of technology in experiences of dying and grief. Previous studies have explored online forum use in issues related to the end-of-life, but were more limited in scope and focused on one or more specific pre-defined group (Brodbeck et al., 2017; Davies et al., 2020; Lenferink et al., 2021; McNeil et al., 2022). No previous author has conducted a

study of our scope, encompassing data from across a duration of more than 17 years, and without limitation to pre-defined groups.

To achieve our aim, we studied discussions of people using online forums focusing on dying and grief, including people with life-limiting illness, people caring for someone with a life-limiting illness, and people experiencing bereavement. Our study includes data generated during the emergence of Covid-19, adding meaningfully to knowledge about how medicalisation has impacted dying, death, and grief in the pandemic. We utilised machine learning and natural language processing (NLP) techniques to categorise a large dataset and analyse conversations captured in online written data. NLP is useful for identifying trends and sentiments across vast amounts of online data (Guhl et al., 2022) and as an adjunct to qualitative data analysis (Skeen et al., 2022). This approach has ensured our research is guided by the language found in the data from first analytical stages.

Objective

This study aims to investigate how people living with life-limiting illness and their loved ones experience, negotiate, and resist the medicalisation of dying, and grief through online internet forums. To achieve this, we conducted retrospective data collection in 2020 through web-scraping, aiming to collect available data from as far back as obtainable.

Methods

Summary of methodology

Our methodological process is summarised in Figure 1.

Data sources

We identified a range of relevant online forums through searches of social media sites with sections focusing on end-of-life issues and through search engines. We selected forums which contained data that were reasonably expected to be 'public': were from large forums; the forums were obtainable through search engines, were accessible to anyone without logging in or making a profile and were accessible without invitation; there were no requests against automated data collection; no community rules forbid extracting data (Anonymous, 2021). As per our Research Ethics Statement, we are not publishing the names of the forums to maximise anonymity and privacy of forum users.

Data collection

Data collection was carried out using *Method52*, a natural language processing and machine learning suite of tools for collecting and analysing large free-text datasets developed by XXX in partnership with XXX (CASM Technology 2023). To collect posts, *Method52* conducted web-scraping, i.e., obtained the contents of discussion threads on each site and saved them to a database. Web-scraping was conducted in September 2020 to obtain retrospective data. We did not pre-define a start date of interest, but wished to collect past data as far back as we could access. After web-scraping was completed, we had collected data spanning from May 2003 to September 2020. On collection, and before data analysis, the data were anonymised by removing metadata including social and site usernames and mentions, images, and originating URLs. Only the text of the extracted posts was available for further analysis.

<u>Cluster analysis</u>

We used Clustering to identify initial categories in the data. Clustering is an NLP technique which aids discovery of characteristic terms, phrases, and discussions within large datasets through an algorithm which determines commonly co-occurring words (Rose et al., 2020). This occurred in repeated iterations, firstly with the machine acting without human supervision, then presenting us with lists of terms which regularly appear together, followed by several refining iterations of human interpretation and machine training, until meaningful clusters were obtained. Through these processes we began to identify categories of interest, representing a cross-section of discussions taking place online around dying and grief.

<u>NLP Classification</u>

We used the initial categories obtained from Clustering as a basis to generate relevant keywords, and then tested the keywords against the data. This was useful to start to identify posts containing a term likely relevant to the specific data category. We then conducted more detailed decisions on inclusion or exclusion of data using NLP classification (Bartlett et al., 2014). We used keyword filters to identify posts containing a term likely relevant to the category, and then, within that subset of data, trained NLP classifiers to judge if posts were indeed relevant or irrelevant to the category. During training, the performance of each classifier was measured against a 'gold standard' of documents labelled by humans, allowing us to measure accuracy in each specific case. During this process we interacted with the data and reflected on themes and nuances arising.

<u>Surprising Phrase Detection</u>

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Our data collection was complemented by Surprising Phrase Detection: a process by which our foreground dataset (all the web-scraped data) was compared to a large background dataset (Miller et al., 2019). We used the entirety of Wikipedia's English language section as our background dataset (Wikipedia, 2023). This background data was used to establish how often words should be expected to appear. Words appearing in the foreground data were then ranked according to how 'surprising' they were, i.e., how much more often they appear than we might expect them to. For the surprising phrases, we searched the dataset for those that seemed like they belong to a coherent theme to find matching posts. This increased the robustness of our methods, and ensured inclusion of relevant data which may have been missed through other processes.

Inductive thematic analysis

Our approach was guided by language found in the data, and no external analytical framework was used. Instead, we were guided by the initial machine-generated categorisation stages which resulted from the NLP techniques, and built on this in undertaking human-led inductive thematic analysis (ITA). ITA provided us with theoretical flexibility but also sufficient rigour to meaningfully answer our research question (Braun and Clarke 2006). The process involved identifying initial themes which represented the messages of the data, and then searching the data to check the themes against the dataset and further refine the results. As analysis progressed, generated themes were discussed within the research group to ensure understandings were shared and there was team agreement that the findings were grounded in the data.

Research Ethics Statement

We conducted this research according to ethical principles for social media research (Anonymous, 2021). We limited our collection only to data which would be considered publicly available, as described above. We aimed to maximise anonymity of users at every stage. Data were stripped of identifiable metadata before analysis. To maintain privacy of individuals, we are not publishing the names of the forums which provided data sources. We aimed to exclude data from any person under the age of 18, by filtering the dataset to remove content which was likely posted by users who were under 18. This study was granted Research Ethical Approval by the Ethics Sub-Committee, St Mary's University Twickenham. Data extracts included in this article have been bowdlerised and anonymised.

Results

Volume of posts

We initially collected 116,748 posts using data scraping from seven online forums. Data collected were from 2003 to 2020 inclusive, with an increase in volume over time. The volume of total online posts across the seven forums increased around 2020, corresponding to the onset of the Covid-19 pandemic (see Figure 1). Following the process of Clustering, NLP Classification, and Surprising Phrase Detection, 7,048 posts were assessed as relevant to our research aim and included in our thematic analysis.

Inductive thematic analysis

The machine-generated initial categorisation provided direction to undertake further detailed data analysis. Through the subsequent ITA, we generated two major themes that correspond

to the research aim: Comfort and Capability, which we explained through constituent subthemes (see Table 1). These are further explicated below. Data extracts are provided as representative examples.

Comfort

This major theme relates to forum users seeking support to ease psychological suffering, including people who may be experiencing life-limiting illnesses, accompanying someone else who has life-limiting illness, or who have been bereaved. The need for this comfort may be exacerbated by experiencing uncertainty, pain, or fear, and there are barriers to obtaining adequate comfort, as we elucidate in the following subthemes.

Comfort when it cannot be found elsewhere

Forum users may provide a sense of solidarity and recognition which may not be achieved in the user's offline life. For example, for grieving people, support from online forums may be necessary because they lacked support systems nearby. They often seek understanding from others experiencing grief, and this was more useful to them than a standard offer of condolences they may receive from people they encounter offline. In addition, many found forums to be useful repositories of information on grief, which helped them feel less isolated and better understand their own grief.

> *Our forum is like sitting down with a group of friends. We can listen to each other in our grief. Our 'like' button is a way to tell others they've been heard.*

Forum users expressed grief about losses over periods of days, weeks, months, or years, after other people they knew had stopped grieving, or when it is seen as no longer socially acceptable to grieve.

> *I am really glad that I found this...nobody understands the loneliness I'm feeling...I don't have a normal I can return to.*

Other users described the therapeutic benefits of being listened to, potentially at any time of day or night.

Sharing sources of comfort

Forum users also shared experiences of comfort they have found elsewhere. For example, forum users often shared the need for comfort from animals in response to death or dying.

> *My dog is a great comfort, like I know they are for many here. He was my husband's service dog and is by my side all the time.*

Forum users also shared their beliefs as sources of comfort, including spiritual, religious, philosophical, and existential beliefs. These beliefs may be more difficult to share in offline interactions, e.g., when encountering healthcare professionals who appeared untrained to discuss spiritual issues.

Freedom to speak and explore ideas

Online forums allow users to express themselves and document events, even if they do not desire a response, and provide space for people to explore ideas. These discussions ranged from healthcare discussions to supernatural and existential ideas. Some of the most surprising phrases detected included NDE (Near Death Experience); Scientific; Atoms; Beings. Discussions included people's understandings of consciousness and the afterlife.

> *Before your birth, were you just floating around in the nothingness? No - you did not exist then, and you won't exist after you die. For me, comforting.*

However, sometimes users may offer words that they view as comforting which are not appropriate to what another forum users appreciates.

> *How the hell does someone think this is even slightly comforting?*

Barriers to comfort

Many forum users expressed frustration at being unable to comfort others who they cared for, due to constraints and challenges of the care system. This included unpaid carers and those with loved ones in care homes.

> *Who is better placed to hold vigil at the bedside of a loved one and comfort them than family? They are completely competent to provide these basic comfort measures.*

Families should be given the training and resources to confidently help a loved one die

- it can be a beautiful experience.

After the onset of the Covid-19 pandemic, forum users expressed the challenges in comforting others, for example the perceived harm social distancing would be causing to care home relatives with dementia, or difficulty obtaining clinical investigations given demand on the health service. Posts also described the lack of offline support people were receiving, and the value of online forums to express frustrations of barriers to comfort they were encountering.

Capability

This major theme relates to forum users building their own capabilities and supporting others to do so. In addition to using forums for psychosocial support and comfort (described above), such capability-building is done through information-seeking and giving. This includes information on managing technicalities (e.g., legal documents), self-managing symptoms, and information for relatives and carers seeking to know what to expect when a person is dying.

Online spaces as irreplaceable resources

Forum users reflected on how the forums' live and archived posts are a resource for them, for medical knowledge and experience, advice on providing care, or on how to deal with different forms and processes of loss. Some users commented they had been using these online spaces for several years as sources of information, but only rarely personally created posts. In many posts, users noted it was difficult to find resources of similar usefulness elsewhere. Often, forum posts which were considered to contain useful resources are well known to longstanding

forum users, who directed newer users to these or to other knowledgeable users. Furthermore, if these resources were lost to users, e.g., through deletion of a thread of information, users expressed unhappiness at the loss of this support.

Threats to capabilities

Forums were also used to express feelings of disempowerment which threatened individuals' sense of capability. This sense of disempowerment may be expressed by people with life-limiting illness or by people caring for them. Many users felt they were engaging with a care system which they must struggle against. Users voiced personal and political criticisms of the care system, how it was undermining their capabilities to be a carer or be cared for, and feelings of not being listened to or being treated poorly.

> *The [UK National Health Service] lets us down, the social care system lets us down, social workers, [UK Department of Work and Pensions] civil servants, and charities who say they represent us all let us down. Most of all, politicians let us down. 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.*

However, users also described online forums helping them navigate the care system and potentially be treated better within it. This support from online spaces seemed particularly useful for people experiencing rapid changes in their lives. Online spaces may counteract threatened agency through offering support and validation, as well as practical or political advice and information. For example, we found users seeking and offering understanding of

medical procedures which was not provided elsewhere, or users suggested actions such as online campaigns or contacting the media to try to counter challenges. Occasional users stated they had been carers for years but had been unaware of the rights and benefits available to them until they had accessed online forums.

Capabilities in a time of crisis

Data since the onset of the Covid-19 pandemic indicate the emergence of specific limitations to forum users' capability. Forum users sought clarity over how to deal with care commitments given social distancing, financial difficulties, and challenges such as communicating remotely with relatives. Users were also concerned about elderly relatives in care homes.

> *It sounds like such a wrong thing to do to help her leave the care home, but I would not be able to live with myself if in a few weeks she dies from Covid.*

Many forum users criticised poor experiences with authorities during the pandemic. Criticisms included a lack of, or delayed, communication from health services, being kept out of meetings about care, and feeling relegated compared to patients with Covid-19. Other critical posts related to societal issues, with people drawing on their own experiences to argue that unpaid carers were being ignored in Government Covid-19 support efforts. Some feared the pandemic would adversely affect the future of care provision and access to welfare benefits.

Connection in the time of Covid

Forum users reported that visiting restrictions in hospital and care homes introduced during the pandemic meant people could not be present at the time of their loved ones' deaths, and social distancing rules meant they had to attend funerals by videoconferencing software rather than in person. Many users sought to make others aware of videoconferencing software as an online substitute for in-person gatherings, doctors' appointments, widow groups, carers courses, and staying in touch with loved ones in hospitals and care homes. Forum users reflected on the merits of videoconferencing, for example, being able to see each other's faces, as opposed to in-person meetings where masks obscure faces. Conversely, some users struggled to grieve when the only option was online communication.

> *I invited my family on [videoconferencing software] to be a part of a memorial for my sister, but it wasn't the same as being at her side as she left this world and so didn't feel alone, and then honouring her memory by sharing stories with my family. It feels very unreal.*

Some users were unsatisfied with videoconferencing but valued other online means of connection. For example, they may dislike the real-time nature of videoconferencing calls and prefer the asynchronicity of online forums, and others felt videoconferencing lacked the sense of community that forums offered.

> *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.*

Discussion

Principal findings

Our study utilised machine learning to comprehensively identify written posts from a range of online forums from over 17 years, which guided our qualitative analysis investigating how dying people and their loved ones' experience, negotiate, and resist the medicalisation of dying and grief in the context of the post-digital age. The volume of posts increased over time, consistent with increasing digitalisation and increasing familiarity with the internet that occurred over the study period. Additionally, there was a substantial leap in online forum use since the onset of the Covid-19 pandemic (see Figure 2), corresponding with observations of increased public awareness of dying (Myers and Donley, 2022). We have determined several findings which contribute significantly to the existing literature and implications for how we consider the medicalisation of dying and grief, and digitalisation in the future.

Our findings demonstrate that online forums are places where people express their feelings or concerns about their experiences, and facilitate people receiving psychosocial support and comfort. From our analysis, we can see that many people are experiencing dying and grief in a way contrary to the apparent motivations of death revivalist movement, i.e., under the surveillance of healthcare professionals, with needs and wishes often being unmet. Indeed, systems which are ostensibly meant to help dying people and their loved ones are experienced as forces against which people must fight. The findings also add to existing literature indicating that barriers to having wishes met at the end-of-life increased during the pandemic, including social isolation during dying, having no family accompaniment at the point of death, and lack of in-person opportunities to grieve (Strang et al., 2020). These challenges correspond with

the concept of medicalisation: the dying person is institutionalised, away from their community, and acted upon by the healthcare establishment.

The major theme of 'Comfort' demonstrates that online forums can offer support which may be perceived as better in quantity, quality, and duration from what is available from formal care systems or may compensate for deficiencies offline, including inadequacies encountered during the pandemic. The findings give insights into different priorities and values which are not recognised by traditional care systems. For example, while a medicalised view of dying focuses on diagnosis of disease and control of symptoms, our research demonstrated the repeated presence of the value people place on animal companions and on metaphysical beliefs about spirituality and life after death. Furthermore, the medical approach may pathologise sadness and grief following the death of a loved one, especially if it is extended (Davies, 2013). We found forum users express grief for extended periods of time, something that they are aware is socially unaccepted outside of online forums, and which has outlasted any offline bereavement support which was originally available to them. Online forums provide a space for them to express their ongoing grief, find repositories of information for dealing with grief, and are accessible 24-hours a day, unlike formal institutional structures.

Furthermore, the major theme of 'Capability' demonstrates that online forums themselves can help to remedy or mitigate the problems experienced by those facing dying and grief. This includes providing information and guidance which is not available or is made difficult to find or understand elsewhere. This corresponds to existing evidence that dying people and their loved ones are often disempowered by lack of access to health information, professionals in care interactions, and by medical systems (Nickel et al., 2017). Our findings suggest that online forums developed and led by dying people and their loved ones can be an essential part of providing much needed information, democratising death, and retaining or regaining agency when facing the end-of-life. This allows people to build their sense of empowerment, increase

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their personal capabilities, and counteract threatened agency. Online forums are therefore not only a means of psychosocial support. In fact, they provide a sustained, constantly available community which has practical impact on people's experiences of dying and grief. While care systems are largely deemed to be obstructive, online forums may compensate for and provide tools to overcome systemic difficulties, thereby potentially combating medicalisation.

The relative flexibility and accessibility of online forums may also have negative consequences. Not all users found posts made by others to be comforting or conducive to their needs, and useful information is vulnerable to deletion or change. The nature of online forums also provides the potential for abuse of people made vulnerable by their challenging life circumstances, and for disinformation to spread online, which is especially noteworthy as the Covid-19 pandemic has escalated concerns about online misinformation (Wang et al., 2022). This raises ethical questions over how forums should be facilitated and funded. Forum users frequently express that healthcare systems do not make them feel safe, and so oversight from professionals or institutions may mean online forums are perceived as similarly unsafe, be perceived as paternalistic interference, and undermine the nature of grassroots communities. However, practitioners we have engaged with in discussion of our findings have raised the issue that, without oversight, the risks to vulnerable users may be exacerbated (Anonymous, 2021a).

Strengths and limitations

No previous research has studied the use of online forums in the field of palliative and bereavement care to this open, iterative, and comprehensive extent. Confidence in the study's trustworthiness (Nowell et al., 2017) is increased by our rigorous and systematic methodological approach and situating our processes in language found in the data from first

principles. Our research team collaborated throughout the study to ensure consistent checks that findings, interpretations, and conclusions were clearly derived from the data.

The study also has limitations. There was no explicit public, service-user involvement in the design, conduct, and analysis of this study. When examining posts, our analytical methods examined each post in isolation, rather than a series of posts comprising conversation analysis. In some cases, the wider meaning may have been lost. We included a sample of online forums. Although wide-ranging, this research presents an overview of how online discussion of dying and grief relate to medicalisation and is not exhaustive. We have analysed the perceptions and experiences of people who were able and willing to access these publicly accessible forums and write posts, from posts which were written in English. We can make no claims about those who do not access or write on these online forums, those who are digitally excluded, e.g., through poverty, disability, or by lack of fluency in English language (Bowyer et al., 2020). As practitioners have raised with us, in discussion of our findings (Anonymous, 2021a), under-representation of minority groups is especially significant given that groups who are excluded in our study may also be groups more vulnerable to neglect, mistreatment or systematic exclusion in health and care systems (Hamed et al., 2022), and less likely to have end-of-life care needs met (UK Parliament, 2022).

Furthermore, since the onset of the pandemic, certain minority communities have been disproportionately affected by Covid-19 and health inequalities, and potentially need greater support (GOV.UK, 2022). However, our findings add to the literature showing that digital spaces can provide a means of providing necessary information and empowering those who are otherwise marginalised or excluded. In the next section, we recommend that future work focuses on how the benefits of online forums could be realised by marginalised communities and those who are currently digitally excluded. Additionally, future research should consider

other means of negotiating and resisting medicalisation which may be employed by communities who are digitally excluded or do not access online forums.

We also deliberately excluded posts likely to be from users aged 18-years old and under. The needs and challenges of children who are experiencing life-limiting illness, or pre-bereavement or grief for a relative or loved one who has a life-limiting illness are likely to be different from adults (Kentor and Kaplow, 2020; Spathis et al., 2012). Furthermore, children may engage with online communities in different ways compared to adults (Ofcom, 2022). We therefore cannot assume that our findings are transferable to the experiences of children.

Implications

Our findings indicate that current conditions for people experiencing dying and grief do not correspond with the person-centred aspirations of death revivalism and the stated aims of its successor, palliative care, and instead fit within the paradigm of medicalisation. However, we found that dying or grieving people may receive effective support online which differs in quality and value from what is available offline, and that online forums are used to share information through which people build their autonomy, and capability to counter-act medicalised power structures. Furthermore, people facing dying and grief value parts of their lives which are not adequately contained or explained by the medical model, e.g., animal companions and spirituality.

As the post-digital age progresses, online forums can form a significant part of the range of tools available to people, complementing health services, and counteracting deficiencies in care systems. This must also be considered as a future-proofing measure, especially as we are likely to face future pandemics (The Lancet Respiratory Medicine, 2022). Indeed, changes in expectations initiated by the Covid-19 pandemic have led to many people preferring essential

services, including healthcare, to be accessible both online and offline (Anonymous, 2021b). Investing in the development of online support forums may provide protection for the future, form a coherent and transparent part of what is available for dying people and the bereaved, and enhance autonomy.

The form any future development and investment takes must be determined through research and collaboration with dying people and their loved ones, and with bereaved people. Research should seek to lead to transformative change, while prioritising the voices of people affected by life-limiting illness and grief and incorporating them as co-researchers (Malterud and Elvbakken, 2020). Future work should explore the possible benefits to formalising and making explicit the role of online forums for people experiencing dying and grief, including incentivising and rewarding the civic labour of moderators; ensuring the legacy of important data and information; counteracting exploitation, and other forms of abuse; providing training in relevant areas such as digital skills, safeguarding, social benefits, and carer rights. However, we must be conscious of the risks of routinising any interventions meant to promote a person-centred revivalist approach to dying and grief. As we have discussed, when efforts to counteract medicalisation of death and dying are institutionalised, they can lose their values and become incorporated into a wider system of medicalisation (Floriani and Schramm, 2012). Part of the unique value of online forums is that they are informal spaces, where ideas can be freely expressed, and where users can collectively determine how they operate the space. The empowerment that users gain through online forums may be lost through external oversight or professionalisation. These tensions must be carefully mediated through co-developing a model, where the roles of formal and informal support services are clearly defined, while foregrounding autonomy of non-professionals and also enabling better access to professional support for those who need it.

Such a new model should also foreground equality of access and support as a vital issue. Groups who are already vulnerable to systematic exclusion and poor access to palliative care, including during the pandemic (Bowyer et al., 2020; GOV.UK, 2022), also may be excluded from access to online forums, further compounding their inequality. Future research must consider how access to online forums for currently excluded groups, including minority ethnic groups and people who primarily speak languages other than English, can be improved, and how risks of exploitation or abuse to vulnerable users can be mitigated. To ensure such research effectively meets this goal, it must involve patient and public involvement to give a voice to people from these vulnerable groups in its design and conduct. Additionally, future work which is specifically designed to investigate how children can be supported in using online spaces when facing life-limiting illness, pre-bereavement, or grief should be a priority.

Conclusions

The (re)medicalisation of dying and grief encompasses a societal approach including dying people being disempowered in relation to healthcare professionals, dying people being institutionalised away from their community, and people experiencing loss being expected to maintain tight control over their emotions. We have found that online forums allow dying people, their caregivers, and grieving people to negotiate and resist this (re)medicalisation by experiencing support and comfort beyond the perceived constraints of mainstream systems, including allowing people to express grief in a way which is not medicalised or pathologised even if it is long lasting. Concerns and values of dying and grieving people include animals and spirituality, which is far removed from the medicalised model of dying. Furthermore, online forums allow people to retain or regain autonomy, and become empowered to challenge disempowering structures, for example, by making bureaucratic processes and information on

legal rights transparent and easier to navigate. The value of community-led online forums has implications for policy and practice as society continually advances into the post-digital age. Future work must develop new models where online forums can be integrated into existing systems, made transparent and accessible, and be optimally funded, structured, and sustainable.

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Figure and Table Captions

Table 1: Major themes and subthemes identified from analysis.

Figure 1. Summary of methodological process.

Figure 2. Total volume of online forum posts web-scraped from seven online forums of interest over time (Total number 116,748). Adapted from Anonymous (2021a) with permission.